

MESSAGE FROM THE DIRECTOR

I decided this summer to stop watching the news. I just couldn't take the violence, racism, and divisiveness anymore. Of course, I wasn't completely insulated from the world. It would have been impossible to escape news about Brexit, the controversial results of the US Presidential primaries, or the heartbreaking attacks in Orlando, Dallas, and Nice. I did keep up with the latest news about Zika, gene editing, the Cancer Moonshot, and how Artificial Intelligence may help blind people see and restore memory to individuals with dementia. But the overwhelming sadness and senselessness that permeated from the news channels on a daily basis was too much for me to bear. I needed a break.



In June I was invited by one of our community advisory members, Nancy Dunlap, to attend Spotlight Health, the opening segment of the Aspen Ideas Festival. A theme at this year's conference was Ethical Choices and there were many fascinating sessions on ethical issues in health policy, emerging technologies, and end of life. At the opening session, one of the speakers shared the heartbreaking story of his daughter's death. He mentioned that he felt lost and alone after she died and that he himself had contemplated suicide. But then he read the seminal book, "Man's Search for Meaning" by Viktor Frankl, which had a profound impact on him and he went on to create a very meaningful life and successful business. I was immediately curious how a book could transform someone's outlook on life so dramatically, so I pulled out my phone and with 2 clicks downloaded the audio version of the book. I spent the next week devouring Dr. Frankl's autobiographical account of his experience as a prisoner in Nazi concentration camps. Woven throughout the story is an exploration of what it means to live a good life, even under the worst of circumstances, and what it looks like to die with dignity. "Everything can be taken from a man but one thing: the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way." For Dr. Frankl, "the meaning of life is to give life meaning." He acknowledges that "suffering is an ineradicable part of life, even as fate and death" but believes that even in death we all have the opportunity to create meaning: "The way in which a man accepts his fate and all of the suffering it entails... gives him ample opportunity... to add a deeper meaning to his life. He may remain brave, dignified and unselfish. Or in the bitter fight for self preservation he may forget his human dignity and become no more than an animal."

On January 17, 2017 we are hosting our third annual community outreach event. Our goal this year is to begin a public conversation about the questions that are at the heart of Dr. Frankl's story: how can we all live a good life, and what does it mean to have a good death? Our event co-chairs Nancy Dunlap and N.J. Pierce have planned a wonderful evening, beginning with a performance by famous actress and playwright Anna Deavere Smith of her riveting one-woman show, Let Me Down Easy, which explores the fragility and resilience of the human body, and ending with an engaging dinner and discussion with Center faculty. For more information about the event or to purchase tickets visit our [website](#).

UPCOMING EVENTS

Journal Club: Sept. 1
Grand Rounds: Sept. 21
DIVAU Speaker Series: Oct. 13
Community Outreach Event: Jan. 17

As we gear up for this event and summer comes to a close, I will inevitably turn back on the news and re-immers myself in world affairs, both good and bad. But it is through events like the one that we are planning, where we come together as a community to explore the difficult questions that we all face by virtue of our own mortality and the uncertainty of the human condition that I am reminded once again of the words of Viktor Frankl, "[I]f life is never made unbearable by circumstances, but only by lack of meaning and purpose."

Amy McGuire

EDUCATION

Ethics Track Graduation

On May 31, 17 graduating medical students presented their capstone projects and received their certificates for completing the Ethics Track. This was the largest graduating class the Track has ever had! A complete listing of the graduates and their capstone projects can be found on our [webpage](#).



Baruch A. Brody Award Winner

The top three capstone projects received the Baruch A. Brody Award, named after the founder and former director of the Center. Congratulations to these recipients and all of our graduates!

1st Place - Michelle Nguyen, Casuistry versus Prudence: An Ethical Framework for Recommending Mode of Delivery in Common Obstetric Diseases and Conditions

2nd Place - Effie Rahman, Physician's Role in Reporting Visual Impairment to the Department of Motor Vehicles

3rd Place - Anthony Wood, "What are my Odds?" – An Oncologist's Dilemma

Ethics Track Student Publications

4th year Ethics Track graduate, Saba Shaikh, and her faculty mentor, Courtenay Bruce, published **An Ethical Appraisal of Financial Incentives for Organ Donation**. *Clinical Liver Disease*. 2016;7(5):109-11.

NARRATIVE MEDICINE PROGRAM

Off Script Stories from the Heart of Medicine

Our colleagues in the **Program for Narrative Medicine**, Erika Versalovic (BCM) and Woods Nash (UT Houston), organized the first *Off Script* storytelling event on June 29. The aim of this community outreach event was to provide a forum for healthcare providers and students to promote the humanistic practice of medicine through the sharing of stories. The organizers solicited story ideas from around the TMC and then invited participants to workshop their stories before performing them in front of an audience. Presenters included students, a medical resident and fellow as well as two members of the Program in Narrative Medicine. Topics ranged from reflections on the passing of a cancer patient and solving a diagnostic conundrum to heroic measures in the ED and the challenges of providing care to a rowdy pediatric patient. The stories presented will be recorded and compiled into a podcast, which will be posted on the Center's website.

EVENT DETAILS

Journal Club: Monthly, brown-bag lunch, open-forums available to anyone interested in attending. ***Subscribe to our email distribution list to learn more.***

Grand Rounds: Monthly events held at Houston Methodist Hospital (5-6p Rio Grande Room) for their healthcare professionals, but are open to anyone interested in attending.



HEALTH POLICY

New Health Policy Program Update

The Health Policy Program has progressed significantly since Associate Director Chris Scott completed his transition from Stanford to Baylor. Shortly after his arrival, Drs. Scott and McGuire met with all the stakeholders who participated in the strategic planning process and provided an update at Academic Council to the department chairs and center directors. There is great momentum with the program:

- The program leadership is setting research trajectories at the nexus of emerging technologies and human health.
- The Office of the President is formally launching the program, officially introducing the college-wide program to the Texas Medical Center and the public at large.
- We are in the process of rolling out Introduction to Policy and Management, which will be available to first year medical students starting in August and will be the first course in a new Health Policy and Management Track for BCM students (formerly the Medical Management Track).
- We are coordinating a post-doc interest group with associated speaker series that aims to partner science researchers interested in policy and BCM faculty with the hopes of generating meaningful scholarship on the policy implications of science and new biotechnologies.

IN THE NEWS

Check out the latest ***hot topics in medical ethics and health policy*** capturing national public attention.

JOIN THE CONVERSATION

Subscribe to our email distribution list to receive the latest updates on Center activities and Health Policy Program Developments

Follow us on Twitter [**@BCMethics**](#)

Join our [**LinkedIn**](#) group

Like us on [**Facebook**](#)

Visit our website [**www.bcm.edu/ethics**](http://www.bcm.edu/ethics)

HEALTH & WELLNESS

Congratulations to John Antonio for riding the MS 150 and raising \$626.82 for the cause. He continues to implement health and wellness activities in the Center, like spa days in the conference room, back alignment, and healthy potlucks.



CLINICAL ETHICS

Welcome New Fellows

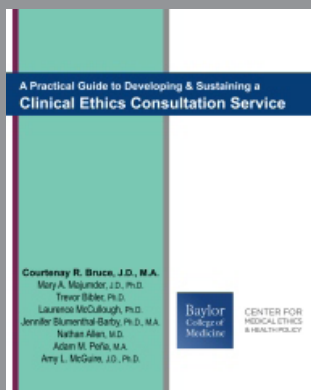
On August 15, the Center is pleased to welcome two new clinical ethics fellows. Katarina Lee received her JD with a concentration in health law and bioethics from the University of Minnesota Law School and her MA in Bioethics from New York University. Peter Koch received his PhD in philosophy from SUNY at Buffalo and served as an instructor, researcher, and clinical ethicist.

Clinical Ethics Scholarship

The clinical ethics team had five presentations at the 12th Annual International Conference on Clinical Ethics Consultation (ICCEC) in Washington, D.C. May 19-22. Topics included living donors, diversity of clinical ethics consultation services, and miracles at the end of life. [Click here](#) for more information.

A PRACTICAL GUIDE TO DEVELOPING AND SUSTAINING A CLINICAL ETHICS CONSULTATION SERVICE

The American Journal of Bioethics “highly recommend the Guide for both consultants and those who train them” and said “for many ethics committees and consultation services, this resource will be no less than a godsend.” The guide was described as a “welcome addition to our clinical ethics repertoire due to its practicality, its ease of use, and its demonstration of how the Core Competencies can be put into practice.” **Buy your copy today!**



INTENSIVE BIOETHICS COURSE APRIL 11-15, 2016



The Center and Houston Methodist offered the second annual Intensive Bioethics Course April 11-15 to 46 participants from all across the country and various backgrounds, including chaplaincy, clinical case management, clinical ethics, government affairs, internal medicine, palliative medicine, pediatrics, plastic surgery, psychiatry, and risk management. To learn more about the course or sign-up for the 2017 Course Interest Form, [click here](#).

WHAT INTENSIVE PARTICIPANTS SAY ABOUT THE COURSE

- 100% of participants will change their practice as a result of participating in this course
- 4.8 out of 5 on overall course quality
- “Excellent course for diverse group.” – 2016 Intensive course participant
- “Very informative and helpful to my profession.” – 2016 Intensive course participant



RESEARCH

Select Presentations

Blumenthal-Barby, J. Ethics and Society at Rice University. Humanities Texas High School Summer Enrichment Program. Houston, TX. June 2016.

Bruce, C. The Ethics of Xenotransplantation. The New Orleans Conference: Practices in Cardiac Surgery & Extracorporeal Technologies. New Orleans, LA. June 2016.

Childress, A. Narratives of Burn Injury: Patient's Reflections After 5 Years. American Burn Association. Las Vegas, NV. May 2016.

Guerrini, C. Administrative Law & Public Health Ethics in the Context of Citizen Science. UT School of Public Health. Houston, TX. June 2016.

Majumder, M. Risks and Harms Potentially and Realistically Posed by Aggregate Genomic Data (and Current Policies). NHGRI Workshop: Aggregate Genomic Data. Rockville, MD. May 2016.

McGuire, A. Ethical Issues in Disruptive Technologies. Medical World Americas Conference. Houston, TX. April 2016.

McGuire, A. Building a Medical Information Commons: Data Sharing Ethics and Policy. University of Pennsylvania. Philadelphia, PA. May 2016.

Morain S. Public Opinion, Policy Feedbacks, and Strategic Policymaking. Northeastern University: Public Health Law Conference. Boston, MA. April 2016.

Scott, C. Ethical Issues in Stem Cell Research. Medical World Americas Conference. Houston, TX. April 2016.

Malek, J. Parental Perspectives on Whole Exome Sequencing in Pediatric Cancer: A Typology of Perceived Utility. Clinical Sequencing Exploratory Research Consortium Meeting. Seattle, WA. April 2016.

Malek, J. Decision-Making in the Periviable Period: An Ethical Framework. American Academy of Pediatrics Section on Neonatal-Perinatal Medicine, Perinatal and Developmental Medicine Symposium. Aspen, CO. June 2016.

Pereira, S. Parents' and Physicians' Attitudes toward Newborn Screening and Genomic Sequencing: Preliminary Findings from the BabySeq Project. Newborn Sequencing of the Future Conference. San Diego, CA. March 2016.

Select Publications

Blumenthal-Barby J. **Biases and heuristics in decision making and their impact on autonomy.** *Am J Bioeth* 2016, 16(5): 5-15.

Blumenthal-Barby J, Lazaridis C. **A woman in her 30s whose family becomes distrustful after an initial prognosis proves inaccurate.** *Chest* 2016, 149(4): 115-7.

McGuire AL co-author of Green RC et al. **Clinical sequencing exploratory research consortium: Accelerating evidence-based practice of genomic medicine.** *Am J Hum Genet* 2016, 98(6): 1051-1066.

Malek, J. **Responding to refusal of recommended cesarean section: Promoting good parenting.** *Seminars in Perinatology*. 2016, 40(4): 216-21.

Health Policy Publications

As the challenges facing science and healthcare continue to grow, we have an unprecedented opportunity to apply our research and expertise to help advocate for responsible and ethically sound policy. Check out some of our latest publications in health policy research:

Guerrini C, McGuire AL, Majumder M. **Clearing complexity from the Common Rule NPRM.** *J Law Biosci*. 2016, Epub ahead of print.

Moore QL, Majumder MA, Rutherford LK, McGuire AL. **Ethical and legal challenges associated with public molecular autopsies.** *J Law Med Ethics* 2106, 44(2): 309-318.

Pereira S, Robinson JO, McGuire AL. **Return of individual genomic research results: What do consent forms tell participants?** *European Journal of Human Genetics* 2016, Epub ahead of print.

Curnutte MA, Frumovitz KL, Bollinger JM, Cook-Deegan RM, McGuire AL, Majumder MA. **Developing context-specific next-generation sequencing policy.** *Nat Bioethnol*. 2016, 34(5): 466-470.

Morain SR. **Tobacco 21 laws: Withdrawing short-term freedom to enable long-term autonomy.** *Am J Bioeth* 2016, 16(7): 26-28.

Morain SR, Kass NE. **Ethics issues arising in the transition to learning health care systems: Results from interviews with leaders from 25 health systems.** *eGEMS* 2016, 4(2): Article 3.

Scott, CT, DeFrancesco L. **Gene therapy's out-of-body experience.** *Nat Biotechnol* 2016;34(6):600-7.

BLOGS ON BIOETHICS.NET

Read Dr. Blumenthal-Barby's recent blogs on Bioethics.net.

COMMUNITY

The Center values creating a meaningful connection between the work we do and the people whose lives are impacted by these important ethical questions. We are committed to building relationships with the community and starting a dialogue around these very issues.

Register for the Decisions, Issues, and Values Affecting U (DIVA U) Speaker Series

Through thought provoking lectures and discussions, U are invited to explore your own decisions, issues, and values in the context of the current complex medical ethics and health policy landscape. During each lunchtime session, a Center faculty member will present a relevant medical ethics dilemma. **Register today!**



Tickets on Sale Now - Outreach Event January 17, 2017

The Center is thrilled to welcome playwright, TV star and stage actress Anna Deavere Smith for the Houston premiere of her theatrical hit, *Let Me Down Easy*. The docudrama examines the body as it relates to health and human existence in verbatim excerpts from real-life interviews, where Smith builds a kaleidoscopic one-act play full of heart, humor and heroism. **Tickets** for the performance and dinner are available now. Individual tickets for the performance only will go on sale in September. **Click here for more information.**

Meet our Advisory Council

Meet our wonderful members of the **Advisory Council** that serve as ambassadors on behalf of the Center.



DONATE

The Center for Medical Ethics and Health Policy researches and influences policy on today's most pressing ethical issues, like what to do about the Zika virus, stem cell therapies that can make you live longer, face transplants, the rights of Alzheimer's patients, end of life decision making, and genetically designing babies. We are one of the biggest and fastest growing ethics centers in the country, and our goal is to build the infrastructure so that we can respond immediately to issues like these and help government and health care providers decide how to do the right thing. In order to accomplish this, we need your help. Please consider donating to the Center. **Click here** to learn more or **contact us**.



AWARDS & RECOGNITION

Laurence McCullough retired from the Center after 28 years of excellence. He now holds the Distinguished Professor Emeritus appointment. To honor his retirement, the Center has created the Laurence McCullough Travel Award in recognition of his commitment to training Baylor physicians in the responsible practice of medicine. This award gives two Ethics Track students each year the opportunity to attend the American Society for Bioethics and Humanities Annual Meeting. Thank you to the alumni and Center supporters who have funded this award. If you would like to contribute, please do so [here](#).



Laurence McCullough, Ph.D.

Courtenay Bruce is leading the ethics committee workgroup for the “Financial Disincentives White Paper” for the United Network for Organ Sharing.

John Coverdale, secondary faculty member, is the recipient of the prestigious Barbara and Corbin J. Robertson Jr. Presidential Award for Excellence in Education.

Fellow Spotlight

Name: Ashley Stephens

Professional interests: Quality improvement in clinical ethics consultation, organizational ethics, critical care ethics

Educational background: MA: Medicine, Health & Society from Vanderbilt University; BA: Philosophy from Vanderbilt University in Nashville, TN

A day in the life: There is no “typical day” in the life of a clinical ethics consultant. My schedule is a constant balance of research, teaching, and time on-call. We are on-call 24/7 and never know whether the next consult will be a quick 1-hour case or a case that we follow for a few weeks depending on the complexity of the case. If the service volume is heavy, I prioritize a little bit of self-care in the evenings so I can recharge mentally, emotionally and physically before coming back into the hospital the next day. My version of self-care can include anything from having some quiet time poolside, binge-watching Netflix, getting a pedicure, trying a new workout class with friends, or scheduling a post-call weekend hiking trip to ATX.



Ashley Stephens, M.A.

Biggest accomplishment during fellowship: My biggest accomplishment this year was presenting at the International Conference on Clinical Ethics Consultation in Washington, D.C. this past spring. Getting to this point in my early career as an ethicist where I am able to make contributions of my own with colleagues I have met along the way is a milestone for me. I look forward to continue contributing to the field as I grow professionally during the remainder of the fellowship.

Most memorable experience during fellowship: I automatically think of my most memorable cases. The first that comes to mind is a positive one when we had a case where the patient had been in the hospital for several months. All of the members of my team, myself included, had been involved with this patient and his family at some point during his admission. The final time that our service’s involvement was requested, the attending physician paged and asked for me specifically since he felt like the family had connected with me in our previous encounters. This request was an incredibly humbling experience for me because it was one of those moments where I was recognized as a trusted member of the team and encouraged me to reflect on how much I’ve grown as a clinical ethicist over the past year.

