



**CENTER FOR  
BIOETHICS**

HARVARD MEDICAL SCHOOL

# MASTER OF BIOETHICS

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CAPSTONE SYMPOSIUM

MAY 3, 2022



# Symposium Agenda

## Welcome

### **Rebecca Weintraub Brendel, MD, JD**

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

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## Reflections on the Capstone Program

### **Melissa Abraham, PhD, MSc**

Co-Director of the Capstone Program, Center for Bioethics;  
Assistant Professor of Psychology, Harvard Medical School;  
Psychologist, and Director, Research Ethics Consultation Unit, Division of Clinical  
Research, Massachusetts General Hospital

### **David Sontag, JD, MBE**

Co-Director of the Capstone Program, Center for Bioethics;  
Lecturer on Medicine, Harvard Medical School;  
Director of Ethics and Senior Associate General Counsel, Beth Israel Lahey Health;  
Co-Chair, Ethics Advisory Committee, Beth Israel Deaconess Medical Center

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## Invitation to Poster Presentations

### **Crystal Chang, MPH**

Associate Director of Education, Center for Bioethics

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## Poster Presentation Group 1

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## What Do Bioethicists Do?

### **Christine Mitchell, RN, MS, MTS, FAAN**

Executive Director, Center for Bioethics

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## Poster Presentation Group 2

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## Wrap-up and Celebration

# What Do Bioethicists Do?

## Keynote:

Christine Mitchell, RN, MS, MTS, FAAN

Executive Director, Center for Bioethics



Christine Mitchell is the Executive Director of the Center for Bioethics and a Lecturer in the Department of Global Health and Social Medicine at Harvard Medical School.

She founded the clinical ethics program at Boston Children's Hospital, directing the ethics consultation service and leading the Ethics Advisory Committee for over 30 years. She has consulted with clinical ethics committees throughout New England, across the United States, and in other countries. She developed the Harvard Ethics Leadership Group, the Harvard Medical School Community Ethics Committee with Carol Powers, and helped to launch the Center for Bioethics in 2014 with Robert Truog, where she developed the Capstone Program for Master of Bioethics students and the Consortia on Clinical Ethics, Organizational Ethics, and Research Ethics.

Christine worked with Sebastian Porsdam Mann to develop a Right to Science Study Group at Harvard Medical School and contributed to the publication of *The Right to Science: Then and Now* ([Cambridge University Press 2021](#)), as well as the development of an ongoing group at Cambridge University of international colleagues working together on furthering a universal human right to science. Her other research focuses on ethics consultation and public engagement in ethical aspects of institutional policies. She has lectured on topics in clinical ethics all over the United States, Denmark, Finland, Germany, Indonesia, Japan, Norway, Sweden, Switzerland, and the United Kingdom.

Christine is the current president of the Association of Bioethics Program Directors. She has served on numerous national committees and commissions, including the Clinical Ethics Consultation Committee for the American Society for Bioethics and Humanities, the Ethics Committee for the American College of Obstetricians and Gynecologists, and the Ethics Advisory Board for the Human Brain Project funded by the European Commission. Her published work includes documentary films, one of which was nominated for an Academy Award. She has written over 175 articles and chapters on topics in bioethics. Christine Mitchell is an elected Fellow of the American Academy of Nurses.

## Vincent Bain, PhD, MDiv

### **Capstone Mentor: Maggi A. Budd, PhD, MPH, ABPP**

Member, Harvard Medical School Center for Bioethics; Rehabilitation Psychologist & Neuropsychologist, and Assistant Chair, Clinical Ethics Consultation Committee, VA Boston Healthcare System

### **Chaplains Serving on Healthcare Ethics Committees: The Barriers and Enablers to Full Participation**

Chaplains are an underutilized resource in healthcare ethics committee work whose participation could enhance the scope and diversity of this work. Prior research has demonstrated that chaplains' participation on healthcare ethics committees has been limited, despite their having appropriate professional skills and training to enhance the work of these committees. This effect is more pronounced in smaller and rural communities. Minimal reliable data exists to explain this phenomenon. This study sought to bridge the gap in knowledge regarding the barriers and enablers to chaplains' full participation on healthcare ethics committees. This pilot study solicited perspectives from ethics committee leaders and members of Harvard-affiliated teaching hospitals who have experience with chaplain participation in their work. A survey tool utilizing a parallel, convergent, mixed methods approach was designed and field tested. This tool included five scaling questions and five narrative answer questions. After receiving Institutional Review Board (IRB) approval, the survey was distributed through Qualtrics to the target population. Initial data served to validate the survey tool. Preliminary results suggest bioethical training as well as healthcare ethics committee intentionality were essential to supporting chaplains' participation on healthcare ethics committees. These results will be used as the basis to justify a more extensive study to be conducted in the future.



**Vincent Bain, PhD, MDiv**, is a chaplain in the United States Army. He received his BS in Christian ministry from Crown College, Minnesota, his MDiv from Concordia Seminary, St. Louis, and his PhD in organizational leadership from Concordia University, Chicago. He is assigned to the student detachment of the U.S. Army. His areas of expertise are religious support and ethical advisement. His main bioethical interests are soldier care, military planning, and military actions. He is a past honoree as the Chaplain of the Year for the 101st Airborne Division. After graduation he will be serving on the chaplain staff of Walter Reed Military Medical Center as a Chaplain Bioethicist.

## Arturo Balaguer, BA

### **Capstone Mentor: Travis Baggett, MD**

Assistant Professor of Medicine, Harvard Medical School; Faculty Clinician- Investigator, MGH Division of General Internal Medicine

### **A Moral Argument for the Federal Decriminalization of Safe Injection Sites**

Safe injection sites (SISs) are potentially one of the most effective public health measures for harm reduction in the increasingly fatal opioid overdose epidemic in the United States (US). Although the existing bioethical literature explores whether SISs are morally permissible, little work has explored whether the US federal government has a moral obligation to actively provide SISs notwithstanding ethical objections. Some SIS proponents argue that the government has an inherent responsibility to provide effective health measures such as SIS. Others argue against such an obligation, instead arguing that the federal government is ethically obligated to criminalize SIS because the use of harmful, illicit narcotics is inherently immoral, and that individuals with substance use disorders (SUDs) have lesser claims to government-sponsored public health measures than other ill members of society. This capstone project challenged these moral arguments against SISs by probing commonly held moral intuitions regarding drug use, addiction, and SUDs. In doing so, this work concluded that the immediate federal decriminalization of SISs on ethical grounds should occur. Finally, future research is needed to evaluate whether the federal government's political decisions surrounding the opioid crisis directly exacerbated the crisis. These data may help determine whether the federal government can be held morally accountable to the more stringent obligation of actively providing SISs from a restorative justice perspective.

**Arturo Balaguer, BA**, received his BA in history with a minor in philosophy from Boston College. In college, he worked on the psychology and neuroscience of kin-specific moral decision-making. He also served as a Spanish translator for an international theological ethics conference in Sarajevo and volunteered as a clinical assistant at the Boston Healthcare for the Homeless foot clinic. His bioethical areas of interest include neuroethics, global health ethics, drug policy ethics, and the ethics of medical commodification. After completing his MBE, he will be attending the Feinberg School of Medicine at Northwestern University.



Rohin Bhatt, BSc, LLB (Hon.)

**Capstone Mentor: John Peteet, MD**

Associate Professor of Psychiatry, Harvard Medical School; Fellowship Site Director, Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Physician, Psychiatry, Brigham And Women's Hospital

**Death Be Not Proud: Dignity, Death, and the Pandemic**

The COVID-19 pandemic has caused the most deaths in a century. Simultaneously, public health concerns, including early uncertainty and misinformation regarding the transmissibility of COVID-19 from dead bodies, have prevented families from partaking in post-death rituals (e.g., funerals) that generally support the grieving process. Studies have shown that there is an inverse relationship between post-death rituals and levels of bereavement, raising concerns about a risk of prolonged grief disorder and persistent complex bereavement disorder in the population. This capstone project sought to examine the contours of dignity at the end of a life and the relevance of post-death rituals to a dignified end to life. It surveyed the literature on dignity and the relationship between post-death rituals, dignity, grief, and mental health. It also reviewed scholarly literature and news reports surrounding COVID-related deaths. This capstone argues that the dignity of a person exists on a continuum that does not end with their physical death. A right to death with dignity thus encompasses dying without indignity as well as post-death claims, including a claim to a funeral in line with the cultural beliefs of the deceased. This claim, when coupled with the interests of the family in providing a dignified end to their deceased relative, strengthens the case for enabling post-death rituals such as funerals to occur, even in a pandemic context. Given that earlier public health concerns regarding the transmissibility of COVID-19 from dead bodies have been disproven, families should be allowed to perform funerals for the victims of COVID-19.



**Rohin Bhatt, BSc, LLB (Hon.),** received his undergraduate degree in law from Gujarat National Law University (GNLU), India. His primary area of interest is the legal and ethical issues surrounding assisted reproductive technologies and reproductive rights for LGBTQ populations. His papers have appeared in multiple bioethics journals including the Hastings Center Report, Indian Journal of Medical Ethics, and Voices in Bioethics. He co-founded the Indian Bioethics Project at GNLU and has served as the Editor-in-Chief of GNLU Issues in Science, Law, and Ethics. After the MBE program, Rohin hopes to practice law and advocate for queer rights in India.

## Eon Cabuhat, BS

### **Capstone Mentor: Roberta Driscoll, JD, MBE**

Director of Ethics, Risk, and Compliance, Novartis Institutes for Biomedical Research

### **Unregulated Entities: Exploring Fact-Checking Technology to Combat Medication Misinformation on Social Media**

Ethical issues emerge when drug companies, patients, and other stakeholders use social media to discuss medications. Although the Federal Trade Commission (FTC) and the Food and Drug Administration (FDA) govern advertising by pharmaceutical companies, no regulatory body exists to oversee statements made by non-company-sponsored or unaffiliated entities on social media. As a result, the 70 percent of internet users who seek health information online do so in an environment in which nearly anyone can post nearly anything about any drug on any social media platform. To address the potential for dissemination of drug misinformation in social media, this capstone explored the feasibility of implementing an automatically generated tag on all social media posts mentioning a particular drug name. Similar to Instagram's automatic fact-checking technology for COVID-19 vaccine information, the proposed tag would link to the specific drug's patient prescribing information in order to present objective and scientifically-valid information in a consumer-accessible manner. Alternatively, this technology could be described as a digital version of patient package inserts or labels included in a medication package. To inform the possible application of this technology, the project explored potentially analogous examples of fact-checking technology in social media regarding politics and vaccines, concluding that this fact-checking technology could be feasibly and effectively applied to social media posts involving medication. Future directions for this work include conducting field research to test this fact-checking technology in real time with actual consumers.

**Eon Cabuhat, BS**, received his BS in biology from University of California, Los Angeles. Since college, he has worked in various roles in the pharmaceutical industry, including marketing, quality operations, and compliance. Eon's bioethical areas of interest include the ethics of direct-to-consumer advertising of therapeutics as well as the ethical use of social media platforms in pharmaceutical communications with patient consumers. After receiving his MBE, Eon plans to assume a regulatory role in the pharmaceutical industry with a focus on advertising, promotional materials, and labeling.



Ilona Cenolli, BA

**Capstone Mentor: Rebecca S. Feinberg, JD, MBE, MS**

Teaching Associate Professor, Department of Health Sciences, Lecturer in Law, DePaul University College of Law

### **Same-Gender Parentage in the European Union and Transnational Surrogacy: Upholding Respect for Persons Through a Mutual Recognition of Parentage Policy**

There are strict anti-surrogacy laws and incompatible policies on same-gender parentage across the European Union (EU) Member States. Consequently, queer intended parents from the EU who use international gestational surrogacy services risk not being identified as the child's legal parents in different Member States. This project assessed whether regulating parentage recognition between Member States would enhance children's rights to respect for persons. It focused on children born through transnational surrogacy to same-gender parents. The analysis evaluated respect for persons through the European bioethics and biolaw principles of autonomy, dignity, integrity, and vulnerability. A discourse analysis on legal parentage in EU and Member States' national case law applied these principles, focusing on eleven cases covering transnational surrogacy. Key findings on how respect for persons is violated for children whose parents are not legally recognized as custodial parents included diminished access to citizenship, mental healthcare, right to privacy, and seeking healthcare EU-wide. The project concluded that designing a policy on mutual parentage recognition is consistent with respect for persons. By including children born through transnational surrogacy to same-gender parents, the proposed policy would enhance children's access to their guaranteed human rights according to existing provisions under EU law. To address the effect that universal recognition of parentage across Member States would have on ensuring children's health, future steps for a policy proposal should include explicit reference to European bioethics and biolaw principles.



**Ilona Cenolli, BA**, is an education team administrator at the Center for Primary Care at Harvard Medical School. They received their BA in politics and international relations from Queen Mary University of London. Their research has focused on end-of-life discourse and provisions in the UK, legislative-executive relations in public mental health policies, and reproductive ethics in global health. Ilona has provided immigration advice as a licensed Level 1 Office of the Immigration Services Commissioner adviser in the UK. Their bioethical areas of interest lie at the intersection of law, genomics, and assisted reproductive technologies. Following the MBE, Ilona will return to their advocacy work for health equity and access to healthcare.



## Emily Cerciello Ferraro, BSPH

### **Capstone Mentor: Insoo Hyun, PhD**

Member, Center for Bioethics, and Senior Lecturer on Global Health and Social Medicine, Harvard Medical School; Director, Center for Life Sciences and Public Learning, Boston Museum of Science

### **Prospective Applications of Participatory Research to Multi-Cellular Engineered Living Systems**

Participatory research (PR) comprises a range of methods that engage impacted communities to collaboratively create knowledge or interventions. In biomedicine, PR involves patients as active partners in the research process rather than as merely impassive research subjects. Although well-documented in clinical, public health, and environmental spheres, PR is relatively new to the basic sciences. This capstone first documented the limited existing precedent for PR in the basic sciences through a literature review. It further explored if and how PR is relevant to the promising, but speculative, basic science field of multi-cellular engineered living systems (M-CELS). M-CELS are complex living systems engineered to harness biological emergence and developed to model and treat disease. Through literature review and exploratory interviews with M-CELS researchers, this capstone identified theoretical and practical concerns that PR could help to address through deliberate engagement of the public. Theoretical concerns include whether engineered biological machines are considered objects of moral concern, which specific abilities might trigger moral concern, and whether there should be limits placed on the ability of M-CELS to mimic natural systems. Practical concerns include deciding which disease applications should be prioritized and whether equity and accessibility should act as design constraints. Future directions include facilitating interactions and building trust between M-CELS researchers and specific disease communities. Community engagement through PR could lead, for example, to M-CELS researchers understanding the acceptability of eventual therapeutic applications, which might redirect early technology development from the start.

**Emily Cerciello Ferraro, BSPH**, is associate director of digital health and engagement at the Crohn's & Colitis Foundation. She received her BSPH in health policy and management from the University of North Carolina at Chapel Hill. In her work, Emily creates partnerships to bring new digital health technologies to research and builds tools for stakeholder engagement across the research ecosystem. She advocates for the voices of patients and caregivers in research priority setting and conduct. Emily's primary bioethics interests include research ethics, moral issues surrounding technology development and dispersion, feminist ethics, and participatory justice. Upon completing her MBE, Emily will continue to work in chronic disease research.



## Perla Citlalli Cervantes, BA

### **Capstone Mentor: Charlene Galarneau, MAR, PhD**

Member, Center for Bioethics, and Senior Lecturer on Global Health and Social Medicine, Harvard Medical School; Associate Professor Emerita, Women's and Gender Studies Department, Wellesley College

### **Unity in the Minamata Disaster: Japanese Notions of Justice and Environmental Law**

Minamata disease (MD), or methylmercury toxicosis, is a central nervous system disorder with symptoms such as limb contortions, paralysis, and cerebral palsy. MD first appeared in the Minamata region of Kyūshū, Japan, in outbreaks from the 1950s to the late 1960s, caused by industrial companies dumping effluent into fishing waters. This project identified bioethical notions of justice that emerged during these epidemics via a literature review and a legal-historical analysis. The literature review aimed to distinguish the indigenous origins of Japanese environmental ethics. The legal-historical analysis involved examining the literature written by affected persons and their allies that led to the pollution trials in the 1970s. This analysis was paired with textual analysis of government-published legal documents. This project found that Japanese environmental ethics originated from Shinto and Zen Buddhist teachings on food sacredness and the ideologies of the “oneness” or interconnectedness of all life promulgated by Japanese farmer and fisher philosophers. In their struggle for recognition and compensation, the ill, their families, and allies drew on indigenous environmental ethical thought in their bioethics activism, defining justice as unity in the face of disaster, recognition of the affected, and adoption of environmental protections conducive to health. These conceptions of justice appeared in the drafts of environmental criminal laws, modifications to previous environmental protection policies, and the legitimization of anthropogenic disease as a reason for tort litigation. Japanese environmental law exemplifies how bioethical thought and activism can influence the development of legal protections against anthropogenic disaster.



**Perla Citlalli Cervantes, BA**, is a musician, historian, and scholar of Japanese law and ethics. She received her BA in history and Japanese studies from Earlham College. As an undergraduate, she served as an Institutional Review Board member, assistant archivist, and copy editor for the Earlham Historical Journal. Perla has conducted multilingual bioethics research on topics ranging from Rinzaï Zen Buddhist-informed end-of-life care to transnational biopesticide developments. As a trans reproductive rights and farmworker justice activist, she seeks to continue developing the method of bioethical historicism to reform pesticide laws, improve farmworker workplace conditions, and remove eugenical language from legal gender recognition systems.

## Mei-Yoke Chan, MBBS, MMed

### **Capstone Mentor: Jonathan M. Marron, MD, MPH**

Member, Center for Bioethics, and Instructor in Pediatrics, Harvard Medical School; Attending Physician, Dana-Farber Cancer Institute and Boston Children's Hospital; Ethics Associate, Boston Children's Hospital

### **Ethical Challenges in Pediatric Precision Oncology Decision-Making**

The sequencing of the complete human genome in 2003 facilitated discovery of genetic aberrations that could improve cancer diagnosis and therapy and spawned the field of precision oncology. However, there are challenges to implementing genomic testing in the oncology setting, including uncertainty about its utility and cost-effectiveness, difficulties in interpretation of results (particularly unexpected and/or unrelated findings), and difficulties in communicating complexity of the findings to facilitate informed decision-making by patients or surrogates. This capstone project used stakeholder interviews to explore ethical challenges related to the informed consent process for clinical genomic testing for diagnosis and therapy in pediatric oncology. A literature review examined the informed consent experience in pediatric precision oncology, identifying various potential ethical challenges. Stakeholders including parents, pediatric oncologists, and other clinical team members were invited to participate in virtual one-on-one interviews, during which the consent process, workflow logistics, reflections, and suggestions to improve the process were explored. Common interview themes were identified from eight completed interviews. All interviewees identified "information overload" as an obstacle, particularly at diagnosis. Parents, oncologists, and social workers also referenced complexity of the science and time pressures as challenges to ensuring adequate informed consent. Parents desired written information and better communication and follow up of clinical genomic testing results. Social workers suggested a "check-back" at 30 days after the consent process to assess and confirm parents' understanding. Future applications of this work include designing information pamphlets for patients and parents as well as expansion to other cultural populations to assess similarities or differences.

**Mei-Yoke Chan, MBBS, MMed**, is a pediatric hematologist-oncologist at KK Women's and Children's Hospital in Singapore. She received her MBS and MMed in pediatrics from National University of Singapore and Royal College of Physicians, UK, and trained in pediatric hematology-oncology at Great Ormond Street Hospital in London. Mei-Yoke also has an interest in pediatric palliative care. Due to the nature of her work in hematology-oncology and palliative care, Mei-Yoke has a keen interest in clinical ethical dilemmas, particularly shared decision-making. She is the chair of her hospital ethics committee and aims to use what she has learned in the MBE program to advance her and her colleagues' ethical practice.



## Chad Childers, BA

### **Capstone Mentor: Gregory A. Abel, MD, MPH, MFA**

Member, Harvard Medical School Center for Bioethics; Associate Professor of Medicine, Dana-Farber Cancer Institute

### **Clinical Ethics Consultation Documentation in the Era of Open Notes**

The note that follows a clinical ethics consultation (CEC) is a critical document for many stakeholders. In 2021, new federal rules from the Cures Act mandated most clinical notes, including notes from CECs, be made available in real-time to patients through online portals, in a practice known as “open notes.” This legislation was intended to reinforce trust in the physician-patient relationship and give patients greater voice and responsibility in their care. However, the practice of open notes adds a new dimension to the physician-patient relationship and raises questions about what should be included in notes intended to be read by both clinicians and their patients. This capstone explored benefits and implications of open notes for ethics consultation, reviewed CEC documentation styles and current standards, and explored recommendations for documentation in this era. A literature review found that, even prior to the legislative mandate for open notes, proper documentation of a CEC was contentious due to the common presence of competing interests, differing moral values, disagreement about pertinent medical information, and countless other conflicts that arise in any given CEC encounter. Open notes now invite patients to access documentation of these discussions, which broach sensitive ethical topics related to a patient’s capacity, autonomy, hope, and understanding. In the era of open notes, CEC notes must be designed not only to be effective, accurate, and helpful for healthcare workers and ethics committee members, but also sensitive to the needs of patients and their family members.



**Chad Childers, BA**, is an osteopathic medical student at Marian University College of Osteopathic Medicine. He received his BA in medical humanities and health studies from Indiana University, Indianapolis. He is an editor for In-Training, an online peer-reviewed publication for medical students. His research focuses on the documentation of clinical ethics consultations in the era of OpenNotes and the ethics of using Nazi medical illustrations in medical training. Before medical school, he helped create a death education course to address a gap in end-of-life care training for future healthcare practitioners. Following graduation, Chad will return to medical school to pursue his dream of becoming a hospice physician.

Peter Choi, MS

**Capstone Mentor: Anthony Weiss, MD, MSc, MBA**

Senior Vice President and Chief Medical Officer, Beth Israel Deaconess Medical Center

**Leave Me Alone! How Motivation, Trust, and Preference for Autonomy Could Impact Medication Adherence**

Clinicians have long struggled to ensure patient adherence to recommended medication schedules. Personalized approaches to behavioral interventions may significantly improve adherence rates. This capstone piloted an experimental vignette study to explore the relationship between individual preferences for autonomy, trust, and medical decision-making behaviors relevant to patient medication adherence. Prior literature suggests that individuals with high preference for autonomy, as measured on the Autonomy Preference Index (API), may be more responsive to internal sources of motivation, such as the severity of their disease, when it comes to following medical recommendations, whereas people with low preference for autonomy may be more responsive to external sources of motivation, such as the perceived trustworthiness of the clinician. Using a survey-based approach, this study presented each participant with two successive vignettes, the first of which presented information about the severity of disease (mild or severe) along with a treatment recommendation from a clinician (doctor or nurse), and the second of which varied the clinician type and treatment recommendation. The pilot study (n = 257) found that, for participants with higher API scores, the trust-reducing factor of receiving conflicting treatment recommendations increased participant sensitivity to internal motivation factors (e.g., disease severity), increased their likelihood of seeking a third opinion, and reduced their likelihood of concern for missed dosages. Understanding patients' preferences for autonomy has important implications for understanding trust in providers and adherence to clinician recommendations and may inform customized behavioral approaches to increase adherence. The full study will involve 1000 participants.

**Peter Choi, MS**, is a senior manager of strategy for Mass General Brigham's Data & Tissue Sharing Committee. He received his BA in sociology from Emory University and MS in neuroscience and education from Columbia University. He has previously worked as an industry relationship manager at Massachusetts General Hospital Cancer Center and as a quality and safety program manager at University of California San Francisco Medical Center. His academic interests include using game theory, behavioral economics, social psychology, and neuroscience to inform bioethical questions surrounding health care, disability rights, and sports policy. Peter is a coxswain at the U.S. Rowing National Training Center and was the 2021 Tokyo Paralympic Games alternate.



## William Choi, BS

**Capstone Mentors: Joseph Giacino, PhD**, Member, Harvard Medical School Center for Bioethics; Professor of Physical Medicine and Rehabilitation, Spaulding Rehabilitation Hospital; Neuropsychologist, Department of Psychiatry, Massachusetts General Hospital; **Yelena Bodien, PhD**, Research Scientist, Department of Physical Medicine and Rehabilitation, Spaulding Rehabilitation Hospital and Department of Neurology, Massachusetts General Hospital

### **Defining “Acceptable Outcome” After Acquired Brain Injury (ABI): A Comparison of Stakeholder Perspectives**

Patients with acquired brain injury (ABI) and their families often face uncertainty in clinical treatment due to significant limitations of current diagnostic and prognostic tools for disorders of consciousness. This project sought to (1) summarize existing published definitions of favorable outcomes after ABI; (2) characterize and compare patient, caregiver, clinician, and researcher perspectives on an “acceptable outcome” after ABI; and (3) understand the bioethical principles that underlie those perspectives. A preliminary review of clinical studies of brain injuries revealed that the notion of “favorable outcome” was not standardized across the studies and was usually determined by physicians’ and researchers’ clinical perspectives rather than caregivers’ and patients’ values. This variability can generate prognostic discordance between clinicians and families of patients, which negatively impacts the shared decision-making process and increases moral burden for both the caregivers and the care team. A survey was developed and administered to individuals with a history of brain injury, caregivers, clinicians, and researchers to obtain their ratings of acceptability for different recovery milestones and explore bioethical values in their decision-making. Participant responses were quantitatively and qualitatively analyzed using a constant comparative methodology. This study revealed discrepancies in how professionals and families rate the acceptability of different recovery milestones and their underlying bioethical evaluations. Addressing these discrepancies through a conversational guide for families and clinicians in the future may encourage more patient-centered approaches to ABI outcome assessment.



**William Choi, BS**, received his BS with honors in neuroscience and philosophy from Johns Hopkins University. As an undergraduate, William researched the proteomic origins of SYNGAP1, a rare neurological disorder, and investigated psychosocial stressors for caregivers of children with SYNGAP1. His bioethical interests include investigating diverse cultural and philosophical conceptions of the “good death” and ensuring patient-centered medical decision-making for individuals with disorders of consciousness. After completing his MBE, William plans to attend medical school.

## Rachel Cooper, BA (Hon.)

**Capstone Mentors:** **Dr. Sophie Soklaridis, PhD**, Senior Scientist, Centre for Addiction and Mental Health, Toronto, Canada; **Steve O'Neill, LICSW, BCD, JD**, Member, Harvard Medical School Center for Bioethics; Social Work Manager and Behavioral Health Specialist, OpenNotes, Beth Israel Deaconess Medical Center; **Gillian Strudwick, RN, PhD, FAMIA**, Independent Scientist and Chief Clinical Informatics Officer, Centre for Addiction and Mental Health, Toronto, Canada

### **There's Power in the Notes: Exploring Power Dynamics in Shared Clinical Mental Health Documentation**

In Ontario, Canada, patients are provided access to their electronic medical records through secure online patient portals (OpenNotes). These portals are designed to enhance communication and facilitate shared decision-making, although they raise particular challenges in the context of mental health (MH). Existing literature regarding OpenNotes in MH contexts elucidates the risks and benefits of the practice for both clinicians and patients. However, the literature largely ignores the inherent power imbalances that exist between MH clinicians and patients. This capstone project explored whether and how power dynamics factor into MH clinicians' perceptions of and experiences with OpenNotes. It included deductive and inductive thematic analysis of semi-structured qualitative interviews with 12 Ontario MH clinicians. Clinicians cited concerns about maintaining objectivity, manifesting judgment, and accurately documenting their perceptions of patients' presentations in their shared clinical notes, indicating an awareness of the potential for power imbalances to be perpetuated through OpenNotes. These data suggest that patients who access OpenNotes may perceive clinicians' observations, findings, language and/or tone to be judgmental of, or even at odds with, patients' perceptions of their own experiences. Further, reading clinical notes that are discordant with their own narrative may result in the patient feeling that their self-knowledge is being minimized, oppressed, or invalidated, thereby exacerbating the power imbalance between clinician and patient. Future research is needed to ascertain patient perspectives on power imbalances experienced with OpenNotes.

**Rachel Cooper, BA (Hon.)**, is a freelance qualitative researcher in Toronto. She received her BA from the University of Waterloo, Canada, where she majored in social development studies with a specialization in social work. Rachel's professional work spans Ontario's mental health sector, including roles as a front-line worker, manager, researcher, educator, and advocate. Her bioethical interests include psychiatric ethics, qualitative research ethics, and the complexities of patient and family engagement. Rachel is a Fulbright Canada Student Award recipient. Following graduation, she will pursue a Master of Education degree at the University of Toronto, where she will focus on issues of power, social justice, and equity.



## Priya Dave, BA

**Capstone Mentors: Ammar Sarwar, MD**, Associate Professor of Radiology, Harvard Medical School; Interventional Radiologist and Co-Director of the Liver Tumor Program, Beth Israel Deaconess Medical Center; **Shahla Siddiqui, MD, MSc**, Assistant Professor of Anesthesia, Harvard Medical School; Assistant Professor, Department of Anesthesia, Critical Care, and Pain Medicine, Beth Israel Deaconess Medical Center

### Characterizing Moral Distress in the Practice of Radiology

In a recently published article, American Roentgen Ray Society president Jonathan Kruskal called for increased attention on moral injury in radiology. He asked the radiology community to “excavate the problem until it becomes clear” due to its impact on the health and wellbeing of practicing radiologists. This capstone project sought to better characterize moral distress in interventional radiology through assessing radiologists’ responses to a series of 15 commonly encountered clinical scenarios in practice taken from the validated Italian Moral Distress Scale-Revised and adapted for radiology following discussion with radiologists. Participants rated the severity and frequency of each scenario on a 0 to 4 scale, assessed the usefulness of interventions, including ethics consultation, additional curricula, and grand rounds, and answered an open-ended question about coping strategies. A total of 75 radiologists, who received the survey via the Society for Interventional Radiology Connect website, completed the survey during the months of March and April, 2022. Preliminary results showed that interventional radiologists experience moral distress due to perceived futility in care and poor teamwork. The top two strategies for mitigating moral distress were opportunities to engage in inter-specialty dialogue and utilizing additional ethics consultations. These results may help the field to better classify clinician distress and lead to action-guiding solutions.



**Priya Dave, BA**, is a medical student at Icahn School of Medicine at Mount Sinai. She received her BA in medical humanities from the Indiana University School of Liberal Arts. Priya leads the center-wide Ethics Luncheon at Mount Sinai and serves on the Doctors for America FDA Task Force. Priya’s interests in bioethics include climate justice, global health ethics, and artificial intelligence ethics. She has presented her work at the American Society of Bioethics and Humanities and the Health Humanities Consortium. Priya is a recipient of the Osler Society Bean Award and the Healthcare without Harm Emerging Physician Leader Award. Upon graduation, she will finish medical school and work on climate justice curricula as a Sadler Fellow.



## Vrushali Dhongade, MBBS, MS

### **Capstone Mentor: Benjamin C. Silverman, MD**

Member, Center for Bioethics, and Instructor for Medical Ethics and Professionalism, Harvard Medical School; Senior IRB Chair, Mass General Brigham

### **Development of an Institutional Review Board Learning Module to Understand and Reduce Variability in Risk-Benefit Assessments of Research Protocols**

Institutional Review Boards (IRB) work to protect the rights and welfare of human participants in research. Existing regulations direct IRBs on the criteria a research study must meet to secure approval to proceed. However, significant variability remains in how IRB members apply these criteria and make decisions about research protocols, particularly in evaluating whether the risks of a study are reasonable in relation to its benefits. Therefore, it is vital to educate IRB members on the expected scope and nature of IRB review. This capstone project involved fieldwork, including attendance at the Mass General Brigham IRB meetings, during which the process of decision-making in IRB meetings was observed. Meetings provided an opportunity to observe how ethical principles are applied in a real-life setting and helped identify the process of risk assessment as a topic for IRB member education. These observations were extended and developed through a literature review and discussion with IRB staff to facilitate the development of a learning module to be distributed to IRB members. The learning module under development will provide IRB members with examples of different methods to analyze the risk-benefit balance in a research protocol. This learning will better enable IRB members to evaluate whether the risk-focused approval criteria for a study are met. The module aims to enhance consistency in IRB review practices and will ensure core ethical principles for research studies are met throughout the protocol review process.

**Vrushali Dhongade, MBBS, MS**, is a physician.

She received her MBBS from Bharati Vidyapeeth Medical College, India, and her MS in clinical research from Boston University School of Medicine. She worked on a digital phenotyping study involving Alzheimer's disease patients at Boston University and a COVID-19 coagulation study at Boston Medical Center. Vrushali is interested in clinical ethics, research ethics, and processes of decision-making by Institutional Review Boards. She volunteers at Infinite Youth, a Mumbai-based non-profit organization for youth development. Following graduation from the MBE program, she plans to pursue a residency in psychiatry and become a physician-scientist.



## Siham Elhamoumi, BA

**Capstone Mentor: Pardis Sabeti, MD, DPhil**, Professor, Department of Organismic and Evolutionary Biology and Center for Systems Biology, Harvard University; Professor, Immunology and Infectious Diseases, Harvard T. H. Chan School of Public Health; Institute Member, the Broad Institute of MIT and Harvard

### **The Ethical Considerations of Data and Benefit Sharing in Pathogen Genomics**

The COVID-19 pandemic amplified lessons from previous Ebola outbreaks regarding the importance of pathogen genomics data in research and public health response to infectious disease. To facilitate ethical use of these data, there is a need to reconsider data sharing principles in pathogen genomics research. This capstone project investigated ethical considerations related to data sharing in pathogen genomics, ways risks to individuals might be balanced with potential population-level benefits of data sharing schemes, and duties owed to persons contributing their data. A literature review identified numerous ethical considerations related to pathogen genomics data sharing. Benefit sharing emerged as an approach theorized to ensure fair distribution of the benefits resulting from pathogen genomics research. Semi-structured interviews with data scientists, genomics experts, and bioethicists from academia and biotech revealed broad-based consensus with these findings and identified practical steps. Specifically, this study identified data linking as well as open and rapid pathogen genomics data sharing as best practices for maximizing the utility of pathogen genomics data. It underlined the need to explore various levels and types of data sharing, harmonize data standards, and capitalize on novel technological approaches to address data privacy, confidentiality, and data security concerns. When considering moral obligations to those contributing their data, reciprocity was identified as a guiding principle. Going forward, benefit sharing should be considered to be a duty owed to participants who, by sharing their data at the onset of pathogen genomics research and surveillance initiatives, make possible crucial population-level benefits.



**Siham Elhamoumi, BA**, is the program lead for a portfolio of translational projects within the viral genomics group at the Broad Institute. She received her BA in economics from Saint Michael's College, Vermont. Siham has worked in international development and global health policy and has conducted population health research in East Africa and the Middle East. Her interests in bioethics focus on access to health, translational science, and benefit-sharing schemes in genomic surveillance. Following graduation, Siham will continue to work on equitably delivering the benefits of the health sciences to improve the health of communities with the greatest need.

## Rémy Enoch, MS

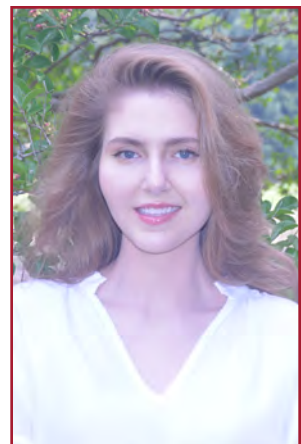
### **Capstone Mentor: Martha Montello, PhD**

Member, Center for Bioethics, and Lecturer, Department of Global Health and Social Medicine, Harvard Medical School; Editor-in-Chief, Perspectives in Biology and Medicine, Johns Hopkins University Press

### **Arts Education for Bioethics Students**

Arts education is an approach within medical humanities used to improve diagnostic skills and foster empathy within students. However, pedagogical practice has not been widely established for the exploration of art within the context of bioethics education, leaving its potential role in developing bioethical skills of close attention and reflection poorly understood. This capstone aimed to bridge aesthetic experience with moral thinking by examining the impact of arts exploration on learning in bioethics. A literature review was conducted with the goal of identifying core features of an effective arts-based, bioethics curriculum. Key themes included active engagement of emotion and empathy in pedagogy, narrative medicine as a lens for ethics education, and visual literacy as a means to expand thinking through experiential learning. These themes were used to curate select artworks across mediums to explicate theoretical lenses introduced in a foundational bioethics course offered through Harvard Medical School's Master of Bioethics Degree Program. The experiential component of the project involved facilitating artist talks and workshops, which provided opportunities for bioethics students to reflect on topics such as trauma, suffering, spiritual distress, and belonging. This capstone demonstrated how arts-based paradigms can be integrated with curricula to humanize bioethics education, foster community, and cultivate space for healing and transformation. By exploring diverse forms of embodiment and personhood through art, bioethics students can develop an attuned sensitivity to the complexities of the human moral experience. Future directions include semi-structured interviews to examine participant experiences in workshops and further inform pedagogy.

**Rémy Enoch, MS**, is an artist, educator, and researcher in adolescent health care. She received her BA in art history and studio art from the University of Virginia and her MS in narrative medicine from Columbia University. Rémy founded the Young Healers preventative intervention program based on her research at Johns Hopkins Bloomberg School of Public Health and Harvard T. H. Chan School of Public Health. Her work in bioethics stems from her passion for integrating narrative and arts-based frameworks within clinical and educational settings. Following graduation, Rémy will continue designing curricula and workshops for youth and adult learners to foster opportunities for experiential learning through empathy, embodied awareness, and narrative humility.



## Danielle Ferguson, JD

**Capstone Mentors: Wendy J. McHugh, RN, MS**, Clinical Nurse Ethicist, Beth Israel Deaconess Medical Center; **Leanne Homan, BSN, RN, MBE**, Clinical Ethicist, Beth Israel Deaconess Medical Center; Clinical Research Nurse, Massachusetts General Hospital; **David Urion, MD**, Associate Professor of Neurology, Harvard Medical School; Director, Learning Disabilities and Behavioral Neurology Program, Boston Children's Hospital

### **Face to Face: Investigating Racial Disparities in Clinical Ethics Consultations**

Recent attention has focused on disproportionately negative health outcomes for Black patients in the United States, yet little research has examined racial disparities in the clinical ethics consultation process. Specifically, the ethics literature regarding racial disparities in clinical ethics consultation is scant, consisting of predominantly qualitative metrics with little published quantitative data. To approach this knowledge gap, this capstone with the Ethics Support Service at Beth Israel Deaconess Medical Center (BIDMC) asked whether the racial demographics of the hospitals' clinical ethics consult requests reflected those of its patient population, and assessed associated qualitative metrics regarding those consults. The results showed that the proportion of consults requested for Black patients did not significantly differ from the proportion of Black patients at the institution overall (13% vs. 10% respectively). However, the study revealed a lack of additional racial, ethnic, and socioeconomic data about the hospital's ethics consultations. Data was also unavailable regarding whether ethics consultants' recommendations and consultation outcomes differed for Black patients, consistent with a national lack of data. Absent such data, the field of clinical ethics remains ill-equipped to address and respond to the needs of Black and other patients who belong to marginalized communities. Concerted efforts to address this knowledge gap nationally are imperative for clinical ethicists to understand the extent to which race, ethnicity, socioeconomic status, and implicit bias may contribute to requests for and outcomes of clinical ethics consultations.



**Danielle Ferguson, JD**, is an attorney currently transitioning to a career in healthcare. She received her BS in political science from Andrews University and JD from Western New England University Law School. In law school, Danielle received academic excellence awards for access to justice and environmental law. In her position at Baystate Healthcare, she assisted in investigating adverse clinical events, participated in policy development, and contributed to provider education in risk prevention. Danielle is interested in the role of racism and bias in clinical ethics consultations. After graduation, Danielle plans to utilize her legal and bioethical expertise to pursue a directorial position in compliance and ethics for a healthcare center.

Kelsey Flynn, RN, BSN

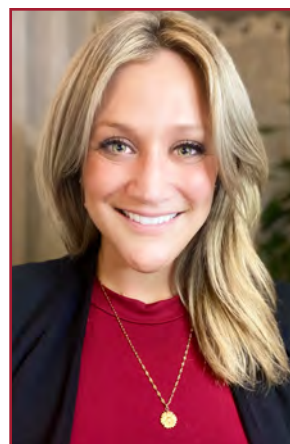
**Capstone Mentor: Aimee Milliken PhD, RN, HEC-C**

Member, Harvard Medical School Center for Bioethics; Clinical Ethicist, Nurse Scientist, and Director of Research, Brigham and Women's Hospital

**Measuring and Mitigating Moral Distress in the Oncology Nurse Population**

Nurses experience high levels of moral distress (MD). MD occurs when a person is unable to act according to their core values and perceived obligations due to internal or external constraints. Only four studies have assessed MD specifically in oncology nurses. Educational initiatives about clinical ethics and moral resilience have been shown to decrease levels of MD in other areas of nursing. To explore the possibility of bringing similar interventions into oncology nursing, this project measured the effects of a new educational intervention on MD levels and resilience in inpatient oncology nurses in two Boston hospitals. The program was developed by local clinical experts and featured information about clinical ethics, MD, career sustainability, and self-care practices. The program was delivered in January of 2022. Pre- and post-intervention surveys quantitatively measured program effects on participants' MD using the Measure of Moral Distress for Healthcare Professionals (MMD-HP) and the Rushton Moral Resilience Scale. Surveys also gathered qualitative data to assess the program's impact and to investigate previously unrecognized factors contributing to MD in oncology nursing. Pre- and post-intervention quantitative data from 65 participants showed little change in nurses' MD levels. However, qualitative results showed that program participation led to nurses feeling that their MD was "seen," heard, and validated. Participants requested future programming to address and mitigate MD. Given the prevalence of MD among oncology nurses, this study supports allocating funding to make such educational programs more available.

**Kelsey Flynn, RN, BSN**, is an inpatient oncology nurse at Massachusetts General Hospital. She received her BSN from The Catholic University of America. Kelsey advocates and provides for oncology patients with emphasis on family-centered care and patient education. She works with patients receiving chemo- and biotherapy, Phase-I clinical trials, and hospice and palliative care. Her interest in bioethics stems from her desire to improve her practice and to educate nurses in moral decision-making. Kelsey's work includes measuring and mitigating moral distress within the oncology nurse population in the Boston area. Following graduation, she will continue this work and expand understanding of clinical ethics as a best practice throughout the country.



## Kennan Gawlowicz, BS

### **Capstone Mentor: Barbara Bierer, MD**

Professor of Medicine (Pediatrics), Harvard Medical School; Senior Physician, and Faculty Director, Multi-Regional Clinical Trials Center of Brigham and Women's Hospital; Director, Regulatory Foundations, Law, and Ethics Program, Harvard Catalyst

### **Expanding Post Trial Drug Accessibility through Implementation of Access Planning as Part of Sponsor Responsibilities**

Stakeholders in research performed in low-and-middle-income countries (LMICs), including the pharmaceutical industry, investigators, funders, and government entities, have post-trial responsibilities (PTRs) to clinical trial participants once the research is completed. Existing guidance recommends the transfer of these responsibilities from sponsors to local governments over a transitional period once research is completed. However, clinical trial participants are not always guaranteed continued access to clinical trial therapeutics by their governments, especially in resource-limited settings where governments rely on sponsors' continued support. Further, researchers and communities may hold differing priorities regarding access to the medications being studied. This project explored the unique challenges that arise when research is conducted in LMICs. Informal interviews were conducted with principal investigators, academicians, and employees of large pharmaceutical companies to understand the degree to which stakeholders have an interest in supporting post-trial medication access in LMICs once the research concludes. These interviews revealed a general consensus that plans for continued access should be made. However, the ethical rationale for providing post-trial access varied according to individual patient considerations. Ultimately, this work concluded that because no person should be valued merely as a means to further the interest of others, access planning — the intentional planning of continued access to medicines shown to have clinical benefit for participants — should be required of sponsors prior to IRB approval.



**Kennan Gawlowicz, BS**, is a member of the Institutional Review Board (IRB) at Boston Children's Hospital. Kennan graduated magna cum laude from the University of Alabama at Birmingham with a BS in public health with a global health concentration. As an IRB analyst, Kennan manages the review of protocol submissions and maintains oversight for approximately 500 approved protocols, including 70 clinical trials. Kennan's interests lie at the intersection of intergovernmental relations, research ethics, and global health delivery. Kennan is specifically interested in the ethics of international clinical trials and expanding access to medicines for those in resource-limited settings. Kennan will continue pursuing her passion for human subjects research protection in clinical trials following graduation.

## Nkatha Gitobu, BS

**Capstone Mentors: Joan Gakii Masunga, MBE**, Research Fellow, Department of Global Health and Social Medicine, Harvard Medical School; **Sadath Sayeed, MD, JD**, Member, Harvard Medical School Center for Bioethics; Assistant Professor of Global Health and Social Medicine

### **Bioethical Analysis of Experiences Surrounding Implementation of the First Milk Bank in Kenya**

The World Health Organization (WHO) recommends exclusive breastfeeding for the first six months of life for optimal nutrition. Yet barriers to breastfeeding, including inadequate education about proper breastfeeding practices, insufficient milk production, and lack of access to donated breastmilk, remain common in Kenya, accounting for roughly 55-75% of slum-born child deaths. Recently, the Kenyan Ministry of Health established a pilot milk bank at Pumwani Maternity Hospital to increase access to donated breastmilk in hope of reducing childhood mortality. This capstone explored cultural practices that may present barriers to the utilization of donated breast milk by Kenyan tribeswomen. A qualitative analysis of the literature on maternal perceptions surrounding the use of donated breastmilk and cultural impacting breastmilk utilization revealed a prevalent negative regard for donated human milk. In addition, the literature documented traditional beliefs among certain tribes that may decrease mothers' use of breastmilk to feed their children, such as the belief that male infants need solid food early in life to nurture strong bones. Despite the potential health benefits milk banks offer, these findings suggest milk banks may place Kenyan tribeswomen in culturally compromising positions that might cause more harm than good. Enhanced sensitivity to the values and beliefs held by tribeswomen and tailoring interventions to address local barriers are essential steps if milk banks are to be successful in increasing breastfeeding rates and meeting WHO recommendations.

**Nkatha Gitobu, BS**, is a scholar and a model. They received their BS in microbiology, immunology, and molecular genetics from the University of California, Los Angeles. Nkatha's research focuses on ethical concerns surrounding the availability of breastmilk coupled with the integration of cultural beliefs on breastfeeding in Meru, Kenya. Their interest in bioethics concerns the intersection of science and intercultural awareness and adaptability. Following graduation, Nkatha intends to continue their bioethics scholarship by pursuing a terminal degree, with the goal of becoming a professor of bioethics.



Taylor Goss, MPH

**Capstone Mentors: Vardit Ravitsky, PhD, FCAHS**, Member, Center for Bioethics, and Senior Lecturer on Global Health and Social Medicine, Harvard Medical School; Professor, University of Montreal; **Tim Turnham, PhD**, Vice President of Client Services, VOZ Advisors

### **What is Important to Patients and Caregivers? Ethical Considerations in Cell and Gene Therapy**

Cell and gene therapy (CGT) raises a number of bioethical issues commonly discussed in the academic literature. However, the patient and caregiver voice is notably absent from these accounts. This project aimed to compare bioethical issues commonly discussed in the academic literature to the most pressing ethical issues identified by patients, caregivers, and advocates who stand to benefit from CGT. A scoping review of the academic literature identified four major themes in bioethics discussion of CGT: 1) informed consent and patient education, including pediatric assent and surrogate decision-making; 2) safety and efficacy; 3) cost and access; and 4) privacy concerns. Two roundtables were conducted in the US (n=11) and Europe (n=7) with patient communities to explore priority ethics issues in CGT. Qualitative analysis identified a central theme of poor communication from providers, investigators, and industry sponsors which resulted in uninformed or misinformed treatment decisions, disparities in access, and a broken informed consent process. Although overlapping with current themes in academic literature, there is a disconnect in language and ethical priorities between academic literature and patient communities. The disconnect could result in misplaced resource allocation and research funding, leaving gaps and unmet needs in patient and caregiver education and support. Including the patient and caregiver voice in CGT research and development is well-supported by feminist epistemological and bioethics theory. Doing so would provide researchers and bioethicists with a better understanding of how to guide ethical and scientific conversations forward in a way that is meaningful to all stakeholders.



**Taylor Goss, MPH**, is an associate for VOZ Advisors, a patient engagement and advocacy firm that advises biotechnology and pharmaceutical companies on incorporating the patient voice into drug development. She holds BS degrees in biomedical and health sciences from the University of Central Florida and received her MPH in health policy and management with a certificate in comparative effectiveness outcomes research from the Columbia University Mailman School of Public Health. Taylor's research has included menstrual health equity, opioid addiction in women, and patient perspectives on cell and gene therapy. She is interested in the moral, ethical, and legal dimensions of clinical decision-making and plans to pursue a patient-facing clinical role in the future.



Eliana Greenberg, BA

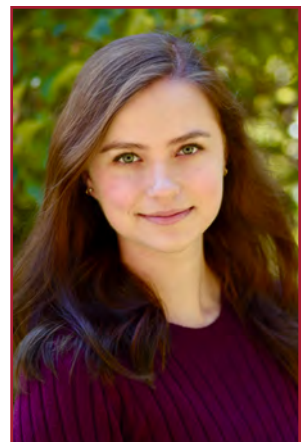
**Capstone Mentor: Francis Shen, JD, PhD**

Member, Harvard Medical School Center for Bioethics; Professor of Law, and McKnight Land-Grant Professor, University of Minnesota

**Biological Explanations for Sexually Violent Behavior in United States Courts: Analysis of Judicial Opinions 2020-2021**

Whereas neuroscientific and genetic explanations for murder have increasingly been introduced into U.S. legal proceedings, questions remain about the legal use of biological explanations for sexually violent behavior. This capstone explored some of these questions through an analysis of 2020-2021 U.S. appellate judicial opinions. Multiple legal databases were reviewed to construct a dataset of 27 cases in which an offender was convicted of a sex offense and attempted to present a biological explanation for their criminal conduct in order to mitigate their sentence. Because biological explanations are rarely pursued in cases involving only sex offenses, the majority of cases additionally involved murder. A systematic analysis found that the most common biological explanations were brain-based, namely head injury and frontal lobe dysfunction. Approximately two-thirds of cases were habeas corpus petitions in which the biological explanation was raised in the context of a claim of ineffective assistance of counsel. Only three offenders prevailed on this claim; in all three cases, a failure to present the biological explanation co-occurred with the failure to present other mitigating evidence. Overall, judges did not appear to give biological explanations for behavior more weight than other mitigating factors such as mental illness or childhood trauma. Biological explanations were nearly always utilized to explain violent behavior in general, rather than addressing the sexual aspect of an offender's criminal conduct. Future research is needed to increase understanding of the bases of these patterns.

**Eliana Greenberg, BA**, earned her BA in human biology from Stanford University with a self-designed concentration in biological and behavioral approaches to justice. Before coming to Harvard, Eliana worked as a paralegal in a law firm representing victims of workplace discrimination and harassment. She is particularly interested in the interactions among science, medicine, and the law, and how professionals in these fields evaluate each other's disciplines and conceptualize morally challenging issues. Following graduation from the MBE program, Eliana will attend law school.



## Celeste Hsu, BA

**Capstone Mentors: Ingrid A. Holm, MD, MPH**, Member, Center for Bioethics, and Professor of Pediatrics, Harvard Medical School; Attending Physician, Division of Endocrinology, and Division of Genetics and Genomics, Boston Children's Hospital; **Nina Gold, MD**, Geneticist, General Pediatrician, and Attending Physician, Division of Medical Genetics and Metabolism, Massachusetts General Hospital for Children

### **Understanding Ethnically and Racially Diverse Parental Perspectives on Disorder Preference in Genomic Newborn Screening Results**

With recent advances in genomic sequencing technology, future newborn screening (NBS) could include screening for any known genetic disorder. It is crucial that a broad range of ethnic and racial populations are engaged in any research that will inform how genomics are integrated into NBS in order to ensure this integration occurs in a just and ethical manner. This study examined how parents from communities under-represented in research view the information that could become available to them if genomic sequencing were included in NBS. In two 75-minute focus groups with parents from under-represented communities, participants reflected on the types of disorders they would like to receive NBS results for: severe vs. non-severe, preventable vs. non-preventable, and adult-onset conditions. Audio recordings of the focus groups were transcribed and coded for themes and domains. Preliminary findings suggest that participants generally desire sequencing results regardless of disease severity or preventability, whereas results about adult-onset disorders were less preferred. Participants who were hesitant to receive results cited uncertainty about the development of disease as the main reason. Participants identified more education about the NBS process as the most important change they wished to see. These results, and those of a larger Greenwall Foundation-funded project on diverse parental perspectives about genomic NBS, will advance the crucial ethical commitment of ensuring community views, barriers, and impact on families inform the future integration of genomics into NBS.



**Celeste Hsu, BA**, earned her BA in molecular and cell biology and psychology from the University of California, Berkeley. As an undergraduate, she conducted research on jellyfish neural networks, competed as a member of the Cal Figure Skating Team, and volunteered as an EMT. She is particularly interested in clinical ethics, medical decision-making, neuroethics, and genomic testing in healthcare settings. She won the Cell and Developmental Biology Best Poster Award for her senior honors thesis research on the neuroscience of sleep-like states in jellyfish. After graduation, Celeste will attend medical school at the University of California, San Diego, where she will integrate her bioethics experience with her practice of medicine.

## Georgina Jorge Ramírez, BA

### **Capstone Mentor: Bizu Gelaye, PhD, MPH**

Member, and Co-Director of Research Ethics, Harvard Medical School Center for Bioethics; Assistant Professor of Psychiatry, Massachusetts General Hospital and Harvard Medical School; Assistant Professor of Psychiatric Epidemiology, Harvard T. H. Chan School of Public Health

### **Gender-Based Violence in the Mexico City Metropolitan Area: A Bioethical Analysis**

During the COVID-19 pandemic, Mexico City adopted strict public health restrictions that included stay-at-home orders. These orders confined many female victims of gender-based violence (GBV) in living spaces alongside their aggressors. This capstone project sought to explore the silent pandemic of GBV resulting from COVID-related confinement. First, the project undertook a conceptual analysis of violence and GBV, exploring meanings of each and notions of moral responsibility that frame attention to the latter. This analysis clarified the importance of recognizing GBV as a distinct category of violence. In addition, it highlighted the importance of adopting a contextualized understanding of GBV, with attention to the unique economic, cultural, and social factors surrounding GBV within a particular setting. Second, the project reviewed secondary data published by national and international institutions to assess the rate of complaints of GBV in the period corresponding to the pandemic. This review found a positive correlation between GBV complaints and COVID-related confinement. Deficiencies in reporting were identified as a barrier to accurately estimating the number of women who suffer GBV. Finally, an ethical analysis identified principles of justice and non-maleficence as relevant ethical commitments for governmental authorities addressing GBV. This work will proceed through a journalistic lens to further develop attention to and work on GBV in Mexico City.

**Georgina Jorge Ramírez, BA**, is a political scientist, activist, and educator. She received her BA with honors in political science and public administration from the National Autonomous University of Mexico and participated in the 2015 Sherwin B. Nuland Summer Institute in Bioethics at Yale University. She is a founding member of the NGO Somos Empatía AC, which focuses on civic and political education, and has also worked with Marie Stopes Mexico, Proyecto Desprincesamiento and Proyecto Andrómeda. Her bioethical interests include gender equity, the relationship between technology and politics, theoretical ethics, and social neurosciences. Following graduation, she will return to Mexico to continue her activism while applying to PhD programs in bioethics and philosophy.



## Maggie Kirber, MSW

### **Capstone Mentor: Lisa Moses, VMD**

Member and Research Fellow, Global Health and Social Medicine, Harvard Medical School Center for Bioethics; Visiting Scientist, Vertebrate Genomics Group, Broad Institute of MIT

### **Broadening the Scope: Bioethics' Consideration of Nonhuman Animals**

Humans are interconnected with nonhuman animals in arguably every aspect of life, from the food humans eat and the clothing they wear, to the household products they use and the medicines that save human lives. Survival of the human species, along with that of other species humans depend upon, is at risk due to anthropogenic planetary changes. This capstone project examined the extent to which nonhuman animals are included in the field of bioethics. A systematic PubMed search was conducted to identify the prevalence of scholarly bioethics articles dealing with nonhuman animals. It yielded few results; for example, only 23 articles containing MeSH terms bioethics and nonhuman animals were identified. Most of these focused on animals as biomedical research models. Of these, several works recounted competing visions of the field at its origins, including Van Rensselaer Potter's original conception of bioethics, which included the environment and nonhuman animals in its scope. Renewed interest in this framework is reflected in a recent increase in published calls for a return to Potter's more comprehensive conceptualization of the field. Bioethics graduate curricula were also surveyed to determine the extent of nonhuman animal inclusion in bioethics education. Only five of the 32 programs included in the survey listed environmental or animal ethics courses, reinforcing a strong bias toward the more widely accepted medical focus of the field. These investigations suggest that there is a gap in bioethics concerning nonhuman animals. Given human dependence on nonhuman animals, this lack of bioethical consideration is ethically problematic and has negative implications for the field's stated goal of promoting human flourishing.



**Maggie Kirber, MSW**, is a clinical social worker in the medical/surgical intensive care unit (MSICU) at Boston Children's Hospital (BCH). Maggie earned her BA from Bates College and her MSW from Simmons College. Maggie's current work in the MSICU focuses on supporting families of critically ill children including crisis intervention, child protection work, and bereavement support. Maggie is a member of the BCH Ethics Committee. Her bioethical interests include decision-making in pediatrics, particularly at end-of-life and for children in custody of the Department of Children and Families. She has a personal interest in nonhuman animal and environmental ethics. After graduation, Maggie will continue her work in the MSICU and on the Ethics Committee at BCH.

Ryan Lam, BSA

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

Member, Center for Bioethics, and Associate Professor of Psychology, Harvard Medical School; Clinical Psychologist, Nurse, and Bioethicist, Boston Children's Hospital

**Empathy and Informed Consent in Anesthesiology Practice**

Informed consent is a crucial element in healthcare, yet anesthesiologists face significant barriers to obtaining this consent. In encounters that typically last no longer than ten minutes, anesthesiologists must establish a trusting relationship with their patients and obtain consent for highly stressful anesthetic procedures. One way anesthesiologists can quickly establish rapport with their patients is through empathy. This capstone project identified ways anesthesiologists can express empathy during the informed consent process and examined how an understanding of empathy could contribute broadly to healthcare settings. It began with a literature review to gain familiarity with current clinical conceptions of empathy and then developed and piloted a semi-structured qualitative interview protocol with practicing anesthesiologists. The literature review revealed that current definitions of empathy in medicine capture only a limited range of empathy expression and support personalized approaches sensitive to the particularities of each patient encounter. Interview findings included the emergence of three major themes: expressions of empathy in anesthesiology vary with the clinical circumstances of each encounter, anesthesiologists are heavily constrained by time, and empathy education is lacking. Specific ways anesthesiologists demonstrated empathy included offering warm blankets, repeating patients' concerns back to them, and following up after surgeries. These findings have implications to broaden the scope of what constitutes the expression of empathy in anesthesiology, and to highlight concerns related to temporal pressures and the need for educational reform.

**Ryan Lam, BSA**, received his BSA in biochemistry with a minor in philosophy from the University of Texas at Austin (UT). At UT, he conducted research analyzing linguistic trends in physician consultations and their impacts on patient outcomes. He also spent several years as a photographer for the university newspaper, The Daily Texan. Ryan is interested in the nexus of philosophy and bioethics, such as how ordinary language philosophy and conceptual engineering can be used to better understand bioethical issues. Ryan plans to attend medical school after completing his MBE.



Kristina Baldwin Larson, JD

**Capstone Mentor: Insoo Hyun, PhD**

Member, Center for Bioethics, and Senior Lecturer on Global Health and Social Medicine, Harvard Medical School; Director, Center for Life Sciences and Public Learning, Boston Museum of Science

**Stem Cell-Based Therapy for Parkinson’s Disease: Patient Engagement and the Ethics of Sham Surgery**

Ensuring that clinical research goals and study designs align with the needs and concerns of patients is fundamental to conducting ethical human subject research. Patient engagement (PE) is the process by which patient values are ascertained and incorporated within the research enterprise. This project considered the role of PE in connection with clinical trials of stem cell-based therapy (SCBT) for Parkinson’s Disease (PD). A literature review mapped the landscape of ethical concerns associated with SCBT for PD and examined the ways in which PE intersects with these considerations. Interviews with leading clinical researchers in the field and the director of PE at an international PD advocacy organization probed expert perspectives on (1) which ethical issues require multi-stakeholder deliberation and (2) mechanisms for conducting PE in this context. Transcript analysis revealed unanimous agreement that the use of simulated operation (“sham surgery”) to facilitate double-blinded randomized controlled trials for clinical studies of SCBT for PD is unethical. However, interviewees nonetheless believed that sham surgery would be required by the US Food and Drug Administration. The next phase of this project will develop a PE module (including a recorded audio component and facilitated Q&A session) to address the ethical permissibility of sham surgery for SCBT trials with relevant stakeholders, including neurologists, clinical researchers, current SCBT trial participants, and others within the PD patient community.



**Kristina Baldwin Larson, JD**, received her BA from Princeton University and her JD from Columbia Law School. She participated in the 2015 Sherwin B. Nuland Summer Institute in Bioethics at Yale University and has taught courses in the History of Medicine at Stevens Institute of Technology. She currently acts as a course coach at the John F. Kennedy School of Government at Harvard University. Kristina is interested in neuroethics, medical research ethics, public engagement in science, and bioethics pedagogy. Her recently published research analyzed data sharing intentions for COVID-related interventional trials. After graduation, Kristina will continue her teaching and scholarship with a goal of facilitating mutual learning among scientists, clinicians, and patients with Parkinson’s Disease.

## Arielle Lawson, BA

### **Capstone Mentor: Ole Frithjof Norheim, MD, PhD**

Adjunct Professor, Harvard T. H. Chan School of Public Health; Professor of Medical Ethics, University of Bergen; Director, Bergen Centre for Ethics and Priority Setting

### **The Role of Health as a Human Right in the Development of Universal Health Coverage Plans**

It is unclear whether arguments surrounding a human right to health actually play a role in practical decision-making processes, including those in which governments and other entities set priorities for what should be included in universal health coverage (UHC). This capstone project sought to (1) examine whether and how ethical arguments about a right to health play a role in the development of priority guidelines in UHC, and (2) assess how useful human rights language is to the practical implementation of UHC. To gain insight into these topics, this capstone began with a literature review surveying existing discourse on the subject and then collected data from interviews with five human rights, legal, and UHC scholars, focusing on their professional experiences at the intersection of health as a human right and UHC. These interviews revealed that, while health as a human right is not often explicitly involved in the development of priority guidelines in UHC, it does undergird many discussions and serves to promote human dignity. However, the data also showed that human rights language presents challenges insofar as there is no common understanding of what a right to health entails, thus highlighting barriers to translating a human right to health from theory into practice, especially in resource-limited settings. Given that UHC is inherently designed for resource-limited environments, going forward, effective human rights arguments may require resource-conscious constraints when used as a justification for UHC.

**Arielle Lawson, BA**, received her BA in philosophy from Princeton University. Prior to beginning the MBE program, Arielle completed a fellowship at the Burke Foundation, a private grantmaking organization working to address inequities in maternal health and early childhood development by funding innovative initiatives. Arielle's bioethical interest in public health ethics, human rights, and the just allocation of scarce resources stems from her undergraduate research, which focused on the moral issues and obligations that arise from disparities in health outcomes. After completing the MBE program, Arielle will attend medical school.



Vy Ly, BS

**Capstone Mentor: Eric Krakauer, MD, PhD**

Member, Harvard Medical School Center for Bioethics; Associate Professor of Medicine, Department of Global Health and Social Medicine; Attending Physician, Division of Palliative Care and Geriatrics, Massachusetts General Hospital

**Understanding and Re-interpreting Filial Piety (*Hiếu*) in the Context of Invasive Life-Sustaining Treatments in Vietnam**

Filial piety (Vietnamese: *hiếu*) is the duty to obey and care for one's familial elders, and it is a core tenet of Confucianism that has firmly withstood the test of time in Vietnam. This expectation for familial devotion may conflict with the optimum use of invasive life-sustaining treatments (LSTs) and lead surrogate decision-makers to push for their universal use in all contexts in order to fulfill their filial duties, regardless of potential harms and the patient's values and wishes. This project aimed to understand the traditional role of filial piety in Vietnamese modern medicine and offer a re-interpretation that could minimize the harm of administering LSTs. The project began with a literature review on filial piety in Confucian literature and its role in Chinese and Vietnamese cultures to demonstrate that it is a dynamic value that has historically been adapted to fit into the current social context. Subsequently, an ethical analysis demonstrated that minimizing the usage of LSTs in certain cases could still be considered to be fulfilling one's filial duties using systems of virtue ethics from Confucius and Le Huu Trac, regarded as the father of Vietnamese medicine. The findings of this project provide a more protective definition of filial piety that allows Vietnamese physicians to have more nuanced conversations with their patients and family members regarding administering harmful and/or ineffective LSTs.



**Vy Ly, BS**, received her BS in neurobiology with a minor in philosophy from the University of California, Davis. She has led National Alzheimer's Buddies, a nonprofit organization that aims to address the social isolation associated with dementia. She has also worked at various health clinics to advocate for under-resourced communities. Her bioethical interests include the role of culture in patient autonomy and decision-making, global perspectives in palliative care and end-of-life care, and health equity. After completing the MBE program, Vy will continue her work in bioethics and advocacy in medical school.



## Virginia “Gigi” Morris, BA

### **Capstone Mentor: Anna Gosline, SM**

Executive Director, Massachusetts Coalition for Serious Illness Care;  
Vice President, Executive Office, Blue Cross Blue Shield of Massachusetts

### **Be My Voice: A Video to Prepare Health Care Decision-Makers for the Job Ahead**

Over the past three decades, significant resources have gone into promoting advance care planning (ACP) as a way of ensuring that patients get the care they want when they can no longer speak for themselves. Recent literature shows that these efforts—for example, signing a living will, assigning a health care agent, and discussing one’s wishes, values, and goals of medical care—have largely failed in preventing patients from getting excessive and unwanted treatments. In addition, those appointed to make decisions on behalf of patients often are traumatized by the decision-making process. Although many factors contribute to the failures of ACP, dozens of interviews with clinicians and family members over many years suggest that people are woefully unprepared for the emotional aspects of this task. This capstone explored a new approach to ACP by creating a video to prepare people emotionally and practically for the decisions ahead. It aimed to help them understand, in the simplest terms, the complexities, uncertainties, instinctual responses, fear, and grief that often arise when a loved one is critically ill, and to offer recommendations on how to be a more effective agent. This capstone culminated in a brief (under 3 minutes), cartoon-style video developed in collaboration with a filmmaker. Plans are underway to secure funding for focus groups, create a final video and website, and make the video widely available for viewing at any stage in the decision-making process.

**Virginia “Gigi” Morris, BA**, is a medical writer, lecturer, and clinical instructor at Dartmouth’s Geisel School of Medicine. She is also a member of the Ethics Committee at Dartmouth-Hitchcock Medical Center. She received her BA from Princeton University. She is the author of *Talking About Death and How to Care for Aging Parents*, the latter of which won the Books for a Better Life Award and was featured on Oprah, Good Morning America, The Today Show, CBS This Morning and other national media. Her current work focuses on doctor-patient-family communication and serious illness decisions. Going forward, Gigi hopes to create video content to prepare health care agents for the job ahead.



## Theodore Oja, BS

### **Capstone Mentor: Brendan Abel, JD**

Member, Harvard Medical School Center for Bioethics; Legislative and Regulatory Affairs Counsel, Massachusetts Medical Society

### **Ethical Issues in the Self-Administration Requirement in Medical-Aid-in-Dying Statutes**

Patients unable to self-administer medications are not accommodated in present Medical Aid in Dying (MAID) statutes. This capstone project evaluated self-administration requirements in light of the “slippery slope” to euthanasia alleged by professional societies, moral theorists, and politicians by assessing all MAID statutes in the United States for restrictive language such as “physical” or “ingestion” that have limited MAID self-administration methods. Statutes differed in their specification of acceptable administration methods and pharmaceutical vectors. Patient coercion or lethal injection by a physician or third party was explicitly prohibited in all statutes. Every statute specified self-administration, but no statute accommodated patients incapable of doing so or had a requirement for clinical oversight of self-administration. An increasing proportion of patients opt to self-administer in settings with no clinician present. Current statutory language renders those who facilitate self-administration susceptible to criminal prosecution for homicide at the state’s discretion. Patients who cannot self-administer are informally accommodated through a lack of criminal prosecution of potential violators, a broad practical interpretation of self-administration, and a lack of observation requirements for the act of self-administration. These practices are not sustainable, and the absence of provisions for those unable to self-ingest remains discriminatory. Present and future MAID statutes should implement a non-restrictive self-administration clause and provisions for third-party assistance if the patient is incapable of self-administration. Next steps include drafting a legislative brief outlining the findings of this capstone project and suggesting statutory language for self-administration and third-party assistance.



**Theodore Oja, BS**, is a former United States Coast Guard technician, instructor, and aircrew for the MH-60T search and rescue aircraft. He received his BS in molecular and cellular biology from the University of Puget Sound. His primary interests in bioethics include disparities in healthcare attributable to the financial standing of the patient as well as medical aid in dying. He received two operational letters of commendation, an achievement medal, and an arctic service ribbon during his active-duty enlisted service. Following graduation, he intends to pursue a law degree and focus his career on correcting healthcare disparities in the US.

## Reina Ozeki-Hayashi, MD, MPH, PhD

### **Capstone Mentor: Robert Truog, MD**

Director, Center for Bioethics; Professor of Medical Ethics, Frances Glessner Lee Professor of Legal Medicine, and Professor of Anaesthesia and Pediatrics, Harvard Medical School; Senior Associate in Critical Care Medicine, Boston Children's Hospital

### **Comparing American and Japanese Neurologists' Attitudes Regarding Artificial Ventilation for Amyotrophic Lateral Sclerosis (ALS)**

Whether to accept or reject tracheostomy invasive ventilation (TIV) is a hard decision for ALS patients, their families, and neurologists, in part because once accepted, TIV is rarely discontinued. The aim of this capstone project was to compare the attitudes of American and Japanese neurologists regarding the withdrawal of TIV. First, a literature review was conducted to identify ethical challenges in the decision-making process for TIV. The literature review found that ALS patients are influenced by family and physicians in their TIV decision-making. Japanese neurologists hesitate to withdraw TIV for ALS patients because of fear of criminal prosecution. Even if the neurologists believe the patient has the right to refuse unwanted treatment, withdrawal of TIV for ALS patients remains difficult for neurologists. Finally, the review found there is a substantial gap between neurologists' personal preferences and their professional recommendations for TIV for ALS in Japan. A comparative qualitative study with neurologists in the US and Japan was planned to explore the factors driving this personal-professional gap. The research will include semi-structured online interviews with four to six neurologists in each country. In pilot interviews with Japanese neurologists, two factors were identified for further exploration in the formal study, including the belief among Japanese neurologists that patients' lives hold meaning for both patients and their families, as well as neurologists' perceptions of psychological pressure from Japanese ALS advocacy groups to maintain TIV for patients. These pilot interviews suggest an urgent need for ethical support for neurologists making decisions about TIV.

**Reina Ozeki-Hayashi, MD, MPH, PhD**, received her MD from Sapporo Medical University, Japan, and her MPH and PhD from the Graduate School of Medicine at University of Tokyo. She started her career as a gastroenterologist and trained in palliative medicine in Japan. Her PhD thesis was a qualitative investigation of beliefs held by breast surgeons that impact the treatment decision process for advanced breast cancer patients. Prior to pursuing her MBE, she was an assistant professor in the Department of Biomedical Ethics, University of Tokyo. Reina's current research interests relate to medical futility and decision-making processes at the end of life. She plans to continue bioethics research after completing her MBE.



Alyssa Panton, BA

**Capstone Mentors: Jennifer McGuirl, DO**, Instructor in Pediatrics, Harvard Medical School; Attending Neonatologist, Brigham and Women's Hospital; **Brittany Seymour DDS, MPH**, Associate Professor and Global Health Discipline Director, Harvard School of Dental Medicine

### **Development of a Pediatric Oral Health Care Decision Aid to Promote Dental Homes**

The quality of patient-provider relationships influences health outcomes. In addition, effective communication between both parties enhances patients' autonomy over their health. Both are linked to an increase in the likelihood of treatment follow-through and satisfaction. Decision aids (DA) are informed decision-making tools used primarily in clinical settings to foster open communication, reduce medical paternalism, and promote patient autonomy. This project created a DA in support of the dental home concept and tested its impact on adherence to recommendations for children to first see a dentist within six months of primary tooth eruption or by twelve months of age. The DA was implemented as a quality improvement project in the Connected Care Program (CCP) at Included Health, a telehealth and navigation company. The CCP is a care and case management program that provides support to families and their newborns through the first year of life, including addressing social determinants of health needs. Clinicians within the newborn and pediatric care system at CCP introduced the DA to patient families at their 9-month primary care check-up. Prior to the intervention, surveys indicated a baseline rate of 45 percent of families with 12-month-olds who had considered a dental appointment. Survey data after the intervention showed an increase in the number of families who considered a dental appointment. The goal of this quality improvement measure is to promote a 10% increase in targeted behaviors at the 12-month checkup.



**Alyssa Panton, BA**, received her BA in history and science with an emphasis on science and society as well as a language citation in Twi from Harvard College. As an undergraduate, she competed as a Division 1 athlete for the Harvard Crimson Dance Team and served as editor-in-chief of Synthesis, the nation's only undergraduate history of science research journal. She is interested in exploring bioethics in the context of dental medicine and in expanding access to oral healthcare. Her most recent publication focuses on effective messaging in the transnational infant oral mutilation movement. After completing her MBE, Alyssa plans to become a dentist.

Sarah Grace Parker, BSN

**Capstone Mentor: Katherine Peeler, MD, MA**

Member, Center for Bioethics; Instructor of Pediatrics, Global Health and Social Medicine, Harvard Medical School; Medical Director, Harvard Medical School Asylum Clinic; Instructor in Pediatrics, Boston Children’s Hospital

**Violations of Medical Neutrality: Moral Indifference and the Weaponization of Healthcare**

The principle of non-interference with medical care during armed conflict or civil unrest, or Medical Neutrality (MN), is a core concept of international human rights law and medical ethics. However, despite this long-established principle, violations of MN are a growing global epidemic as depicted by events in Syria, Afghanistan, Myanmar/Burma, Turkey, Israel, Bahrain, Yugoslavia, and, most recently, Ukraine. This project aimed to assess the causal link between moral indifference (MI), lack of action on behalf of the international community towards holding violators of MN accountable, and the weaponization of healthcare. MI refers to inaction in the face of clearly defined moral transgressions as action in itself. In this project, a systematic review of the literature and world events suggested that increased reporting of MN violations has not led to increased prosecution, or increased international condemnation. Instead, repeated and deliberate attacks on healthcare workers and facilities globally have highlighted a distinct and effective war strategy: The Weaponization of Healthcare (WOH). Findings showed that MI and stagnant condemnation have led to the normalization of human rights violations related to MN with attacks on health care becoming a standard and effective weapon of war. By continuing to simply condemn rather than to act, the international community has become complicit in current (and responsible for future) violations of MN, and subsequently the WOH. This idea and the ethical theories and real-world events supporting it will be explored in a forthcoming academic manuscript.

**Sarah Grace Parker, BSN**, is a global health nurse, human rights advocate, and filmmaker. She received her BSN from Marquette University. Over the past decade, Gracie has worked in community outreach programs, hospitals, and clinics in more than 13 countries, focusing on the health and human rights of vulnerable populations. Gracie’s extensive work in film and television development and production focuses on socially relevant content that advocates for the discussion of ethical issues. Her interest in bioethics stems from her work in healthcare and advocacy and from a desire to elucidate complex ideas through narrative storytelling. After completing her MBE, Gracie plans on attending law school.



## Ausubel Pichardo, BA

### **Capstone Mentor: Kelsey Berry, PhD**

Associate Faculty Director, Master of Bioethics Degree Program, Co-Director, Virtual Master of Bioethics Degree Program, and Lecturer in Global Health and Social Medicine, Harvard Medical School

### **Preventing Financial Toxicity in Healthcare: Organizational and Ethical Obligations**

Oncology patients who endure financial hardship are likely to die sooner than those who do not. About 80% of patients wish to talk with their oncologists about healthcare finances and the burden they impose on patients' lives. Medical bankruptcy forces patients to decline treatment, borrow money, work while sick, and rely on charity (when available). Financial burdens also challenge healthcare teams to reevaluate care delivery to manage patient needs for financial assistance. This capstone project focused on exploring the following question: Do hospitals have an ethical obligation to prevent the financial toxicity of oncology care? It included a literature review and participation in ethics and institutional policy-making committees to address this question and identify practical steps forward. The literature review found that society owes financial protections to patients as a form of egalitarian justice, and hospitals share some of that responsibility. Hospitals rely heavily on charity care to fulfill this promise. However, charity care is not sustainable and reflects the current systemic inequality in medicine. Discussions in organizational meetings and medical ethics committees highlighted hospitals' challenges in accurately assessing the multidimensional needs of vulnerable populations, like the poor. The findings indicated a need for a tool to educate providers on identifying and combating the risks of financial toxicity while upholding principles of clinical ethics. Hospitals are not necessarily the sole body responsible for preventing financial toxicity, but function as "systemic patient navigators" that play a critical role in advocating for justice and a fair opportunity for healthcare access.



**Ausubel Pichardo, BA**, is an implementation specialist for a global health technology company. He received his BA from the University of Massachusetts, Dartmouth, where he studied philosophy and anthropology. His work focuses on helping hospitals deploy software platforms to identify barriers that prevent access to care. He is interested in exploring the ethical and cultural dilemmas that transnational patients experience in navigating medical and surgical care and clinical trials. Ausubel's goal is to write and teach about the bioethics of healthcare costs.

## Alexander Quan, BS

### **Capstone Mentor: Carol L. Powers, JD**

Co-Founder and Chair, Harvard Medical School Community Ethics Committee;  
Member, Board of Trustees, Lawrence General Hospital

### **Applying the Ethics of Workarounds to the Contingency Allocation of Scarce Medical Resources**

Contingency measures are informal modifications to the allocation of space, staff, and supplies to preserve limited resources during hospital surges. These measures mediate between usual care and formal crisis standards of care. However, there is little consensus about the allocation process, decision-makers, or guiding principles of a contingency response, raising ethical concerns. This capstone constructed an ethical framework for contingency allocation, drawing in part on experience with community and hospital working groups on contingency care. This ethical framework approached contingency measures through the lens of workarounds: informal solutions used by healthcare providers to provide patient care otherwise unavailable through formal institutional processes. Viewing contingency measures as workarounds highlighted three directions for guiding ethical contingency allocation. First, it anticipated a decrement in care when allocating on the basis of resource limitations, challenging a frequent assumption that contingency care is functionally equivalent to usual care. Second, it recognized the moral stake of providers in making difficult allocation decisions by acknowledging that a “do more with less” attitude towards scarcity can lead to *ad hoc* rationing, inequitable allocation, and moral injury. Lastly, it required transparency and collaboration among providers, hospitals, and communities to encourage creative solutions to resource scarcity constraints. Future directions include monitoring patient outcomes for patterns of bias and unintended consequences, establishing official avenues for inter-hospital resource sharing, and creating institutional guidelines to help providers navigate allocation decisions with patients during periods of contingency scarcity.

**Alexander Quan, BS**, graduated summa cum laude from Santa Clara University (SCU) with a BS in neuroscience and minors in art history, biology, and philosophy. As a volunteer EMT and quality assurance officer for SCU Emergency Medical Services, Alex updated protocols for COVID-19 and developed strategies to train shift leaders remotely. His interests include the ethical allocation of medical resources during healthcare surges, particularly related to contingency standards of care. At SCU, Alex was a Johnson Scholar, a Honzel Fellow in Health Care Ethics, and the 2021 Nobili Medal recipient. After completing his MBE, Alex will pursue his MD at NYU Grossman School of Medicine.



## Anjelo Luis Reyes, BA

### **Capstone Mentor: Vardit Ravitsky, PhD, FCAHS**

Member, Center for Bioethics, Senior Lecturer on Global Health and Social Medicine, Harvard Medical School; Professor, University of Montreal

### **Making Amends: A Bioethical Response to the Use of Data Sourced from Unethical CRISPR Trials**

As novel reproductive technologies emerge, premature, irresponsible misuse is likely to occur. In 2018, Dr. He Jiankui used CRISPR technology unethically to genetically modify embryos, leading to the birth of three children. This capstone project aimed to understand how the scientific community should respond to such incidents, with a specific focus on whether the data gathered from Dr. He's trials should be published or used. The project used the case study of Nazi experimentation in World War II to broadly examine ethical approaches to data gathered from unethical experiments. Though this project does not suggest a direct analogy between the two cases, it found that several lessons from the historical tragedy of Nazi experimentation are applicable to the current dilemma posed by data unethically obtained from Dr. He's CRISPR trials. The scholarly literature reveals a broad consensus that data obtained in the context of unethical trials should not be used or published except to save lives or mitigate harm. Given that the data sourced from Dr. He's trial may mitigate future harm for his subjects, it may be ethically acceptable to use or publish his findings. These findings must be presented carefully, so as not to encourage further unethical use of CRISPR technology in the future.



**Anjelo Luis Reyes, BA**, received his BA in liberal arts with a focus on philosophy and the history of mathematics and science from St. John's College, New Mexico. There, he served as a senior lab assistant, as founder and president of the American Red Cross Club, and as a Red Cross volunteer in his community. In bioethics, Anjelo is interested in how new medical technologies should be integrated into society, as well as understanding their ethical, political, and legal implications for the future. Upon completing his MBE, Anjelo plans to begin working in the field of healthcare administration.



## Raiany Romanni, MA

### **Capstone Mentor: Jeantine E. Lunshof, PhD**

Lecturer in Global Health and Social Medicine, Harvard Medical School;  
Philosopher and Ethicist, Wyss Institute for Biologically Inspired Engineering;  
Assistant Professor of Genetics, University Medical Center Groningen

### **A New Ethics for Aging Research: Moving Past Mainstream Ethical Objections**

Aging is arguably the most expensive challenge of the 21st century, costing the US nearly half of its federal budget every year. Several laboratories have produced evidence suggesting that the mechanisms of human aging can be reversed. Yet although 80 percent of an average individual's medical expenses occur past age forty, only 1 percent of all funding available through the National Institutes of Health goes to fundamental aging research. Low funding for longevity research may stem from ethical objections to the treatment of aging as a medical condition. Accordingly, this capstone sought to identify and respond—through literature review and philosophical reasoning—to ethical objections to successful aging therapies, including 1) scarcity of resources, 2) inequitable access, and 3) loss of meaning. The review found that in techno-progressive societies, misdistribution, not scarcity, of resources is the pertinent ethical issue. In such societies, longevity research may prove instrumental to maintaining population size in the face of expected declines. The review also suggested that bioethical discussions on inequitable access often overlook dynamics of drug price depreciation. Future ethical arguments should proceed on the premise that aging therapies can be made affordable. Finally, this project identified the concern that humans, by engineering themselves out of aging, would lose a key frame for ascertaining the meaning of life. This would be neither the first, nor the last, time humans would be tasked with creating meaning for themselves. As technology develops, the question of how meaning ought to be ascribed to life will repeatedly emerge, creating an opportunity, and a need, for continued reflection.

**Raiany Romanni, MA**, is a PhD Candidate in German philosophy at Brown University. She received her MA in comparative literature from Dartmouth and her BA in international relations with a focus in philosophy from the Jagiellonian University. She has written extensively on the subject of death with the goal of understanding the secular narrative of the biological process of aging as a mystico-teleological phenomenon designed to furnish human life with meaning. She is a Harvard Kennedy Fellow in effective altruism and a Stanford Existential Risk Fellow, and was recently named an A360 Scholar by XPrize. Following graduation, she will continue her scholarship on death and aging.



Annina Seiler, PhD

**Capstone Mentor: Richard E. Leiter, MD, MA**

Attending Physician and Researcher, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute

**Moral Distress in Palliative Care Clinicians at Three Academic Medical Centers**

Moral distress refers to a clinician's inability to do what they assess to be the ethically appropriate action due to internal or external constraints. Palliative care clinicians (PCCs) regularly face ethical dilemmas in serious illness and end-of-life care, but little is known about their resultant experience of moral distress. Moral distress may impact PCCs' attitudes towards ethics consultation services, including whether and when PCCs call for consults. Despite a broad endorsement of ethics consultation by palliative care specialty organizations, there is limited data regarding its use, perceived effectiveness, and role in mitigating clinicians' moral distress. The aim of this study was to examine PCCs' recent experiences of moral distress, their satisfaction with ethics consultation services, and possible relationships between these variables. This study also evaluated the prevalence and severity of moral distress among PCCs during the COVID-19 post-pandemic period. Moral distress was measured using the validated Measure of Moral Distress for Health Care Professionals (MMD-HP). The MMD-HP was distributed to PCCs at Brigham and Women's Hospital/Dana-Farber Cancer Institute, Beth Israel Deaconess Medical Center, and the Massachusetts General Hospital via Qualtrics online surveys. The study underwent ethics review and was approved at all three academic medical centers. Although the results of this survey are pending, most respondents are expected to have experienced moral distress. The study results may contribute to a better understanding of sources of moral distress in PCCs and inform strategies to address moral distress in this population.



**Annina Seiler, PhD**, is a psychoanalytic psychotherapist and a postdoctoral research fellow at University Hospital Zurich, Switzerland. She received her BA and MA in clinical psychology from the University of Zurich and University of Lausanne and completed her PhD at the University of Fribourg. Annina was the recipient of a Swiss National Science Foundation Mobility Fellowship to complete a postdoctoral fellowship in health disparities at Rice University. Her interests in bioethics focus on ensuring patient safety and integrity in acute hospital care, securing equal health opportunities, and meeting the needs of seriously ill patients. Annina will continue her clinical work after the MBE program.

## Aditya Shekhar, BS

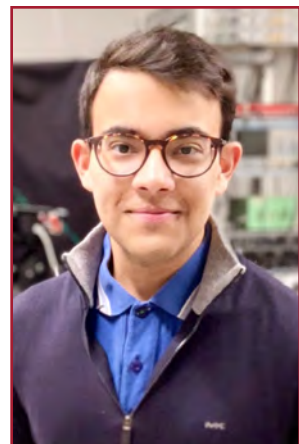
### **Capstone Mentor: Amy Ben-Arieh, JD, MPH**

Director of Research Compliance, The Fenway Institute

### **The Role of Research Institutional Review Boards (IRBs) as Stewards for Equity in Research**

Modern-day research ethics traces its roots to reactionary efforts following egregious research scandals. These scandals prompted a culture shift in biomedical research toward prioritizing the well-being of research subjects, a goal now functionally pursued through review of proposed human subjects research by institutional review boards (IRBs). This capstone explored the unique position that IRBs occupy to act as stewards of equity in research. IRB review promotes equity in a few key ways. First, the prevention of unethical research promotes equity in research. Second, IRBs can also promote equity in research by ensuring fair subject selection. For instance, IRB review involves researchers justifying the choice of population they intend to enroll. IRBs can encourage diverse and representative subject selection. Finally, IRBs can promote equity by encouraging the equitable dissemination of research results and associated benefits. For example, IRBs can encourage researchers to be thoughtful about how they plan on sharing and expanding their results. For IRBs to best act as stewards for equity in research, instances of harmful bias in IRB review must be mitigated to the greatest extent possible. A bias assessment can evaluate potential sources of harmful bias within an IRB by examining the composition and procedures of the IRB. Such an assessment may uncover salient items that have the potential to result in biased decision-making. The work of IRBs in promoting equity in research will only grow in importance considering the growing interest in mitigating disparities throughout medical care and science.

**Aditya Shekhar, BS**, is a researcher studying the epidemiology of life-threatening medical emergencies, such as cardiac arrest. He received his BS in public health at the University of Minnesota. His interest in bioethics stems from his fascination with the intersection of science and philosophy. He is an active emergency medical services (EMS) provider and is affiliated with the Center for Resuscitation Science at Beth Israel Deaconess Medical Center. His research has appeared in leading medical journals, including *Circulation*, *European Heart Journal*, *Resuscitation*, and *Annals of Emergency Medicine*, and has been recognized by the World Heart Federation, the American Heart Association, the European Society of Cardiology, and the American College of Cardiology.



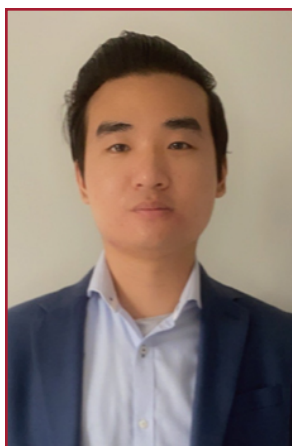
Ricky Shen, JD

**Capstone Mentor: Casey Rojas, JD, MBE**

Member, Harvard Medical School Center for Bioethics; Government Relations Advisor, Massachusetts Medical Society

**Does Defensive Medicine Carry Ethical Implications in Canada?**

The practice of defensive medicine (DM) is poorly studied in Canada, although it is commonly accepted among healthcare stakeholders that DM in Canada is much less prominent than in the United States. The definition of DM for the purposes of this capstone project is “practicing medicine in a particular way to reduce the risk of malpractice litigation.” In contrast to the mounting literature in the US on the subject of DM, there is only one DM study reported from the Canadian perspective, specifically in the field of neurology. This capstone project served as a starting point to elucidate the incidence of DM in high litigation-risk practice areas in other medical fields in Canada. The project created six questionnaires for the following practice areas: (1) obstetrics and gynecology, (2) family medicine, (3) emergency medicine, (4) orthopedic surgery, (5) general surgery, and (6) urology. The questionnaires included several domains such as physician values, type of practice, policy coverage, defensive practices, and perception of the liability environment in Canada. Five practicing physicians in the field of general surgery in the Province of Ontario completed the pilot survey. The preliminary findings suggest that Canadian physicians tend to perceive their medicolegal risk environment more favorably than their US counterparts. Furthermore, the questionnaires were an appropriate tool for assessing DM practices in Canada. Future directions of this capstone project include distributing the questionnaires among a larger sample of surgeons as well as in other high litigation-risk practice areas.



**Ricky Shen, JD**, is a lawyer from Canada specializing in medical malpractice. He received his BHSc from McMaster University and his JD from York University Osgoode Hall Law School, Toronto. He has interned at UNICEF, where he conducted research on bioethical issues affecting children, such as adequate access to healthcare. In addition, he completed his articles of clerkship at a renowned medical malpractice and personal injury law firm in Ontario. His interests focus on the legal and ethical implications of medical malpractice and defensive medicine. Ricky plans on returning to the field of law after completing his MBE, where he will actively apply bioethics in his practice.

## Natalie So

### **Capstone Mentor: Kaarkuzhali Babu Krishnamurthy, MD, MBE**

Member, Harvard Medical School Center for Bioethics; Assistant Professor of Neurology, Beth Israel Deaconess Medical Center; System Director of Epilepsy and System Lead for Ethics (Neurology), Steward Medical Group; Director of EEG Lab and Ethics Committee Chair, St. Elizabeth's Medical Center

### **Promoting Patient Autonomy by Improving Surrogate Decision-Maker Designation**

For patients who are unable to express healthcare preferences, surrogate decision-makers are needed to ensure that the patients' goals and values are respected. In the United States, only one-third of adults have a designated surrogate, with even lower rates in younger persons and people of color. However, almost half of hospitalized patients making life-altering decisions will need a surrogate decision-maker. This capstone project developed a conversation tool to guide patients through the process of appointing a surrogate decision-maker prior to hospitalization. The conversation tool design included verbal delivery by trained non-clinicians to promote equal access to information, enhance completion rates of required documentation, and encourage effective communication among patients, surrogates, and healthcare providers. Through an analysis of the ethical considerations in surrogate decision-making and existing tools for surrogate designation, five main components emerged: definition of terms, legal requirements for surrogate designation, criteria for selecting a surrogate, the importance of communicating with the surrogate, and next steps for the patient to take. To facilitate use, the tool is at Flesch Kincaid Grade Level 7 and can be read aloud in approximately three minutes. Finally, the tool contains a frequently asked questions document for non-clinicians' reference during their conversations with patients. It is anticipated that this tool will promote care that aligns with patients' wishes, thereby respecting and promoting patients' autonomy.

**Natalie So** is a third-year medical student and a 2025 MBBS degree candidate at the University of Hong Kong (HKU). Natalie serves her local community as a student ambassador at the HKU Li Ka Shing Faculty of Medicine and as a volunteer in health-related service projects. Her interests in bioethics center on clinical decision-making at the end of life, communication strategies in health care, and health literacy. After completing the MBE program, Natalie plans to raise public awareness about and facilitate public discussions on bioethical topics while continuing her medical training.



Jessi Stegall, BS

**Capstone Mentor: Miriam Rowan, PsyD**

Instructor in Psychology, Harvard Medical School; Attending Psychologist, Division of Sports Medicine, and the Department of Psychology, Boston Children's Hospital

**Understanding the Bioethical Challenges Faced by Mental Health Clinicians Working with Dance Populations**

Professional dancers experience significant mental health concerns, including eating disorders, anxiety, and Post-traumatic Stress Disorder. The dance community has demanded an increase in quality and quantity of mental health services for professional dancers, but little research exists regarding ethical issues faced by mental health clinicians who work with professional dance companies. This capstone aimed to identify ethical challenges, assess the dance cultural competence required for effective treatment, and understand the moral distress of embedded clinicians to support the integration of clinicians into professional dance companies. Three semi-structured qualitative interviews with mental health clinicians who have experience working in professional dance companies informed this project. The interviews explored how issues of cultural competence, conflicts of interest, and decision-making for treatment arise, how these issues are uniquely situated in dance culture, and how these experiences contribute to clinicians' moral distress. Thematic data analysis identified four overarching themes: 1) clinicians' dance cultural competence impacts their perceived credibility and ability to provide informed care within dance communities; 2) mental health literacy in dance institutions is essential to the therapeutic work of clinicians; 3) dancer autonomy directly influences the effectiveness of shared decision-making with clinicians; and, 4) providing embedded care within dance companies requires considerable effort to avoid conflicts of interest. These findings can inform future research on treating dancers' mental health and provide the foundation for evidence-based policies to guide ethical mental health care in professional dance populations.



**Jessi Stegall, BS**, is a research-practitioner at the Partnering Lab. She received her BS in expressive art therapy from Lesley University. Her work focuses on developing moral literacy in performing arts spaces and providing mental health interventions for professionals in the arts. Jessi's interests in bioethics include understanding the nuances of ethical practice in performing arts medicine, particularly as it pertains to clinicians' interactions with dance settings. Jessi was recently featured on Dance Magazine's list of "25 to Watch" for her research on ethics in dance. After graduation, Jessi plans to continue her work at the Partnering Lab and educate developing artists through her newly developed course, "The Ethics of Artistry."

Jessie Van Leeve, BA (Hon.)

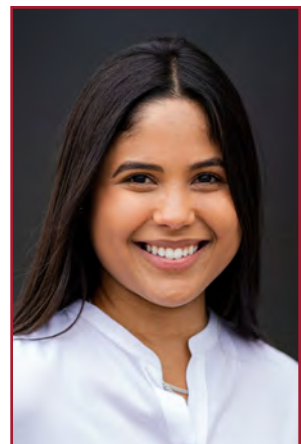
**Capstone Mentor: Priya Kvam**

Director of Strategy and Advocacy, Breakthrough U.S.; Associate Director of Global Development, Forum for the Future

**Can Popular Culture Make More Empathetic Clinicians? Exploring the Impact of Media on Healthcare Providers' Attitudes About Gender-based Violence**

Global media campaigns like *#MeToo* have contributed to an increase in the reporting and discussion of sexual violence and workplace harassment in the United States. Yet, stigma and shame surrounding gender-based violence (GBV) persist, and increased public awareness does not appear to have translated into better outcomes for survivors of GBV. Healthcare providers are often the first encounter for survivors of GBV, particularly in urban communities where hospitals and clinics are relatively accessible. As such, these providers play a critical role in addressing the crisis. Providers' personal attitudes on GBV—shaped not only by their medical education but also by media and popular culture—represent an important and under-recognized target of intervention. The use of entertainment education to inspire attitudinal change is well-documented, but its effect on healthcare providers has not been studied in depth. This capstone project explored whether providers' attitudes about GBV were impacted by media they encountered. Semi-structured interviews with five key stakeholders explored the potential link between media consumption and provider opinion. This project used qualitative methods to identify patterns and themes related to perceived barriers and potential sites for intervention through entertainment education. The findings will be used to inform further research on the potential integration of media-based, bioethical frameworks for GBV into medical education curricula. Such frameworks could inspire attitudinal change in medical professionals and strengthen anti-GBV programs and training to assist physicians in confronting this crisis in their communities.

**Jessie Van Leeve, BA (Hon.),** received her BA in bioethics and English from the University of Toronto in Canada. As an undergraduate, she explored ethical issues related to death and dying, reproduction, and global health, and she volunteered at the Hospital for Sick Kids. Jessie is interested in using her background in writing and film to promote health and social justice, including highlighting bioethical challenges at the intersection of health and human rights. Upon completing her MBE, Jessie plans to work in health policy and advocacy before going on to doctoral studies.



## Jocelyn Wong

### **Capstone Mentor: Kaila Rudolph, MD, MPH, MBE**

Attending Psychiatrist, Boston Medical Center; Assistant Professor of Psychiatry, Boston University School of Medicine

### **The Ethics Behind Misdiagnosis: Comparing Diagnostic Tendencies of Attention-Deficit/Hyperactivity Disorder in Boston and Hong Kong**

The diagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) is complicated by the absence of a specific diagnostic marker or confirmatory medical test. At various stages of the diagnostic process, different stakeholders may provide contrasting interpretations of symptoms subject to their own biases and experiences. Teachers and parents of different ethnicities, for example, have been found to vary in how they set thresholds for behavior that warrants assessment for ADHD. However, research has rarely focused on clinicians and the potential for culture to influence their diagnosis of ADHD. This capstone project aimed to investigate how psychiatrists in two culturally distinct and multicultural locations, Boston and Hong Kong, view psychiatrist and/or patient culture as affecting the psychiatrists' perception of ADHD symptoms and likelihood of diagnosing this condition. A literature review suggested that providers have tendencies to over- or under-pathologize certain behaviors based on the social norms of their settings, such as an emphasis on cohesiveness in non-Western cultures and on autonomy in Western cultures. This project developed a semi-structured interview guide to conduct future interviews with psychiatrists at teaching hospitals in Boston and Hong Kong. It is hypothesized that findings from the interviews may highlight the need for implicit bias training and cultural sensitivity resources to promote accurate ADHD diagnosis in cross-cultural contexts. Supporting accurate diagnosis of ADHD is particularly important in light of the ethical challenges that can arise from misdiagnosis, including stigmatization and the persistence of labels.



**Jocelyn Wong** is a third-year medical student at the University of Hong Kong (HKU). She will receive her MBBS from HKU in 2025. As a medical student and research assistant for the department of psychiatry at the Li Ka Shing Faculty of Medicine, she is conducting research on antipsychotics and cross-cultural factors in psychiatric diagnoses. Her interest in bioethics is focused on psychiatric neuroethics, particularly the area of neurodevelopmental disorders. For both of her pre-clinical years at HKU, Jocelyn received the Presidential Scholarship for Medical Students and Medical Dean's Scholarship. After graduation, she will return to medical school and help develop the bioethics curriculum locally.



Deandra Wright, BS

**Capstone Mentor: Meg Soriano, RN, MBE**

Nurse Director, Lunder 9 Inpatient Oncology, Massachusetts General Hospital

### **Anti-Racism Commitments in Healthcare: Ethical Responsibility in Practice**

The 2020 murder of George Floyd inspired many organizations, including hospitals, to draft anti-racism statements of solidarity with the Black, Indigenous, and People of Color (BIPOC) Communities. Subsequently, these institutions began introducing anti-racist training modules to better equip employees to speak about race and race-related incidents in the workplace. This project aimed to determine whether these modules were sufficient to change hospital culture. This capstone followed the development of a leadership organization within a hospital setting to discover if the addition of a monthly Brave Space—an environment that encourages shared learning and accountability—led to stronger individual, and ultimately organizational, commitments to anti-racism among healthcare professionals. The project first examined current anti-racist commitments and interventions suggested for patients and providers through a literature review. It simultaneously planned and implemented monthly race-related conversations among patient care services leaders that focused on the institution's anti-racist modules. After completing the module-focused conversations, attendees completed a survey to collect feedback, impact statements, and interest in continuing these conversations. Responses showed that most participants found the conversations helpful in engaging with the module content. Additionally, the conversations were successful in attracting leaders who had not watched the modules. All participants surveyed wished to continue the conversations. Because hospitals have an ethical duty to promote the emotional, mental, and physical safety of their patients and providers, developing tangible strategies to fulfill this duty is critically important. This project demonstrated one model for movement toward an anti-racist healthcare environment.

**Deandra Wright, BS**, received her BS in biomolecular science from New York University. As an undergraduate, she served as a teaching assistant and as the vice president of her program's mentorship club. Deandra is interested in supporting the holistic health of Black and Brown communities, especially the health of their children. Deandra and her team at MUSEDORA are recent recipients of the Reed Award for Best GOTV Campaign to Mobilize Diverse Communities for their recent work in civic activation to elect Georgia's first Black senator, Reverend Raphael Warnock. After completing her MBE, Deandra plans to apply to medical school and integrate her new interest in health law into her career.



## Sophia Yin, BS

### **Capstone Mentor: Brian Cummings, MD**

Assistant Professor of Pediatrics, Harvard Medical School; Attending Physician, Pediatric Critical Care Medicine, Associate Chief Quality Officer, Center for Quality and Safety, and Chair, Pediatric Ethics Committee, Massachusetts General Hospital

### **Assisted Reproductive Technology: An Examination of Ethical Frameworks to Address Disparate Access**

Assisted reproductive technology (ART) refers to interventions to address infertility, such as in vitro fertilization. Significant disparities in access to ART, particularly along racial and socioeconomic lines, exist in the United States. The aim of this capstone project was to examine the ethical justifications for broader access to ART. The methodology consisted of a scoping literature review followed by thematic grouping and evaluation of ethical justifications. Four central ethical frameworks were identified: 1) reproductive rights, 2) infertility care as healthcare, 3) disability rights, and 4) reproductive justice. While the first framework of reproductive rights appears straightforwardly applicable to ART access, the lack of established positive rights to reproduction limits the strength of this framework for supporting broader access to ART. With respect to the second and third ethical frameworks, although infertility has been defined as a disease or a disability by various stakeholders and organizations, these arguments do not fully encompass the breadth of people who utilize ART and thus remain limited as arguments for expanding access. Finally, an understanding of infertility as a social condition, with known disparities in access and outcomes of ART, lends itself favorably to a framework of reproductive justice. However, such a framework has had limited success in advancing access in other realms of healthcare. The project concluded with an examination of the gaps left by these frameworks including their lack of attention to injustices underlying inadequate and disparate access to ART, which can be addressed only by dismantling cultural biases. Though none of the identified frameworks alone was comprehensive, each added to an understanding of the challenges of, and multifocal approach needed to establish, equitable access to ART.



**Sophia Yin, BS**, is a medical student at Harvard Medical School. She received her BS in psychology with a concentration in neuroscience from Yale University. As a medical student, she has been involved in medical education curriculum development and surgical outcomes research. She is interested in the intersection of law and medicine, particularly within reproductive ethics, and seeks to apply ethics to health policy to promote a more equitable healthcare system. She received the Triffin Prize at Yale and won the Columbia University Voices in Bioethics Essay Contest in the Reproductive Ethics category. After graduation, she will finish her fourth year of medical school and plans to become an OB/GYN.







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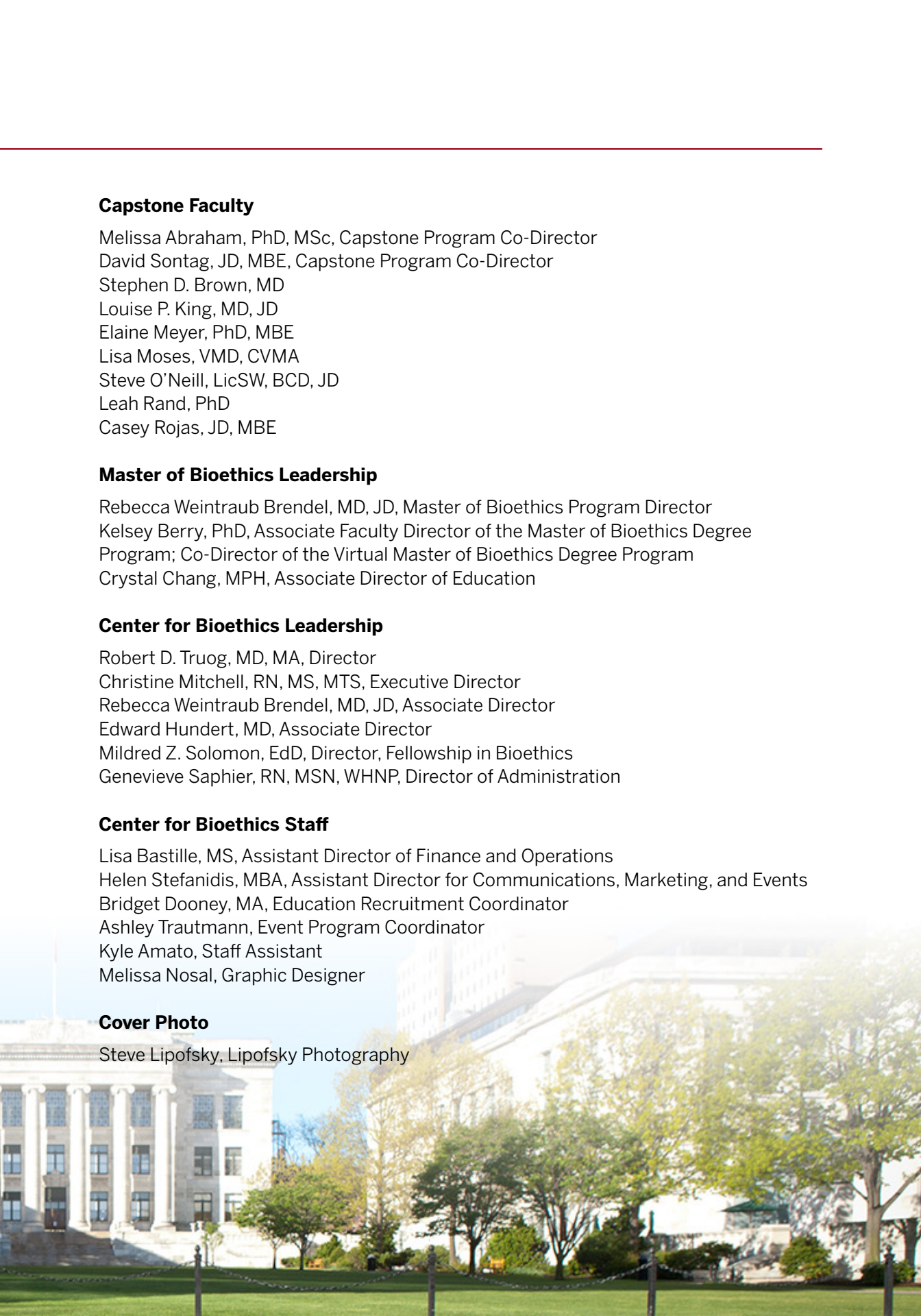
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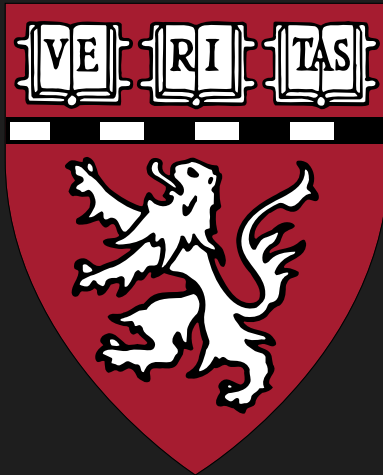
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