

Harvard Medical School Annual Bioethics Conference

# CONTROLLING DEATH?

The policies, practices, and ethics  
of choosing when we die

APRIL 11-12, 2019



CENTER FOR  
BIOETHICS  
HARVARD MEDICAL SCHOOL

“ While I thought that  
I was learning how  
to live, I have been  
learning how to die. ”

—Leonardo da Vinci

### 2019 Conference Planning Committee

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Rebecca Weintraub Brendel, MD, JD  
*Committee Chair*

Nancy Berlinger, PhD

Lachlan Forrow, MD

Linda Ganzini, MD, MPH

Scott Kim, MD, PhD

Timothy E. Quill, MD

Carmel Shachar, JD, MPH

Mildred Z. Solomon, EdD

Sigrid Sterckx, PhD

Matthew K. Wynia, MD

*Capstone Student*

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### Center for Bioethics at Harvard Medical School

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Director

**Christine Mitchell**  
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Associate Director

**Mildred Z. Solomon**  
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## Conference Materials & Digital Connections

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# Controlling Death?

*The policies, practices, and ethics of choosing when we die*

## **A message from the 2019 Conference Chair**



In the wake of the United States Supreme Court's 1990 decision in the Cruzan case and the broad recognition of patients' legal entitlements to make end-of-life decisions akin to any other medical decision, a profound debate has emerged and ensued about the parameters and practices of end-of-life decision making and care. In the 1990s, Oregon led the way in expanding the legal entitlement for terminally ill patients to control the timing and manner of their deaths through access to physician-prescribed medication to end life. Now, more than twenty years later, the debate has continued with expansion of the number of U.S. jurisdictions

permitting this end-of-life option.

Medical assistance in dying forces us to confront our most deeply held beliefs and values about both life and death. Not surprisingly, we hold divergent views about the permissibility, desirability, and consequences of medical aid in dying. The public debate has led to law, and the reality of implementation is upon us. In just the weeks before this conference, another state legislature passed a new medical-aid-in-dying law. Efforts to pass the previously narrowly defeated measure in Massachusetts are on the horizon. Families, patients, colleagues, and parishioners alike will seek guidance and counsel regarding end-of-life options, and we need to be prepared to enter the discussion. The goal of this conference is to lay aside pro and con debates—which have been eloquently and exhaustively articulated—and to consider how we as a community can map the terrain forward in a considered and informed way that is respectful of all persons in light of the increasing availability of medically-assisted end-of-life options.

I am most appreciative of and grateful for the tireless efforts of the faculty planning committee for this conference. Their careful and thoughtful work to conceptualize and create a balanced and visionary agenda for our two days together has created a network of dedicated scholars, researchers, and practitioners who together, I hope, will continue to explore and guide our normative understanding of our most personal and profound questions about living and dying. None of this work could have been possible without the experience and commitment of the leadership and staff of the Center for Bioethics, without whom this conference would not have been possible.

**Rebecca Weintraub Brendel, MD, JD**

*Director, Master of Bioethics Program, Harvard Medical School Center for Bioethics*

# Conference Mission

The Harvard Medical School Annual Bioethics Conference (ABC) convenes leaders in the field to explore ethical questions and concerns in healthcare. Held each April, the conference facilitates conversations among experts and supports members of ethics committees, health care professionals, bioethicists, administrators, attorneys, and others who are interested in addressing ethical issues.

## About the Sponsors

### **The Center for Bioethics at Harvard Medical School**

The Center for Bioethics brings together the rich intellectual resources of Harvard Medical School (HMS)—the largest biomedical research community in the world—including sixteen affiliated hospitals and research institutions; the expertise of more than twelve thousand HMS faculty members, physicians, and research scientists; and partnerships across Harvard University’s schools and academic departments. Based in Boston, a global epicenter of biomedical research and innovation, the Center’s resources are designed to integrate ethics, scientific discovery, and clinical care more closely than ever before. Professionals from around the world participate in the Center’s many programs, including a master of bioethics degree program, fellowship in bioethics, and professional and public education conferences and lectureships that address health care and social justice issues at the intersection of bioethics, law, and public policy. For more information, see [bioethics.hms.harvard.edu](http://bioethics.hms.harvard.edu).

### **The Petrie-Flom Center**

The Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School is a leading research program dedicated to the unbiased legal and ethical analysis of pressing questions facing health policymakers, medical professionals, patients, families, and others who influence and are influenced by the health care system. The Petrie-Flom Center hosts public events and conferences, publishes the *Bill of Health* blog (<http://blogs.harvard.edu/billofhealth>), coedits the *Journal of Law and Biosciences*, runs various fellowship programs, conducts sponsored research, hosts collaborations and produces independent scholarship on a range of topics under the umbrellas of health law policy, biotechnology, and bioethics. For more information, see [petrieflom.law.harvard.edu](http://petrieflom.law.harvard.edu).

### **The Hastings Center**

The Hastings Center addresses fundamental ethical and social issues in health care, science, and technology. Through our scholars’ writing and speaking, and through the work of the many other people who participate in our projects or submit articles to our publications, we shape ideas that influence key opinion leaders, including health policy-makers, regulators, lawyers, legislators, and judges. Our analyses also deeply influence professional practice: from end-of-life care to psychiatric practice to immigrant health care, we have helped to shape the standards of practice adopted by physicians, nurses, and lawyers. Founded in 1969 by philosopher Daniel Callahan and psychoanalyst Willard Gaylin, The Hasting Center is the oldest independent, nonpartisan, interdisciplinary research institute of its kind in the

# Thursday, April 11, 2019

Time	Title/ Description	Speaker(s) / Moderator
7:15 – 8:00 am	<b>Registration and Breakfast</b> Joseph B. Martin Conference Center, Lobby	
8:00 – 8:15 am	Welcome Address	Rebecca Weintraub Brendel
Legal Contours of Physician-Assisted Death and End-of-Life Care in the U.S.		Moderator: Carmel Shachar
8:15 – 8:30 am	Introduction, Terminology, and Background	Carmel Shachar
8:30 – 9:00 am	Legal Update on Medical Aid in Dying, Voluntary Stopping of Eating and Drinking, and Palliative Sedation to Unconsciousness	Thaddeus Pope
9:00 – 9:30 am	Paths to Legalization and the Massachusetts Experience	Brendan Abel
9:30 – 10:00 am	Q & A	
10:00 – 10:15 am	<b>Break</b>	
International Legal Perspectives and Experience		Moderator: Emily Rubin
10:15 – 10:40 am	Canada's Constitutionalized Path to Medical Assistance in Dying: Where is it heading?	Trudo Lemmens
10:40 – 11:05 am	The Regulation and Monitoring of Euthanasia in Belgium	Sigrid Sterckx
11:05 – 11:30 am	Shifting Limits of Self-Determination in Dutch Euthanasia Law and Practice	Britta van Beers
11:30 – 11:45 am	Q & A	
Conceptualizing the End of Life		Moderator: Rebecca Weintraub Brendel
11:45 am – 12:30 pm	Coda di Vita: An argument for a new life stage in a technological age	Michael Bostwick
12:30 – 1:30 pm	<b>Lunch:</b> Joseph B. Martin Conference Center, Lobby	

# Thursday, April 11, 2019

Time	Title/ Description	Speaker(s) / Moderator
Clinical Considerations in End-of-Life Care		Moderator: Christine Mitchell
1:30 – 1:55 pm	A Palliative Care Approach to Responding to Requests for Hastened Death	Laura Petrillo
1:55 – 2:20 pm	Responding to Intractable Suffering: Are palliative sedation and voluntary stopping of eating and drinking enough?	Timothy Quill
2:20 – 2:45 pm	Disparities in Palliative and Hospice Care	Justin Sanders
2:45 – 3:10 pm	Creating Communities of Care through Spirituality	Wylin Wilson
3:10 – 3:20 pm	Q & A	
3:20 – 3:30 pm	<b>Break</b>	
3:30 – 4:30 pm	Should the Option of Physician-Assisted Death Be part of Good Palliative Care?	A discussion with Diane Meier and Timothy Quill, moderated by Vicki Jackson
Family Narratives on Physician-Assisted Death		Moderator: Mildred Solomon
4:30 – 4:50 pm	Brittany Maynard's Perspective on Medical Aid in Dying	Dan Diaz
4:50 – 5:10 pm	Personal Reflections	Marcia Angell
5:10 – 5:30 pm	Discussion	
5:30 – 6:30 pm	<b>Reception:</b> Joseph B. Martin Conference Center, Lobby	

ALL sessions will be in the Joseph B. Martin Conference Center, 77 Avenue Louis Pasteur.  
Time is allotted for written questions submitted on notecards after presentations.

# Friday, April 12, 2019

Time	Title/ Description	Speaker(s) / Moderator
7:15 – 8:00 am	<b>Registration and Breakfast</b> Joseph B. Martin Conference Center, Lobby	
Decisional, Cognitive, and Emotional Capacity		Moderator: David Sontag
8:00 – 8:25 am	Decisional Capacity Assessment and Patients' Requests	Thomas Strouse
8:25 – 8:50 am	Differentiating Suicide from Life-Ending Acts and End-of-Life Decisions	Michael Bostwick
8:50 – 9:05 am	The Dementia Trajectory and the Ethics of Assisted Dying	Nancy Berlinger
9:05 – 9:20 am	Q & A	
9:20 – 9:30 am	<b>Break</b>	
Data on Assisted-Death Practices in the U.S. and Canada		Moderator: Keren Ladin
9:30 – 10:00 am	The Oregon Death with Dignity Act: More than twenty years' experience	Linda Ganzini
10:00 – 10:15 am	Overview of the California End of Life Option Act	Neil Wenger
10:15 – 10:30 am	Medical Aid in Dying in Colorado: More questions than answers	Matthew Wynia
10:30 – 10:55 am	Access, Justice, and the Implementation of Medical Aid in Dying: Lessons from Vermont	Mara Buchbinder
10:55 – 11:20 am	Medical Assistance in Dying in Canada: The first few years	Jennifer Gibson
11:20 – 11:30 am	Q & A	
11:30 – 11:40 am	<b>Break</b>	
Personal and Institutional Perspectives		Moderator: Jonathan Marron
11:40 am – 12:05 pm	Autonomy, Dignity, and the Normalization of Assisted Suicide	John Kelly
12:05 – 12:30 pm	A View to the Possible Future for Massachusetts Hospital Systems	James Tulsky
12:30 – 1:30 pm	<b>Lunch:</b> Joseph B. Martin Conference Center, Lobby	

# Friday, April 12, 2019

Time	Title/ Description	Speaker(s) / Moderator
Implementation and Practice Variability: Lessons from California		Moderator: Lachlan Forrow
1:30 – 1:50 pm	Physician Aid in Dying in California: Facing the challenges of implementation	Barbara Koenig
1:50 – 2:10 pm	Health System Implementation of the California End of Life Option Act	Neil Wenger
2:10 – 2:30 pm	Medical Aid in Dying: Operational experience and learnings at Kaiser Permanente, Northern California	Ann Gordon
2:30 – 2:50 pm	Kaiser Permanente Southern California Medical Aid-in-Dying Implementation: Strategies, challenges, and outcomes	Tracey Bush
2:50 – 3:10 pm	Medical Aid in Dying in California: A two-year report from the bedside	Lonny Shavelson
3:10 – 3:20 pm	Q & A	
3:20 – 3:30 pm	<b>Break</b>	
Charting a Path Forward		Moderator: Robert Truog
3:30 – 3:50 pm	Health System Priorities for Patient-Centered End-of-Life Care	Laura Petrillo
3:50 – 4:10 pm	Addressing Quality-of-Care Complexities in the Context of Disability	Lisa Iezzoni
4:10 – 4:30 pm	Controlling Death? From questions, toward community	Terri Laws
4:30 – 4:40 pm	Q & A	
4:40 – 5:00 pm	The Benefits of Sensitive and Standardized Data Collection around End-of-Life Options	Matthew Wynia
5:00 – 5:20 pm	Lessons, Challenges, and Next Steps for Massachusetts	Lachlan Forrow
5:20 – 5:40 pm	Reflections and Future Directions Challenges for Policy	Mildred Solomon
5:40 – 5:50 pm	Q & A	
5:50 pm	<b>Closing Remarks</b>	Rebecca Weintraub Brendel

FRIDAY, APRIL 12, 2019

# PRESENTERS

## Brendan Abel, JD

*Legislative and Regulatory Affairs Counsel, Massachusetts Medical Society*



Brendan Abel is legislative and regulatory affairs counsel at the Massachusetts Medical Society (MMS) where he directs state legislative affairs representing over 25,000 physicians in the Commonwealth, and has taught in the HMS Master of Bioethics Program. Prior to the MMS, he worked at Partners HealthCare, and was the health policy researcher at the *New England Journal of Medicine*. Upon completing undergraduate studies at Syracuse University, he earned his JD from Suffolk University Law School. He completed a fellowship in medical ethics at Harvard Medical School, where he has recently joined the Center for Bioethics to teach a course on health law, policy, and ethics. Abel's work has been published in a number of academic publications including the *New England Journal of Medicine* and the *Hastings Center Report*. He regularly presents on topics at the intersection of law and medicine.

## Marcia Angell, MD

*Corresponding Member of the Faculty of Global Health and Social Medicine, Harvard Medical School*



Marcia Angell is a faculty associate in the HMS Center for Bioethics. She is former editor-in-chief of the *New England Journal of Medicine*, joining the editorial staff in 1979, she became executive editor in 1988, and then editor-in-chief in 1999. A graduate of Boston University School of Medicine, she trained in both internal medicine and anatomic pathology. Angell is a member of the Association of American Physicians, the Institute of Medicine of the National Academy of the Sciences, the Alpha Omega Alpha National Honor Medical Society, and is a master of the American College of Physicians and a Fellow of the American Association for the Advancement of Science. She lectures and makes media appearances frequently, consults with government agencies and congressional committees, and has written multiple books, contributing frequently to professional journals and the popular media on topics including medical ethics, health policy, the nature

of medical evidence, the interface of medicine and the law, care at the end of life, and the relations between industry and academic medicine.

## Britta van Beers, PhD

Associate Professor, Department of Legal Theory, Vrije University Amsterdam Law School



Britta van Beers' research explores the legal and philosophical meanings of concepts such as person, humanity, self-determination and dignity, especially in the light of biomedical developments. After studying law and philosophy at the University of Amsterdam and New York University School of Law, she obtained a PhD at VU University Amsterdam. Her dissertation, *Person and Body in the Law: Human Dignity and Self-Determination in the Era of Medical Biotechnology* (The Hague, 2009) resulted in prizes from the Dutch Health Law Association and the Preamium Erasmianum Foundation. Recent publications include coediting of *Personalized Medicine, Individual Choice and the Common Good*, *Symbolic Legislation and Developments in Biolaw* and *Humanity across International Law and Biolaw*.

## Nancy Berlinger, PhD

Research Scholar, The Hastings Center

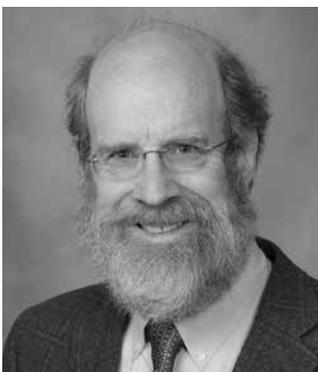


Nancy Berlinger coedited the 2018 Hastings Center special reports *What Makes a Good Life in Late Life?* and *Defining Death* and served on the planning committee for the 2018 National Academy of Medicine Workshop on Physician-Assisted Death. She directed the revision of the Hastings Center's landmark *Guidelines on Treatment Decision-Making and End-of-Life Care* and collaborated with the Society of Hospital Medicine on a pathway for serious illness communication. She codeveloped the open-access *Singapore Bioethics Casebook*. Her books include *After Harm: Medical Error and the Ethics of Forgiveness*; *The Hastings Center Guidelines*, second edition (with Bruce Jennings and Susan M. Wolf); and *Are Workarounds Ethical? Managing Moral Problems in Health Care Systems*. She was a 2018 resident at the Bellagio Center of the Rockefeller Foundation for a book project on migration. She serves on the bioethics committee of Montefiore Medical

Center and on Montefiore's ethics review committees on hospice access for patients alone, and teaches at Lehman College, City University of New York.

## J. Michael Bostwick, MD

Professor of Psychiatry, Mayo Clinic College of Medicine



J. Michael Bostwick is professor of psychiatry in the Mayo Clinic College of Medicine and senior associate dean for admissions for Mayo Clinic Alix School of Medicine. With more than 110 peer-reviewed publications to his credit, he has expertise in suicide epidemiology/prevention, medical marijuana, and numerous psychosomatic topics. He serves on editorial boards for two medical journals, is an avid teacher at Mayo's medical school and psychiatry residency, and frequently collaborates with trainees on research and writing projects. He holds undergraduate degrees from Yale University in art history and the University of Hawaii in zoology. He attended Brown University medical school, and did residency and fellowship training in pediatrics at Massachusetts General Hospital, adult psychiatry at the Cambridge Hospital, and consultation-liaison psychiatry at Brigham and Women's Hospital. Between college and medical school he worked as

a newspaper reporter for the *Cape Cod Times*.

# Rebecca Weintraub Brendel, MD, JD

*Director, Master of Bioethics Program, Center for Bioethics at Harvard Medical School  
Assistant Professor of Psychiatry, Harvard Medical School*



Rebecca Weintraub Brendel is the director of the Master's Degree Program at the Harvard Medical School Center for Bioethics. She bases her clinical work in psychiatry at Massachusetts General Hospital (MGH) where she is the director of Law and Ethics at the Center for Law, Brain, and Behavior, provides medical oversight for the hospital's inpatient guardianship team, and practices clinical and forensic psychiatry. Brendel has served in multiple roles at MGH over the past decade including as medical director of the One Fund Center for Boston Marathon bombing survivors, a psychiatrist on the Law & Psychiatry and Consultation Psychiatry Services, clinical director of the Red Sox Foundation/MGH Home Base Program for post-9/11 service members and their families, and associate director of the MGH-based Harvard Forensic Psychiatry Fellowship. Brendel is an assistant professor of psychiatry at Harvard Medical School. Brendel graduated from both

University of Chicago Law School and Pritzker School of Medicine. She completed her psychiatry residency at MGH and McLean Hospital and a forensic psychiatry fellowship at MGH.

# Mara Buchbinder, PhD

*Associate Professor of Social Medicine, University of North Carolina School of Medicine*



Mara Buchbinder is associate professor of social medicine and adjunct associate professor of anthropology at the University of North Carolina-Chapel Hill (UNC), as well as core faculty in the UNC Center for Bioethics. Buchbinder is a medical anthropologist with broad interests in cultures of health, illness, and medicine in the United States. Her recent work focuses on how patients, families, and health care providers navigate social and ethical challenges resulting from changes in medical technology, law, and health policy. Her current project is an ethnographic study of the implementation and cultural impact of Vermont's Patient Choice and Control at End of Life Act. Buchbinder is the coauthor of *Saving Babies? The Consequences of Newborn Genetic Screening* and *All in Your Head: Making Sense of Pediatric Pain*. In 2017, she received a Phillip and Ruth Hettleman Prize for Artistic and Scholarly Achievement by Young Faculty at UNC. Her research has

been funded by the National Institutes of Health, the National Science Foundation, the Greenwall Foundation, and the Wenner-Gren Foundation.

# Tracey Bush, MSW, LCSW

*Regional Practice Leader, Kaiser Permanente Southern California*



Tracey Bush is the regional practice leader for medical social work and the End of Life Option Act at Kaiser Permanente Southern California. She received her master of social work from Tulane University in New Orleans and has been a licensed clinical social worker since 1993. She has worked with pediatric AIDS patients and their families at Children's Hospital in New Orleans and Children's Hospital Los Angeles. She joined Kaiser Permanente in 2005 as the department administrator for medical social work and subsequently worked as health care ombudsman-mediator. She is also a member of the National Association of Social Workers, California Chapter, and has served as a field instructor for master's-level social work interns from Tulane University, University of California, Los Angeles, and University of Southern California.

## Daniel Diaz

*Patients' Rights Advocate*



Dan Diaz is the widower of Brittany Maynard, a 29-year-old woman with terminal brain cancer who died in November 2014. The couple moved from California to Oregon—one of eight states that has authorized medical aid-in-dying—in order for her to have the option of a gentle dying process. As a result of her story, legislators have introduced bills to authorize medical aid in dying in over twenty-five states. Diaz advocates for expanding the availability of end-of-life options for terminally ill individuals. His efforts were instrumental in securing the passage of legislation in California, Colorado, and Washington, D.C. His efforts across the country continue—keeping a promise to his late wife to be an advocate for patients' rights.

## Lachlan Forrow, MD

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



Lachlan Forrow is a general internist and palliative care physician at Beth Israel Deaconess Medical Center (BIDMC). He is director of ethics programs at BIDMC, associate professor of medicine at Harvard Medical School, and president and board chair of the Albert Schweitzer Fellowship. He served as chair of the Massachusetts Expert Panel on End-of-Life Care (2009-2011), and as lead author of its landmark report *Patient-Centered Care and Human Mortality: The Urgency of Health System Reforms to Ensure Respect for Patients' Wishes and Accountability for Excellence in Care*. He currently serves as chair of the Massachusetts Department of Public Health Interdisciplinary Advisory Council on Palliative Care and Quality of Life. Forrow is also past board chair and CEO of International Physicians for the Prevention of Nuclear War, the 1985 Nobel Peace Prize recipient, and an active member of the International Campaign to Abolish

Nuclear Weapons, the 2017 Nobel Peace Prize recipient. In 2007, Forrow was awarded a Lifetime Achievement Award for Community Service from Harvard Medical School.

## Linda Ganzini, MD, MPH

*Associate Director, Health Services Research and Development Center of Innovation, VA Portland Health Care System*



Linda Ganzini is a professor of psychiatry and medicine at Oregon Health and Science University (OHSU) as well as director of the Geriatric Psychiatry Fellowship Program. She completed her psychiatry training at OHSU, her geriatric medicine fellowship training at the Portland VA Medical Center (VAMC), and received a master's of public health with emphasis in epidemiology and biostatistics from OHSU. She was previously director of the interprofessional palliative care fellowship at the Portland VAMC. She was a Project on Death in America Faculty Scholar. Her areas of research include medical assistance in dying, suicide, end-of-life care, and ethics. Her research on the Oregon Death with Dignity Act has been published in the *New England Journal of Medicine*, *JAMA* and *BMJ*. She was recipient of the Academy of Psychosomatic Medicine Research Award in 2005.

## Jennifer Gibson, PhD

*Director and Sun Life Financial Chair in Bioethics, Joint Centre for Bioethics; Associate Professor, Institute for Health Policy, Management and Evaluation and Clinical Public Health, Dalla Lana School of Public Health, University of Toronto*



Jennifer Gibson has a PhD in philosophy. Her research and teaching focuses on ethical issues at the level of health systems and institutions. She is particularly interested in the role and interaction of values in decision-making at different health system levels, and has served on government and policy committees on issues such as medical assistance in dying, public health emergency preparedness, new and emerging technologies, and drug funding and supply. In 2015-2016, Gibson was appointed as cochair of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, which informed the development of Canada's legal framework for medical assistance in dying (MAID). Recently, she cochaired the Council of Canadian Academies Expert Panel on Medical Assistance in Dying and chaired the Working Group on Advance Requests for MAID, the reports of which were tabled with the Canadian federal government in December 2018.

## Ann Gordon, MPH

*Manager, End of Life Option Program, Kaiser Permanente Northern California*



Ann Gordon joined Kaiser Permanente's End of Life Option as program manager at the launch of the program in 2016. She has worked for the organization in a variety of consulting and health education capacities since 1997. Her roles have included enhancing the care experience for breast cancer patients while serving as a care coordinator and designing and implementing programs to support the launch of organizational initiatives to advance physician leadership, patient communication, and palliative care. Prior to joining Kaiser Permanente, Gordon worked as a lobbyist and legislative aide on health policy issues in Washington, D.C. She earned her MPH at the University of North Carolina School of Public Health.

## Lisa Iezzoni, MD, MSc

*Professor of Medicine, Harvard Medical School and Mongan Institute for Health Policy at Massachusetts General Hospital*



Lisa Iezzoni is professor of medicine at Harvard Medical School and based at the Mongan Institute's Health Policy Research Center at Massachusetts General Hospital. Iezzoni has conducted numerous studies for the Agency for Healthcare Research and Quality, National Institutes of Health, Medicare, and private foundations. Her early career focused on risk-adjustment methods for costs and clinical outcomes and assessing quality of care; she wrote and edited *Risk Adjustment for Measuring Health Care Outcomes*, now in its fourth edition. Since 1998, her research has focused on improving the lived experiences and health care quality of adults with disability. She is author of *When Walking Fails* and coauthored, with Bonnie L. O'Day, *More Than Ramps: A Guide to Improving Health Care Quality and Access for People with Disabilities*. Iezzoni advocates for persons with disability. Representing the Boston Center for Independent Living, she chaired the Medical

Diagnostic Equipment Accessibility Standards Advisory Committee for the U.S. Access Board (2012-2013). Iezzoni is a member of the National Academy of Medicine in the National Academy of Sciences.

## Vicki Jackson, MD, MPH

**Chief, Division of Palliative Care and Geriatric Medicine, Massachusetts General Hospital  
Associate Professor of Medicine, Harvard Medical School**



Vicki Jackson is former fellowship director for the Harvard Palliative Medicine Fellowship. She completed residency and chief residency in internal medicine at Cambridge Hospital, a general medicine fellowship, palliative care training at Dana-Farber Cancer Institute and Brigham and Women's Hospital, joining the faculty of Massachusetts General Hospital (MGH) in 2002, pursuing further research training in the Program for Cancer Outcomes Training. She was selected as the Rabkin Fellow in Medical Education at Beth Israel Hospital (2009), worked to develop the Palliative Care Continuum Project at MGH (2015), and served as cochair of a leadership training program for junior palliative medicine faculty. She is currently a board member of the American Academy of Hospice and Palliative Medicine, PI and mentor on several government and privately-funded studies, and a member of the board for the American Academy of Hospice and Palliative Medicine. She is coauthor of *Living with Cancer: A Step-by-Step Guide to Coping Medically and Emotionally with a Serious Diagnosis*, and her work has been featured in major print and media outlets.

## John Kelly, PhD

**Director, Second Thoughts Massachusetts**



John Kelly is a Boston-based writer and disability rights activist. He is the director of the Massachusetts group Second Thoughts Massachusetts: Disability Rights Advocates against Assisted Suicide, and the New England regional director of Not Dead Yet, the national disability rights group that has led the fight against assisted suicide from a progressive, social justice perspective. He is a graduate of Yale College and trained in sociology at Brandeis University and is ABD for a sociology PhD.

## Scott Kim, MD, PhD

**Senior Investigator, Department of Bioethics, National Institutes of Health**



Scott Kim received his MD from Harvard and PhD in moral philosophy (on Kantian ethics) from the University of Chicago, and trained in adult psychiatry at the Massachusetts General Hospital. Kim combines philosophical, clinical, and empirical research approaches to address a variety of ethical issues including issues in pragmatic clinical trials, assessment of decision-making capacity, surrogate consent for incapacitated patients, theory and practice of informed consent, and physician assisted death). Kim's work has been supported by multiple government agencies, the Michael J. Fox Foundation, American Association for Geriatric Psychiatry, and the Greenwall Foundation. His work has appeared in *New England Journal of Medicine*, *Nature*, *JAMA*, and other journals.

# Barbara Koenig, PhD

*Professor of Bioethics and Medical Anthropology, Institute for Health and Aging, University of California San Francisco*



Barbara Koenig is professor of bioethics and medical anthropology at the Institute for Health and Aging, University of California, San Francisco (UCSF). She is the director of the UCSF Bioethics program which spans ethics research, clinical ethics, and ethics education across the university's four professional schools. Koenig pioneered the use of empirical methods in the study of ethical questions in science, medicine, and health and has long-standing interests in palliative care and technology use near the end of life. She was one of the first anthropologists to work on HIV/AIDS when the epidemic emerged and led the first NIH-funded study of the dynamics of end-of-life decision-making and patient choice in a public hospital. Koenig's research led to her being named a Soros Faculty Scholar in the Open Society Institute's "Project on Death in America." With the passage of California's physician aid-in-dying legislation, she convened a state-wide conference to bring together the law's opponents and proponents to reflect on implementation challenges.

# Keren Ladin, PhD, MSc

*Assistant Professor, Departments of Occupational Therapy and Community Health, Tufts University*



Keren Ladin is a bioethicist, a health services researcher, and assistant professor in the Departments of Occupational Therapy and Community Health at Tufts University. She is also director of Research on Ethics, Aging, and Community Health at Tufts. Ladin has extensive experience conducting health disparities research, particularly in transplantation, advanced kidney disease, and in medically complex populations at the end of life. She has led multiple large mixed-methods and qualitative studies in nephrology, transplantation, and among older populations, examining barriers and facilitators to shared decision-making. Among these are studies examining the role of health literacy as a barrier to shared decision-making and assessing factors contributing to disparities in late-life care among underserved populations. Her research aims to clarify how social factors affect health care utilization and medical decision-making, ultimately informing

clinical and policy interventions to enhance the treatment and quality of life among vulnerable patients, especially among older adults and their care partners.

# Terri Laws, PhD

*Assistant Professor, African and African American Studies and Health and Human Services, University of Michigan-Dearborn*



Terri Laws teaches courses in African American religious experience, Black and womanist religious thought, and medical ethics. She uses theories and methods from the social sciences and the humanities to investigate questions in race, religion, and society with a focus on issues in health care, health policy, and health inequity. Her current project is a monograph on African American religion and health with a working title of *(De)Gentrifying Death, Democratizing Life: The Culture of African American Religion in U.S. Health and Medicine*. Laws currently serves as codirector of the Bioethics and Religion Unit of the American Academy of Religion. She completed a bioethics fellowship at the University of Texas MD Anderson Cancer Center where she completed her dissertation research on religious influences of African American prostate cancer patients and their willingness to participate in clinical trials.

## Trudo Lemmens, LicJur, LLM, DCL

*Professor and Scholl Chair in Health Law Policy, Faculty of Law, Dalla Lana School of Public Health, and Joint Centre for Bioethics, University of Toronto*



Trudo Lemmens is Professor and Scholl Chair in Health Law and Policy at the Faculty of Law of the University of Toronto, with cross appointments in the Dalla Lana School of Public Health and the Joint Centre for Bioethics. His publications include the coedited volumes *Law and Ethics in Biomedical Research: Regulation, Conflict of Interest*, and *Liability and Regulating Creation: Law, Ethics and Policy of Assisted Human Reproduction*, as well as more than 100 chapters and articles in national and international law, policy, science, medicine, and bioethics journals. He has testified before parliamentary committees on medical assistance in dying and he was a member of the Council of Canadian Academies' expert panel on "advance requests for medical assistance in dying." He has been a visiting professor or member at several international institutions.

## Jonathan Marron, MD, MPH

*Attending Physician, Dana-Farber Cancer Institute and Boston Children's Hospital  
Post-Doctoral Research Scholar, Center for Bioethics, and Instructor in Pediatrics, Harvard Medical School*



Jon Marron serves as a clinical ethicist at Boston Children's Hospital (BCH). He received his MD at the David Geffen School of Medicine at the University of California, Los Angeles, and his MPH from the Harvard School of Public Health. He trained in pediatrics at Stanford University and in pediatric hematology/oncology at BCH/Dana-Farber Cancer Institute (DCFI). He completed fellowships in clinical medical ethics at the University of Chicago's MacLean Center for Clinical Medical Ethics and in pediatric health services research at BCH/HMS. He sits on the DFCI's Ethics Committee and is a member of the IRB. At the HMS Center for Bioethics, he teaches in the MD ethics curriculum, codirects "Introduction to Clinical Ethics," and directs "Pediatric Bioethics." Marron leads several ongoing studies querying patients and parents about experiences with genomic sequencing in pediatric oncology, and has been published in leading medical and bioethics journals.

## Diane Meier, MD

*CEO, Center to Advance Palliative Care*



Diane Meier is CEO of the Center to Advance Palliative Care (CAPC.org), a national organization devoted to increasing access to quality palliative care for patients and their families. She is codirector of the Patty and Jay Baker National Palliative Care Center, Professor of Geriatrics and Palliative Medicine, Catherine Gaisman Professor of Medical Ethics, and was founder/director of the Hertzberg Palliative Care Institute from 1997-2011, all at the Icahn School of Medicine at Mount Sinai in New York City. Meier received a MacArthur Foundation Fellowship in 2008, served as a Health and Aging Policy Fellow in Washington, D.C. in 2009-2010, and was elected to the National Academy of Medicine in 2013. In 2017 she received the Gustav O. Lienhard Award of the National Academy of Medicine and the AHA-HRET TRUST Award. Meier has over 200 peer-reviewed publications, and her most recent book, *Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Reform*, was published in 2014.

# Christine Mitchell, RN, MS, MTS

*Executive Director, Harvard Medical School Center for Bioethics*



Christine Mitchell is executive director of the Center for Bioethics. She received her bachelor's and master's degrees in science from Boston University School of Nursing and a master's degree from Harvard majoring in philosophical and religious ethics as a Kennedy Fellow in Medical Ethics through the Interfaculty Program at Harvard's Medical, Divinity, and Public Health Schools. An American Academy of Nurses fellow, Mitchell founded the Boston Children's Hospital ethics program, directing ethics consultation services and leading the Ethics Advisory Committee for thirty years. She was associate director of clinical ethics at Harvard Medical School's Division of Medical Ethics where she developed the Harvard Clinical Ethics Course, an intensive clinical bioethics course, and an all-volunteer citizen Community Ethics Committee for informed public input on ethical aspects of health care and health policies. She leads the monthly Harvard Clinical Ethics Consortium discussion of ethics cases and teaches in the HMS Fellowship in Bioethics Program. Her research has focused on ethics consultation, and public engagement in policies regarding resource allocation related to major natural disasters or pandemics.

Consortium discussion of ethics cases and teaches in the HMS Fellowship in Bioethics Program. Her research has focused on ethics consultation, and public engagement in policies regarding resource allocation related to major natural disasters or pandemics.

# Elisheva Nemetz, MBE '19

*Capstone Student, Harvard Medical School Master of Bioethics Program*



Elisheva Nemetz will be receiving her master of bioethics degree from Harvard Medical School in May 2019. She received her BA from Yeshiva University with a major in political science and minor in biology. She was a dean's scholar and recipient of the Benjamin and Jennie Hammer Memorial Award for Excellence in Political Science. Nemetz was president of the Yeshiva University Medical Ethics Society where she focused on the intersection of law, medicine, and ethics. She plans on enacting health policy change and advocating for communities with strong religious beliefs. She participated in planning this conference as part of her master's capstone project.

# Laura Petrillo, MD

*Palliative Care Physician, Massachusetts General Hospital; Instructor in Medicine, Harvard Medical School*



Laura Petrillo is a palliative care physician and researcher at the Massachusetts General Hospital and instructor at Harvard Medical School. She completed medical school, residency in internal medicine, and fellowship in palliative care at the University of California, San Francisco (UCSF). Petrillo testified as an expert witness before the California State Assembly in the hearing on the End of Life Option Act, which legalized physician-assisted death. She was also a lead organizer of a statewide conference to help health care systems develop policies about the End of Life Option Act, and developed a physician training module on the End of Life Option Act for UCSF. She has published peer-reviewed articles about physician-assisted death in the *American Journal of Public Health* and the *Journal of General Internal Medicine*. Her current research aims to develop supportive care interventions for patients who receive novel cancer therapies and their caregivers.

# Thaddeus Pope, JD, PhD

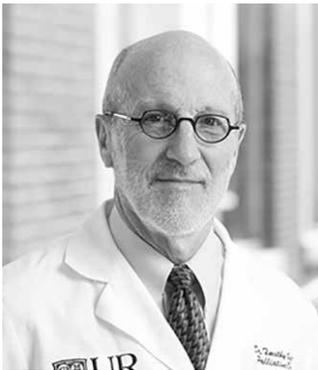
*Director, Health Law Institute and Professor of Law, Mitchell Hamline School of Law*



Thaddeus Pope is a foremost expert on medical law and clinical ethics. He maintains a special focus on patient rights and health care decision-making. Pope is director of the Health Law Institute at Mitchell Hamline School of Law in Saint Paul, Minnesota. While he serves in a range of consulting capacities, Pope has been particularly influential through his scholarship. Pope has over 200 publications in leading medical journals, bioethics journals, and law reviews. He coauthored *The Right to Die: The Law of End-of-Life Decisionmaking*, and he runs the Medical Futility Blog (with over four million page views).

# Timothy Quill, MD

*Distinguished Professor in Palliative Care, University of Rochester Medical Center*



Thomas Quill is distinguished professor in palliative care at the University of Rochester Medical Center (URMC) where he is also professor of medicine, psychiatry, medical humanities and nursing. He was the founding director of the URMC Palliative Care Division and a past president of the American Academy of Hospice and Palliative Medicine. He is acting director of the URMC Schyve Center for Biomedical Ethics. Quill has published and lectured widely about various aspects of the doctor-patient relationship, with special focus on end-of-life decision-making. He is the author of several books on end-of-life care and over 150 peer-reviewed articles. Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the U.S. Supreme Court (*Quill v. Vacco*). Quill is a fellow in the American Academy of Hospice and Palliative Medicine, a master in the American College of Physicians and an American Board of Medical Specialties certified palliative care consultant.

# Emily Rubin, MD, JD

*Assistant in Medicine, Division of Pulmonary and Critical Care Medicine, Massachusetts General Hospital; Instructor in Medicine, Harvard Medical School*



Emily Rubin studied bioethics and religious studies at the University of Virginia and graduated from the University of Virginia School of Law. She attended Dartmouth Medical School and completed a combined residency in internal medicine and pediatrics at the Massachusetts General Hospital (MGH). She completed pulmonary and critical care fellowships at the University of Pennsylvania, where she also completed a master of science in health policy research. She joined the faculty in the MGH Division of Pulmonary and Critical Care Medicine in February 2017 and serves as a cochair of the MGH ethics committee. She is particularly interested in the intersection of intensive care and palliative care, and has conducted research related to decision making by hospitalized patients with serious illnesses about desired treatment intensity. She has published numerous articles and chapters relating to ethical and legal issues in the care of patients at the end of life, including the treatment of patients with

disordered states of consciousness and conflicts over requests for potentially inappropriate treatment.

## Justin Sanders, MD, MSc

*Palliative Care Physician, Dana-Farber Cancer Institute and Brigham and Women's Hospital; Instructor in Medicine, Harvard Medical School*



Justin Sanders is an instructor of medicine at Harvard Medical School. He is a faculty member in the Serious Illness Care Program at Ariadne Labs, which focuses on implementation of a system-level approach for increasing clinician capacity to ensure high-quality discussions about patients' goals, values, and priorities. Sanders' research and implementation work focuses on understanding and ameliorating communication-driven disparities in care for the seriously ill through system-level interventions and social science-informed research. Sanders has a master's degree in medical anthropology. He was recognized in 2016 as an emerging leader in the field of palliative care with a Sojourns Scholar Leadership Award from the Cambia Health Foundation.

## Carmel Shachar, JD, MPH

*Executive Director, Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School*



Carmel Shachar is responsible for oversight of the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics' sponsored research portfolio, event programming, fellowships, student engagement, development, and a range of other projects and collaborations. She is colead of the Center's Involvement with the Regulatory Foundations, Ethics, and Law Program of Harvard Catalyst, the Harvard Clinical and Translational Science Center, and coeditor of the Center's collaborative health policy blog, *Bill of Health*.

## Lonny Shavelson, MD

*Founding Partner, Bay Area End of Life Options*



Lonny Shavelson heads the Bay Area End of Life Options team of consultants and patient advocates. He worked for twenty-nine years as an emergency department physician, then seven years as a primary care physician in a clinic for immigrants and refugees. He is now a consultant, educator, and physician for patients at the end of their lives who are considering various options, including physician aid in dying. He also consults with doctors who have patients requesting aid in dying. Shavelson also leads trainings about California's End of Life Option Act and has been interested in issues surrounding end-of-life care for patients for more than twenty years. He was one of five authors of the proposed "Physician-Hastened Death" guidelines by the Bay Area Network of Ethics Committees, published in 1997 in *The Western Journal of Medicine*. He also was involved in the writing of amicus briefs for the U.S. Supreme Court when it physician assisted death.

## Mildred Solomon, EdD

*President, The Hastings Center; Professor of Global Health and Social Medicine and Core Faculty and Director, Fellowship in Bioethics Program, Center for Bioethics at Harvard Medical School*



Mildred Solomon is a bioethicist and social science researcher who conducts both normative and empirical ethics research. Her own scholarship has focused on the ethics of end-of-life care for both adults and children, organ transplantation, research ethics, professionalism and responsible conduct of research. She has served on committees of the National Academies of Science, on the U.S. Secretary of Health and Human Services' Advisory Committee on Organ Transplantation, and has consulted to numerous foundations and government agencies. Before assuming the leadership of the Hastings Center, Solomon was senior director of Implementation Science at the Association of American Medical Colleges. There, she was responsible for helping the nation's academic medical centers develop capacities in comparative effectiveness research and implementation science. Solomon earned her doctorate in educational research methods and adult learning

at Harvard University and her BA from Smith College.

## David Sontag, JD, MBE

*First Deputy General Counsel, Beth Israel Deaconess Medical Center*



David Sontag is first deputy general counsel at Beth Israel Deaconess Medical Center (BIDMC) and a lecturer in medicine at Harvard Medical School. He advises clinicians regarding guardianships, health care proxies, and informed consent issues, and oversees the process for obtaining guardianships for medical center patients. He is involved in BIDMC's Ethics Liaison program, began a term as co-chair of the Ethics Advisory Committee in January 2017, and is consulted and speaks about legal and ethical issues in the clinical setting. In conjunction with his law practice, Sontag has taught various courses related to health law and bioethics at Drexel University, Rutgers School of Law-Camden, and the University of Pennsylvania Center for Bioethics. He currently teaches the capstone seminar for the Master of Bioethics Program at HMS. Sontag is an active member of the Boston Bar Association and previously served as cochair of the Health Law Section. Before

joining BIDMC, he served as a federal judicial clerk, and was in private practice. Sontag is a cum laude graduate of Washington University in St. Louis, and a magna cum laude graduate of the University of Pennsylvania Law School. Sontag holds a master of bioethics from the University of Pennsylvania Medical School.

## Sigrid Sterckx, PhD

*Professor of Ethics and Political and Social Philosophy, Ghent University*



Sigrid Sterckx is professor of ethics and political and social philosophy in the Department of Philosophy and Moral Sciences at Ghent University in Belgium, where she lectures on theoretical and applied ethics as well as social and political philosophy. Her current research projects focus on ethical and legal aspects of: medical end-of-life practices, in particular euthanasia; big data, AI and health care decision-making; and the global regulation of patents and data exclusivity rights. She has published widely on these issues, including the coedited volumes *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* and *Personalized Medicine, Individual Choice and the Common Good*. Sterckx is a founding member of the Bioethics Institute Ghent and serves on the institutional review board at Ghent University Hospital, one of the largest hospitals in Western Europe.

# Thomas Strouse, MD

**Maddie Katz Professor of Palliative Care Research and Education; Medical Director, Resnick Neuropsychiatric Hospital; Vice-Chair Clinical Affairs, Department of Psychiatry, UCLA School of Medicine**



Thomas Strouse has spent his career working with medically ill adults coping with psychiatric and physical aspects of catastrophic illness. He promotes palliative care clinical research within the UCLA Health System, and is widely recognized for his contributions as a clinician-teacher. He has received the Robert T. Angarola Award by the Southern California Cancer Pain Initiative, is a fellow of the Academy of Psychosomatic Medicine, an American Psychiatric Association Distinguished Fellow, and member of the American College of Psychiatrists. He lectures throughout the country, has published many peer reviewed papers and book chapters, and sits on editorial boards of multiple journals. In 2010 he was appointed associate editor of the *Journal of Supportive Oncology*; is now editor of the *Journal of Community and Supportive Oncology*, and in 2017 became associate editor, the *Journal of Palliative Medicine*. He was educated at Pomona College and the Case Western Reserve University School of Medicine.

# Robert Truog, MD

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



Robert Truog received his MD from the University of California, Los Angeles, and is board certified in the practices of pediatrics, anesthesiology, and pediatric critical care medicine. He also holds a master's degree in philosophy from Brown University and an honorary MA from Harvard University. Truog practices pediatric intensive care medicine at Boston Children's Hospital, where he has served for more than thirty years. He has published more than 300 articles in bioethics and related disciplines; he authored current national guidelines for providing end-of-life care in the intensive care unit, and was PI on the recently completed NIH study, "Toward Optimal Palliative Care in the PICU Setting." His books include *Talking with Patients and Families about Medical Error: A Guide for Education and Practice*, and *Death, Dying, and Organ Transplantation*. He lectures nationally and internationally, is an active member of numerous committees and advisory boards.

# James Tulsky, MD

**Chair, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Professor of Medicine, Harvard Medical School**



James Tulsky has published widely in the areas of clinician-patient communication and quality of life issues. His current research focuses on enhancing communication between oncologists and patients with advanced cancer. He recently served on the planning committee for a National Academies of Science, Engineering, and Medicine Workshop on "Physician-Assisted Death." His work has been recognized with the Presidential Early Career Award for Scientists and Engineers (2002), the Award for Research Excellence from the American Academy of Hospice and Palliative Medicine (2006), and the American Cancer Society Pathfinder in Palliative Care award (2014). He serves as board chair of the Greenwall Foundation, chair of the National Palliative Care Research Center Scientific Advisory Council, and vice-chair of the Roundtable on Quality Care in Serious Illness of the National Academies of Science, Engineering, and Medicine. He is a founding director of VitalTalk ([www.vitaltalk.org](http://www.vitaltalk.org)), a nonprofit devoted to nurturing healthier connections between clinicians and patients through communication skills teaching.

## Neil Wenger, MD, MPH

*Professor of Medicine, University of California, Los Angeles*



Neil Wenger is professor in the Division of General Internal Medicine and Health Services Research at the University of California, Los Angeles (UCLA) and a practicing general internist with an interest in patients with complex illness. He chairs the ethics committee at the Ronald Reagan-UCLA Medical Center and is the medical director for Advance Care Planning at UCLA and a researcher at the RAND Corporation. Wenger's research focuses on measuring and improving the quality of care for vulnerable older persons. He implements practice redesign efforts aimed at improving advance care planning and care toward the end of life. His educational efforts focus on training physician fellows in health services and primary care research, on training resident physicians in primary care general internal medicine, and teaching clinical ethics. He directs the National Research Service Award Primary Care Research Fellowship in the Division of General

Internal Medicine at UCLA. Wenger received his MD from the UCLA School of Medicine and his MPH from the UCLA School of Public Health.

## Wylín Wilson, PhD, MDiv, MS

*Visiting Lecturer and Research Associate, Women's Studies in Religion Program, Harvard Divinity School*



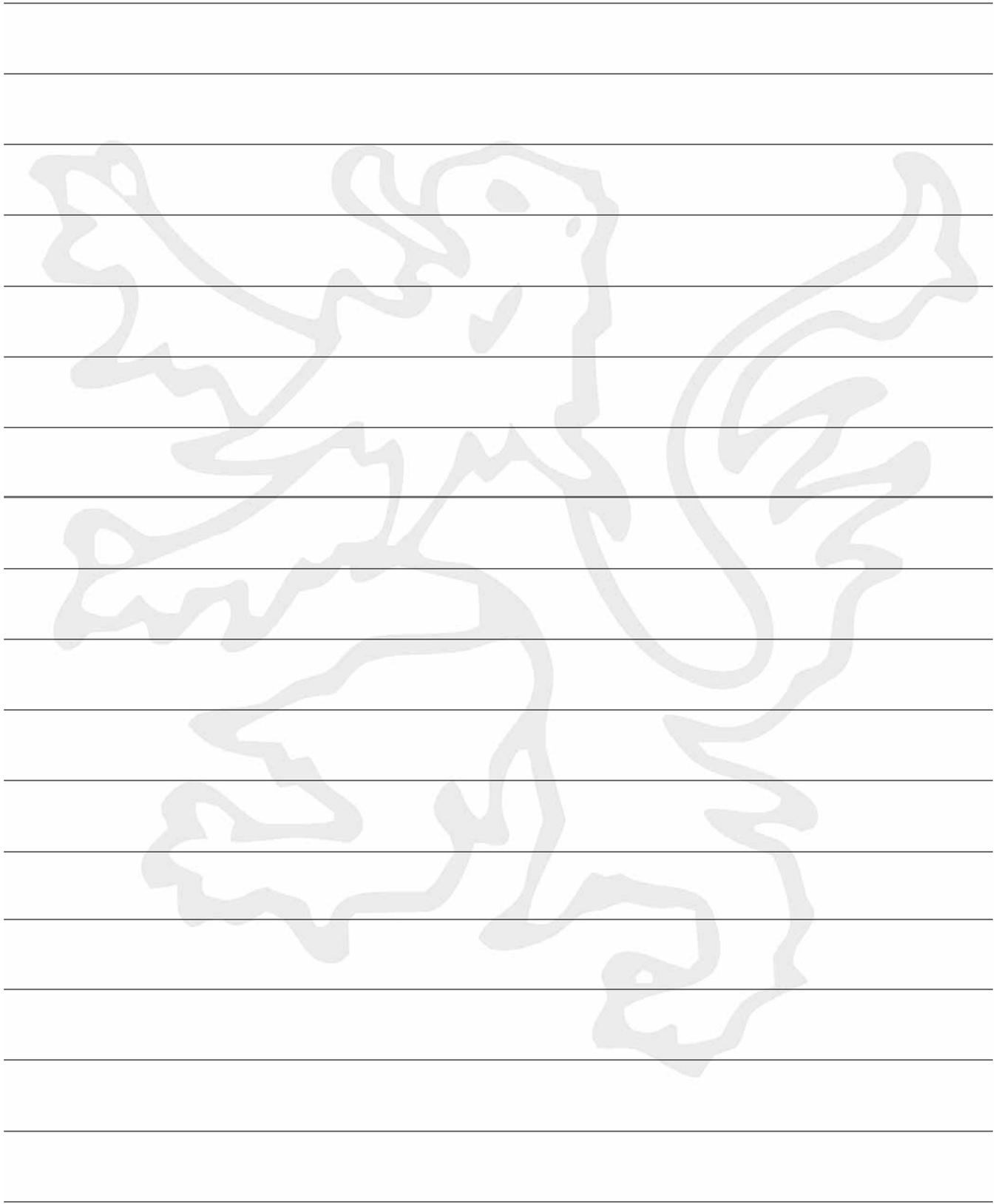
Wylín Wilson is currently visiting lecturer and research associate in the Women's Studies in Religion Program at Harvard Divinity School. She teaches and conducts research at the intersection of bioethics, gender, and theology. Wilson is a member of the American Academy of Religion's Bioethics and Religion Program Unit Steering Committee and serves on the Mount Auburn Hospital Ethics Committee in Cambridge, Mass. She has served as former associate director of education at the National Center for Bioethics in Research and Health Care at Tuskegee University. She earned her PhD in religious social ethics from Emory University and her MDiv at the Interdenominational Theological Center, both in Atlanta. Her MS in agricultural economics is from Cornell University in Ithaca, N.Y. Among Wilson's publications is her book, *Economic Ethics and the Black Church*.

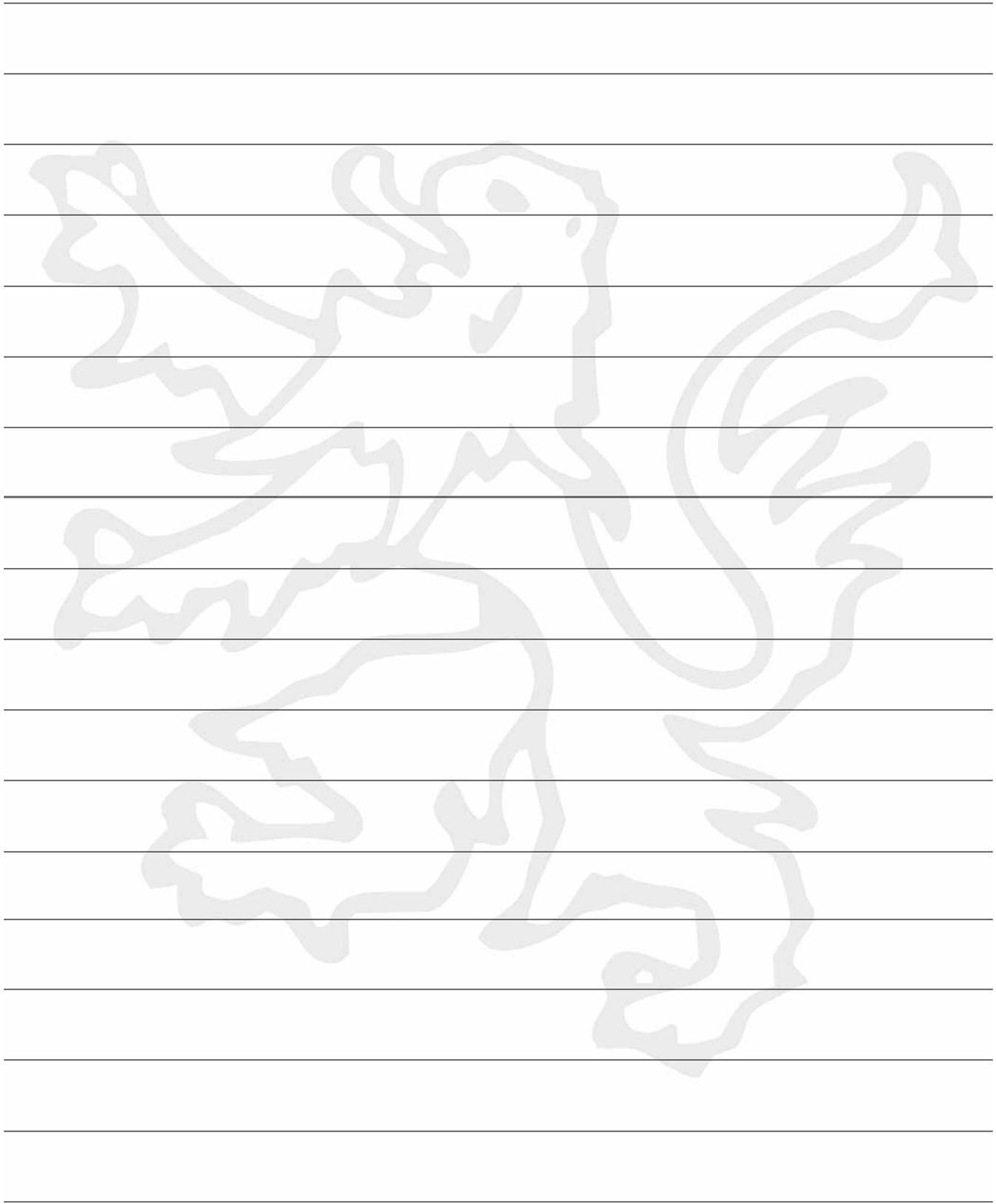
## Matthew Wynia, MD, MPH

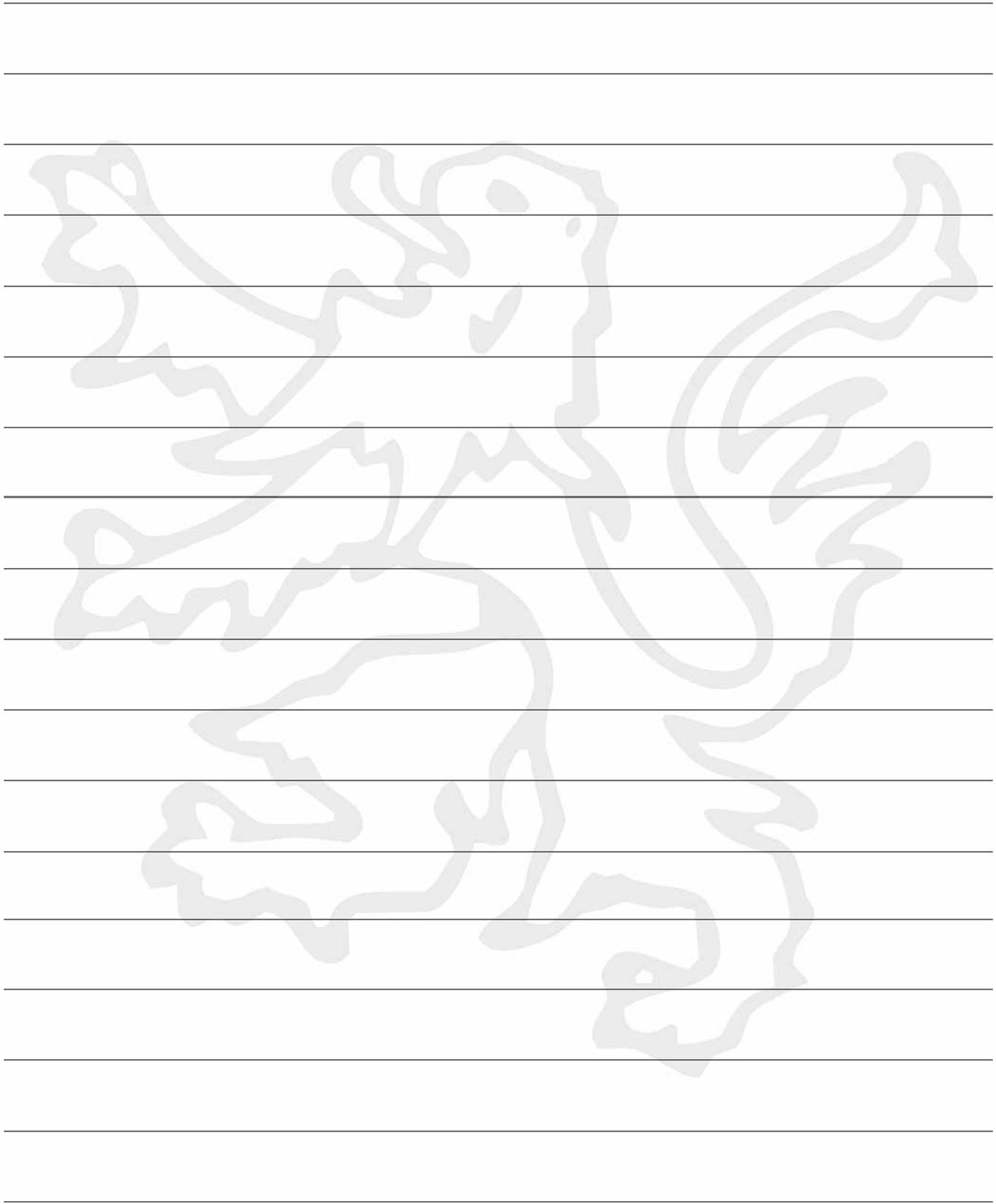
*Director, Center for Bioethics and Humanities and Professor of Medicine, University of Colorado*



Matthew Wynia's career has focused on the intersections of professional ethics, clinical care and health policy. The Center he leads is responsible for a university-wide portfolio of programs for teaching, community engagement, clinical consultation and research related to health humanities and bioethics. Prior to joining the University of Colorado, Wynia directed the Institute for Ethics at the American Medical Association for more than fifteen years, leading projects on understanding the ethical climate of health care organizations, communication and team-based care, physician professionalism and self-regulation, ethics and epidemics, medicine and the Holocaust, and inequities in health and health care.







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