



# **DIRECTOR'S NOTE**

I have had the honor and privilege of serving as Director of the Center for Medical Ethics and Health Policy at Baylor College of Medicine for six years. I am very grateful to our community—including students, colleagues, faculty members and philanthropic donors. Our success can be attributed to our group's fierce curiosity, relentless pursuit of knowledge, and countless hours of teaching, research and outreach



AMY LYNN MCGUIRE, J.D., PH.D.

This annual report summarizes our journey over the past year, highlights our achievements and forecasts what's next.

In the last year, we ramped up our research grants, expanded our education and consultation offerings and amplified our reach. We are proud that our ideas and recommendations in medical ethics and health policy have helped influence how healthcare is delivered.

We accomplished a lot in 2018, but we also lost a lot. The passing of our Center's founder and former director Baruch Brody reinforced the importance of people and relationships. He leaves a lasting legacy at the Center. We also lost Tristram "Tris" Engelhardt Jr., a Distinguished Emeritus Professor and a leading bioethics scholar. We will always fondly remember both of them, honoring their memory and dedication to the field of bioethics.

The work we do has never been more important and relevant. Health and healthcare are universal issues, and as new technologies and medicines emerge, the ethical and policy considerations will continue to magnify and intensify. Through our research, education, clinical consultations and outreach we are bringing medical ethics to the forefront to critically reflect on and respond to challenges, and ultimately improve patient care.

Thank you for your continued partnership and support as we pursue this journey together.

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### GROUNDBREAKING RESEARCH IN MEDICAL ETHICS AND HEALTH POLICY

# ▼ Addressing Critical and Developing Issues ▼



Emerging medical technologies such as genome editing, gene therapy, first-in-human clinical trials, aging research and regenerative medicine.



Existing laws and guidelines that apply to genomic research and medicine to discern gaps and to make recommendations for new approaches.



The impact of policy on biomedical research and how stakeholder opinion shapes decision making in public health policy in areas ranging from Tobacco 21 laws and HPV vaccination to nutrition counseling and obesity.



The challenges of incorporating genomic sequence data into the routine practice of medicine in a variety of clinical settings.



Big data applications and artificial intelligence and their impact on patient care and system costs, an especially important priority as Baylor seeks to become a learning healthcare system.



The philosophical, ethical, legal and social implications of neuroscience and the broader issues that stem from our expanding insight into memory, consciousness and personal identity.



Medical decision-making and how physicians should use knowledge from research on decision-making to shape people's healthcare decisions and related behaviors.

# ▼ Impressive Publication Record ▼

Over the last year, our faculty have been published in high-impact, peer-reviewed journals such as Science, Nature Reviews Neuroscience, Genetics in Medicine, Pediatrics, American Journal of Bioethics, Journal of Medical Ethics and Biology and PLoS Biology (to name just a few). These articles are read and cited by other academics and used to help influence public policy.

#### ▼ By The Numbers ▼ **NEW PROPOSALS (30 NIH) ACTIVE FUNDED** 36.7 43.1 RESEARCH RESEARCH **PERCENT PERCENT GRANTS PROGRAMS** COMBINED **NIH SUCCESS** SUCCESS RATE **RATE** Funded by the National Institutes One of the largest funded of Health, the Patient-Centered research programs of any Outcomes Research Institute and The norm success rate is 20 percent for bioethics program in the Greenwall Foundation. federal grants and 18 percent for NIH. the country

#### **EDUCATING TOWARD EMPOWERMENT**

#### **Medical Student Education**

### Health Policy Pathway

Our Health Policy Pathway is **gaining momentum** and fulfilling its mission of empowering the next generation of healthcare providers and scientists to shape policies that will improve health. The Pathway is only two years old and yet we have—



students enrolled in the introductory course,

20 students in the seminar elective (course cap)

received positive feedback from students about the unique benefits of the offering. The final course, Methods and Analysis in Health Policy, is expected to launch in 2020.

## **▶** Ethics Pathway

Our Ethics Pathway has the **highest enrollment** and completion rate of any Undergraduate Medical Education pathway at Baylor College of Medicine,



ensuring as students become clinicians they are equipped to deal with challenging ethical cases and prepared to conduct research on ethical issues in medicine and biomedical research.

students actively engaged in ethics 280 education in Spring 2019, including students in the Physician Assistant Program, Genetic Counseling Program and Orthotics and Prosthetics Program

>25 of the Baylor student body is currently enrolled in the Medical PERCENT Ethics Pathway

students—over the last five years —have published papers they prepared for their capstone project in journals such as *Pediatrics* and Journal of the American College of Surgeons

#### **Resident Education**

We offer, to our knowledge, the ONLY ethics and policy **Graduate Medical** Education program in the country that is explicitly mapped to the Accreditation Council for Graduate Medical



Education milestones and that provides a consistent and comprehensive curriculum across all residency programs.

### **Quarterly Grand Rounds**

We deliver quarterly ethics grand rounds at Houston Methodist Hospital and, new this year, started offering these sessions at Baylor St. Luke's **Medical Center as** well. Our goal is to keep physicians,



nurses, physician assistants and related professionals abreast of ever-changing topics within the field.



# **SUCCESS SNAPSHOTS**

## ENHANCING PROFESSIONALISM AND PATIENT CARE THROUGH CLINICAL ETHICS

▶ We continue to partner with Houston Methodist Hospital to offer the Intensive Bioethics Course, an advanced course specifically designed for all types of healthcare professionals.

158 HEALTH PROFESSIONALS

26 STATES

**3** COUNTRIES

95
PERCENT

of participants stated they learned information that could be implemented into their clinical practice

100 of participants surveyed said they will change their practice as a direct result of the course.

What other ethics consultants have to say about the course:

"All I can say is I wish I had known about this course years ago! Outstanding and brilliant!"

"Great course and I have already recommended it to my colleagues."

"The breadth, expertise of speakers, energy of delivery, and attention to the needs and hopes of participants resulted in an outstanding conference."



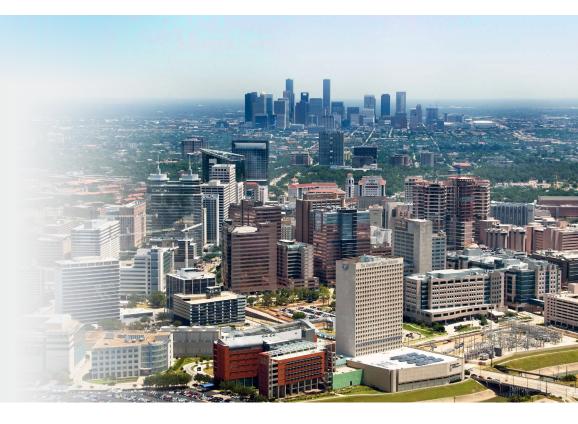
# **SUCCESS SNAPSHOTS**

# As one of the

largest clinical ethics consultation services in the country, we seek to enhance the quality of healthcare in diverse institutions. In 2018, we conducted more than

# 550 CONSULTATIONS

at Houston Methodist Hospital and Baylor St. Luke's Medical Center.



This year, we have three clinical ethics fellows, selected from a pool of more than 70 applicants, training with the Center's nationally renowned faculty and staff.



# SOPHIA FANTUS, PH.D.

Ph.D. from University of Toronto; M.S.W. from New York University; B.A. from University of Toronto



# JAMIE CRIST, J.D.

J.D. from Case Western Reserve University School of Law; M.A. from Case Western Reserve University School of Medicine; B.A. from Michigan State University





#### ERIC MATHISON, PH.D.

Ph.D., B.A. and M.A. from University of Toronto; B.A. from University of Calgary

# DEMONSTRATING THOUGHT LEADERSHIP THROUGH OUTREACH AND COMMUNITY ENGAGEMENT IN 2018

14 PRIMARY FACULTY MEMBERS



**>150** 

PEER REVIEWED PUBLICATIONS

and participated in several journal editorial boards

ATTENDED >50

CONFERENCES, SEMINARS AND EVENTS

- Our blog, Policywise, has 1,500 to 2,000 views each week. Our most popular posts—on topics such as mental illness, transhumanism and the future of catching criminals—have garnered more than 14,000 views.
- We launched a Rapid Response Program, proactively commenting on hot topics in leading news outlets and journals. This has gained us placements in Science, JAMA Pediatrics, Nature Neuroscience, National Geographic, USA Today, Associated Press, Houston Chronicle, Dallas
- Morning News and MedPage Today. See all Center faculty quotes on our website's "In the News" section.
- We continue to focus on bringing people together. In response to feedback from the local community, we revamped the format of our Conversation Series by changing the location and time of day to reach a broader audience. We also garnered publicity and interest from the community, with features on Houston Public Media and TMC Pulse.

# LOOKING FORWARD



#### JOIN US FOR OUR UPCOMING CONVERSATION SERIES

APRIL 11, 2019 | NOON-1:30 P.M

MAY 9, 2019 | 6:30-8 P.M

Faith and Healing

Patients, Miracle Language and a Space for Faith in Medicine

Raising Consciousness?

Minimally Conscious States, Brain Death and our Growing Understanding of Disorders of Consciousness

#### RESEARCH HIGHLIGHT

Over the past four years, we have undertaken an empirically-informed ethical and policy framework for building common resources to support large-scale research and improve public health. This has involved:

- ▶ A landscape analysis of existing data-sharing efforts
- ▶ Two-day deliberative sessions with members of the pubic at three sites across the U.S.
- In-depth interviews with multiple stakeholders from various sectors (e.g., government, academia, and private industry)
- ▶ Based on this research, we developed design principles for building a medical information commons and are in the process of publishing 11 articles on this topic in a special issue of

the Journal of Law, Medicine, and Ethics, forthcoming in spring 2019. Learn more here

Supported by: R01HG008918, National Human Genome Research Institute, NIH

#### **EMBEDDING ETHICS**

- ▶ The First-Year Medical Ethics Course has been added to the newly launched Masters in Genetic Counseling curriculum.
- Dur 2019 Bioethics Intensive Course will take place from April 29-May 3. This year's course will focus on the Healthcare Ethics Consultant-Certified (HEC-C) exam, the first-ever certification program that identifies and assesses a national standard for the professional practice of clinical healthcare ethics consulting. Learn more and register

JOIN US FOR GRAND ROUNDS			
MAY 8, 2019	5-6 P.M.	•	Ethical Issues in Working with Vulnerable Patient Populations
JUNE 12, 2019	TBD	•	Medical Decision Making and Behavioral Economics: How You Influence Your Patients
SEPT. 18, 2019	5-6 P.M.	•	When Our Personal Beliefs Have the Potential to Harm
NOV. 13, 2019	5-6 P.M.	•	Medical Marijuana in the Healthcare Setting
DEC. 11, 2019	5-6 P.M.	•	The Right To Try: The Ethics and Policy of Access to Unapproved Medicines

# HEALTH POLICY LEADERSHIP

Inaugural Health & Science Policy Research Day

**April 2, 2019** 

This event will demonstrate our impact and cultivate our Baylor policy community.

# Register here

- ▶ Dr. Paul Klotman, president, CEO and executive dean at Baylor College of Medicine, will provide opening remarks
- A keynote speaker, Timothy Caulfield, author of *Is Gwyneth Paltrow Wrong About Everything? When Celebrity Culture and Science Clash* and host of "A User's Guide to Cheating Death," will speak on legal, policy and ethical issues in medical research and its commercialization
- ► Center faculty (Drs. Amy McGuire, Christopher Scott, Gabriel Lazaro-Munoz, Christi Guerrini, Jenny Blumenthal-Barby and Stephanie Morain)
- ▶ Health Policy Scholars (Drs. Peter Hotez, Sharmila Anandasabapathy, Laura Petersen, Heidi Russel and Jean Raphael)
- ▶ Poster session highlighting current research





# HADLEY STEVENS SMITH, M.P.A.

is currently working part-time as a Research Associate in the Center and will complete her Ph.D. in May in Health Economics from The University of Texas Health Science Center at Houston. We are excited to welcome her as our first Health Policy Fellow in July 2019. ▶ Several of our faculty attended this year's first-ever "Innovations in Clinical Ethics: A Working Un-Conference" hosted by the Cleveland Clinic. We will bring together experienced clinical ethicists from diverse healthcare systems around the world for a purposeful and productive meeting.



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Thank you for taking the time to read this report. While this is an annual snapshot of our programs and our progress, you can keep up with our latest developments in real time.

Follow us on Twitter @BCMEthics, like us on Facebook and read our Blog.

We invite you to watch a short video summarizing our impact, share our Annual Report and ensure our continued success by donating to help support our future.



