In 2018, the National Endowment for the Humanities (NEH), which supports research and programming in the humanities, granted funding to *The Human Story of Illness: Health Humanities Portraits for Physicians in Training*. This NEH grant project will generate a series of workshops over two years at the University of Illinois College of Medicine (UI-COM), focused on “health humanities portraits.” Each portrait will consist of a first-person story, from fiction or non-fiction sources, offering a patient perspective, that will be accompanied by relevant humanities scholarship illuminating each story’s social, cultural, ethical and affective themes. This approach, using a different format than the clinical cases frequently found in medical education, deliberately and inclusively focuses on the myriad, complex forces present in the lives of patients, notably their family and community ties.

Gretchen Case, as one of five expert faculty consultants chosen from the US and Canada, developed a health humanities portrait on health care access in rural, remote, and underserved areas. Dr. Case based her portrait on a narrative chosen from an ongoing series of interviews that she has conducted with Jennifer Larson, MD, beginning in 2007 in Western North Carolina. The patient interviewed narrates her story of her experience in a rural emergency department and eloquently discusses the challenges to care in such a setting. The humanities research that Dr. Case chose to accompany this first-person narrative comes primarily from the field of performance studies, her home discipline. Performance studies sits at the intersection of anthropology, theater, sociology, literary studies, cultural studies, and many other areas of research and addresses human behavior as performance: why do we act as we do, and how do we learn to act in those ways? Using this distinctive scholarly lens, she was able to create a portrait that interrogates the way that medicine is performed in this specific rural setting.

*Continued on pg. 2*
In May and June 2018, Dr. Case traveled to Chicago to present her portrait to a group of core faculty at UIC who will be taking the health humanities portraits approach in their medical school’s new curriculum. Portraits created by other expert consultants explore other important health stories: global poverty and women’s health, through a lens of history (Ellen Amster, PhD), refugee and immigrant health care, through a lens of literature (Rebecca Garden, PhD), psychiatric disability and cultural stigma, through a lens of American studies/cultural studies (Jonathan Metzl, MD, PhD) and trauma and survival, through a lens of bioethics (Jodi Halpern, MD, PhD).

These initial five portraits will be used as templates for medical and health professional faculty who want to create their own portraits. Sandy Sufian, PhD, the Primary Investigator for the grant, along with her staff at UIC, will create an online repository of these portraits along with supplementary materials that will be utilized by UIC and eventually shared with other institutions. Once the 2-year grant period is completed, these health humanities portraits will be introduced into the UIC curriculum, with the intention of continuing ongoing portrait development through additional funding. This project hopes to strengthen medical training by creating rigorous portraits that highlight and explore the full texture of people’s experiences of illness.

### Evening Ethics

**“The $5000 Icepack: What is the Cost of Emergency Care?”**
with Tom Miller, MD, CMO UHealth, Scott Smith, JD, General Counsel U Health, and Gretchen Case, PhD, Chief, PMEH

Tuesday, September 4, 2018
5:30pm-7:00pm, Research Administration Building, 1st floor Conference Room
CME and light refreshments

Billing for healthcare services is a puzzle to many people in the United States; finding out what care costs in the emergency room might be the most difficult puzzle of all. Patients have reported exorbitantly expensive charges for emergency room services—even when those services were declined—while administrators point out the significant costs of maintaining medical teams ready for any situation that comes through the door. What information do patients need to avoid unexpected bills in the ER? How can individual providers advocate for patients and help them navigate a complex system? How might hospitals and health systems respond to stories of billing practices that may dissuade people from seeking medical care in an emergency?

Two background readings for this session are found at:


When Patient Care Conflicts with the Values of a Religiously-Affiliated Hospital/University

Facilitators: Lars Nielson (Counseling and Psychological Services, Brigham Young University) and James Tabery (Department of Philosophy, University of Utah)

Tuesday, October 2, 2018
5:30pm-7:00pm, Research Administration Building, First floor Conference room
CME and light refreshments

Therapists and counselors at religiously-affiliated universities and hospitals face a challenge when the personal care of their patients/students doesn't align with the values of the institution. How should a counselor at such a university advise a student who feels disillusioned about her faith? How should a therapist at such a hospital counsel a patient who requests services not supported by the institution for religious reasons? This Evening Ethics discussion will draw together practitioners from a variety of professional backgrounds and a variety of religiously-affiliated institutions to assess this pressing challenge with direct implications for patient/student populations. Watch for background articles closer to the event.
Wednesday, August 8, 2018
University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Rachel Borup, PhD

To Siri with Love: A Mother, Her Autistic Son, and the Kindness of Machines
by Judith Newman

In 2014, journalist Judith Newman wrote an article for the New York Times about her autistic son’s fondness for Siri and other technologically-mediated forms of communication. The article went viral and resulted in To Siri with Love, her collection of essays about parenting her twin boys—one neurotypical and one neurodivergent. The essays follow Newman’s growth as a parent from the moment she perceives a difference in her twin babies, to Gus’s diagnosis at age six of being on the autism spectrum, to the twins’ entrance into adolescence with all the attendant issues of sexual identity, independence, and self-sufficiency. The book has been praised as a bracingly honest and humorous account of parenting two very different sons. It also sparked some outrage in the autistic community for, at points, veering too close to what some perceived as ableism and even eugenics. Please join us for a lively discussion of this engaging and controversial book.

Wednesday, September 12, 2018
University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Gretchen Case, PhD, MA

Quackery: A Brief History of the Worst Ways to Cure Everything
by Lydia Kang

In their book, Quackery: A Brief History of the Worst Ways to Cure Everything, Lydia Kang and Nate Pedersen offer a faux-encyclopedic look at many aspects of false medicine. Arranged in sections such as “Antidotes” and “Animals” and punctuated with “Hall of Shame” pronounce- ments, the book gives readers a quick glimpse of the horrors, scandals, and mere embarrass- ments perpetrated by the unscrupulous on the unsuspecting, all in the name of medicine and health.

Wednesday, October 10, 2018
University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Gretchen Case, PhD, MA

The Butchering Art: Joseph Lister’s Quest to Transform the Grisly World of Victorian Medicine
by Lindsey Fitzharris

Long before she wrote The Butchering Art, Lindsey Fitzharris created a modern audience for some of the most “grisly” chapters in the history of medicine and surgery, using striking visuals and compelling stories. (Check out her online presence on Twitter @DrLindseyFitz and Instagram @dlindsayfitzharris for examples!). In this book, Fitzharris focuses on the story of Joseph Lister, the 19th-century surgeon who revolutionized his craft with discoveries about infection, contagion, and sterility.

A recently updated 2018 Schedule of Readings can be found on our website at: http://medicine.utah.edu/internalmedicine/medicaethics/activities/literature/
### Resident Ethics Conferences 12:30-1:15 pm

**When, How, and Why We Evaluate Patient Competence**  
VAMC: Gretchen Case, PhD, MA & Philip Baese, MD  
UUMC Cartwright Conference room: Leslie Francis, PhD & Philip Baese, MD

**How to Deal With Medical Mistakes**  
VAMC: Sam Brown, MD  
UUMC Cartwright Conference room: Brent Kious, MD

### The Physicians Literature and Medicine Discussion Group 6:00-8:30 pm

**U of U Hospital Large Conference Room #W1220**

To Siri with Love: A Mother, Her Autistic Son, and the Kindness of Machines by Judith Newman  
Facilitated by Facilitated by Rachel Borup, PhD

Quackery: A Brief History of the Worst Ways to Cure Everything by Lydia Kang  
Facilitated by Gretchen Case, PhD, MA

The Butchering Art: Joseph Lister’s Quest to Transform the Grisly World of Victorian Medicine by Lindsey Fitzharris  
Facilitated by Gretchen Case, PhD, MA

### Evening Ethics 5:30-7:00pm U of U RAB #117

“The $5000 Icepack: What is the Cost of Emergency Care?” with Tom Miller, MD, CMO UHealth, Scott Smith, JD, General Counsel U Health, and Gretchen Case, PhD, Chief, PMEH  
Does Medical Humanities Still Bridge Only “Two Cultures?” With Louis Borgenicht, MD, Susan Sample, PhD, MFA, and Gretchen Case, PhD, MA  
When Patient Care Conflicts with the Values of a Religiously-Affiliated Hospital/University  
Facilitators: Lars Nielson and James Tabery, PhD

---

**CME Statements Accreditation:** The University of Utah School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians. AMA Credit: The University of Utah School of Medicine designates these live activities for a maximum of 1.5 AMA PRA Category 1 Credit(s)™. Physicians should claim only the credit commensurate with the extent of their participation in the activity. NONDISCRIMINATION AND DISABILITY ACCOMMODATION STATEMENT: The University of Utah does not exclude, deny benefits to or otherwise discriminate against any person on the basis of race, color, national origin, sex, disability, age, veteran’s status, religion, gender identity/expression, genetic information, or sexual orientation, 8365 (Voice/TTY), 801-585-5746 (Fax). 1.5 CME for Evening Ethics and Literature & Medicine.

---

**Keep The Date**

**Rafael Campo, MD** is coming to Utah November 29 to December 1st!

For more information on Rafael Campo, please see  
https://www.rafaelcampo.com/

---

**UtahPresents: Healthcare: Stories of Illness & Wellness**  
in partnership with University of Utah Health’s Resiliency Center and Program in Medical Ethics and Humanities:  
January 19, 2019, 7:30pm, Kingsbury Hall

For tickets and more information see  
https://utahpresents.org/events/healthcare-stories-of-illness-wellness/

See, also, https://krc1.org/blog/radioactive-july-25-2018/  
About 3 minutes into the RadioActive show, Giuliana Serena, the Beekeeper of The Bee, shared Matthew Petersen’s (a former UUH med student) story from 2016, spoke about the UtahPresents storytelling event in January of 2019, and also provided information about the upcoming show at The Bee on August 9th, the theme of which is Healthcare.
PROGRAM IN MEDICAL ETHICS AND HUMANITIES

Division Faculty:
Margaret P. Battin, M.F.A., Ph.D
Jeffrey R. Botkin, MD, M.P.H.
Samuel M. Brown, MD, M.S.
Tencille R. Brown, JD
Gretchen A. Case, Ph.D, MA
Leslie P. Francis, Ph.D, J.D.
Brent Kious, MD, Ph.D
Erin Rothwell, Ph.D
Jim Ruble, PharmD, JD
Susan Sample, Ph.D, M.F.A.
Jill Sweney, MD, MBA
James Tabery, Ph.D
Jay Jacobson, M.D. (Emeritus)

Program Associates:
Howard Mann, MD
Mark Matheson, D. Phil.

Division Associates:
Rebecca Anderson, RN, Ph.D
Philip L. Baese, M.D
Louis Borgenicht, M.D.
Maureen Henry, JD
Thomas Schenkenberg, Ph.D

Academic Program Manager:
Linda Carr

Executive Assistant:
Heather Sudbury
Phone: (801) 581-7170
or (801) 587-5884
Fax: (801) 585-9588

PROGRAM MEMBERS ON THE ROAD AND IN PRINT

Jeff Botkin chaired a Consensus Committee for the National Academies of Sciences, Engineering and Medicine titled “Return of Individual Results to Research Participants: Guidance for a New Research Paradigm.” Jeff Botkin has also been nominated to the NIH’s Council of Councils that oversees NIH-wide Initiatives. Lastly, he has just completed two weeks of teaching medical students in Germany and Poland for an organization titled Fellowships and Auschwitz for the Study of Professional Ethics (FASPE).

Susan Sample presented a paper on “The Personal Lyric and Medical Students: How Writing Poetry Disrupts the Hidden Curriculum on May 11, at the 9th Annual Hippocrates Poetry & Medicine Symposium, Northwestern University in Chicago.

Sam Brown, with SK Bell, SD Roche, A Mueller, E Dente, K O’Reilly, Lee B. Sarnoff, K Sands, and D Talmore, had Speaking up about care concerns in the ICU: patient and family experiences, attitudes and perceived barriers published in BMJ, July 2018.

Peggy Battin has a Wikipedia page! See https://en.wikipedia.org/wiki/Margaret_Battin

Gretchen Case will be the Chair of the program committee for the October 24-27, 2019 annual meeting of the ASBH.