A man stepped off the bus at the Salt Lake City Greyhound station. He was a veteran from Texas and had traveled to Utah to receive life-saving treatment for advanced-stage heart failure. The Salt Lake City VA hospital is one of the only VA hospitals in the country that offers this unique service. He used his entire life savings to get here. He intentionally did not tell his loved ones he was seeking treatment because he didn’t want them to worry. Unfortunately, there were complications during his treatment, and it became clear the man would not leave the hospital. He was transferred to the University of Utah hospital with a slim chance at life, which quickly dissipated to zero, and he was placed on comfort care. It was only then that his family was contacted. They were desperate to be with their loved one as he suffered through the dying process, but his time was expiring quickly. His family did not make it in time. The veteran died in a hospital room, alone.

Stories like this are surprisingly common throughout the United States. Ms. Sandra Clarke, an inpatient nurse in Seattle, Washington, had a similar experience with one of her patients. As she was visiting her patients at the start of her shift, she noticed one who was alone and likely to die. She asked if there was anything she could do for him. His only request was for someone to be with him as he died; he did not want to be alone. She explained she had to visit her other patients but would be back as soon as she was finished. When she came back, the man lay motionless, cold, and pale. He had died with his arm outstretched, beckoning for companionship during his final moments. This experience inspired Ms. Clarke to start the No One Dies Alone (NODA) program.

At the University of Utah, we also saw a need for trained and compassionate companions to be present for University of Utah Hospital patients who die alone. Our patients come from all walks of life and backgrounds. They could be alone in the hospital because they are estranged from family, are only passing through Salt Lake City, or simply have no family or friends left. Since our start in 2017, we have had the privilege to hold presence with over 30 patients dying alone.

The primary goal of the NODA program is to provide one of the world’s most sacred gifts, a dignified death. We currently have over 60 active NODA volunteers who are on call 24/7 to be present at a moment’s notice. Our volunteers are prepared and understand the various physical, mental, and spiritual stages of death and dying. During our training, we discuss the differences between healing and curing, and how we can be a healing presence for patients even as they are dying. We discuss how dying is a process and that each individual experiences that process differently, but nearly all individuals find comfort from companionship in their final moments. Our volunteers have expressed intense feelings of love, respect, peace, and holiness as they have sat with complete strangers in their final moments.

Continued on pg. 2

We began in 1989, when Dr. Jay Jacobson had the inspiration to found us as a division with a Mellon Foundation grant and the support of LDS Hospital and the University of Utah Department of Internal Medicine. In 2009, upon Dr. Jacobson’s retirement, Dr. Jeffrey Botkin took on the role of division chief in what was meant to be an interim capacity, but led us graciously for the next 10 years. In 2018, we became the Program in Medical Ethics and Humanities in the Division of General Internal Medicine and Dr. Gretchen Case became chief. We thank you for your interest in our work over the past three decades and welcome your ideas and support in celebrating this coming year and planning for another thirty.
The NODA program also provides other services, such as staff support, that may initially be overlooked. A death of a hospital patient affects not only the patient’s loved ones. There is also a deep-rooted and much less exposed effect on the clinical care team. This care team of nurses, social workers, physicians, and other health care professionals have cared for this patient and developed a relationship. A death is hard and takes a toll, and a patient who is dying alone only compounds that stress. All members of the care team feel the pull to sit with a patient who is alone. Many nursing units have created covering schemes that relieve others from their clinical duties to sit with a patient who is alone. The NODA program fills this gap. We provide an around-the-clock presence with patients who are dying alone. We support staff throughout the process with these patients and enable them to continue their clinical duties, unhindered by the guilt to be present with a patient alone and in need.

As the NODA program has grown within the University of Utah hospital, so has our presence throughout the community. To date, we have educated over 300 community members through our No One Dies Alone volunteer training and currently have a waitlist of over 80 people eager to participate. Members of our administrative team have presented at several public events throughout the valley and have engaged in community discussions about death and dying. The steady stream of interest and engagement with the NODA program indicates that we have struck a nerve in the community. The current state of medical affairs leaves the public desperate for education about the death and dying process. The NODA program is a small part of the educational process that enables and empowers people to take control of their lives and their final moments. Any conversation we can have with someone about death and dying is an important achievement for us. A reality of life is death, and we are just scratching the surface of a very deep and important conversation.

We are excited to be involved with the upcoming “decision week” events throughout the University of Utah campus in April. We will be promoting completion of advanced directives through open conversations, panels, and planned public events where people can learn more about the death and dying process. These events will be published through the University of Utah public calendar and other news outlets. As we continue to grow, we hope to engage the community in new and unique ways to discuss one of the most sacred moments in life: death.

If you, friends, or loved ones are interested in the No One Dies Alone program or the death and dying process please do not hesitate to reach out and continue this conversation.

The Program in Medical Ethics and Humanities has been a proud and active supporter of NODA since its inception at the University of Utah, and two of our faculty currently sit on its Advisory Board.

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**Evening Ethics**

“Is It Ethical for Physicians to Strategically Lie to Third-Party Payers On Behalf of Their Patients?”

*With Saundra Buys, MD, Professor and Chief, Division of Oncology, U of U Department of Internal Medicine and Susan Sample, PhD, MFA, Program in Medical Ethics and Humanities*

**Thursday, January 24, 2019**

5:30-7:00 p.m.  Research Administration Building, Room #117

CME and light refreshments offered

Deception, or the intentional falsification of information, is not typically considered an acceptable moral norm in American society. Yet when a patient’s survival depends upon an unaffordable, expensive procedure or prescription, the ethical issues become complicated. Physicians are trained to put their patients’ interests first—to advocate for them. Insurance policies are guided by a different ethic: to restrain burgeoning healthcare costs and to manage the use of limited resources. When, if ever, are physicians justified to withhold information or provide inaccurate information to insurance companies in order for patients to receive what their doctors consider to be medically necessary care? Under what conditions does the rule of patient priority take precedence over rules of truthfulness and disclosure, both of which are considered foundational in health care? Should third-party payers be regarded as not having the right to certain information, particularly if insurance coverage policies seem unjust? Are there workable solutions that might help relieve these ethical tensions between physicians and the third-party payer financial gatekeepers? Please join us for what is sure to be an interesting discussion. Please contact linda.carrlee@hsc.utah.edu for the background reading for this session.
Our 2019 Cowan Memorial Lecturer is Douglas B. White, MD, MAS. Dr. White is University of Pittsburgh Medical Center (UPMC) Chair for Ethics in Critical Care Medicine, Professor, Departments of Medicine and Critical Care Medicine, University of Pittsburgh School of Medicine, and Director, Program on Ethics and Decision Making in Critical Illness, CRISMA Center, Department of Critical Care Medicine. Dr. White graduated summa cum laude from Dartmouth College in 1995 with a degree in English Literature, received his MD from UCSF in 1999 and completed a residency in Internal Medicine and a fellowship in Pulmonary and Critical Care Medicine at UCSF. While at UCSF, he also completed a Master’s degree in Epidemiology and Biostatistics and a fellowship in Bioethics under Bernard Lo. He joined the faculty at UCSF in 2005 as an Assistant Professor of Medicine and a Core Faculty of the Program on Medical Ethics. In 2009 he joined the faculty of the University of Pittsburgh in the Departments of Critical Care Medicine and Medicine as an Associate Professor. He was also appointed as a core faculty member in the Center for Bioethics and Health law at the University of Pittsburgh. Dr. White directs the University of Pittsburgh Program on Ethics and Decision Making in Critical Illness. His research program encompasses both empirical research on and normative ethical analysis of surrogate decision-making for patients with life-threatening illness. He has several ongoing NIH funded studies. He has published widely using both quantitative and qualitative methods to examine the process of surrogate decision making in intensive care units. In conducting this work, he collaborates with a multi-disciplinary group of investigators, which includes faculty with expertise in bioethics, law, philosophy, sociology, biostatistics, and health services research. There will be several opportunities to hear Dr. Doug White:

- **Thursday, March 7, 2019: Cowan Memorial Lectureship Internal Medicine Grand Rounds, “Improving Surrogate Decision-making for Patients with Advanced Illness” (noon, Classroom A, SOM)**

- **Thursday, March 7, 2019: Evening Ethics with Dr. Doug White, “Ethical and practical challenges with shared decision making in serious illness” (5:30-7pm, Research Administration Bldg. 1st floor Conference room (#117))**

- **Friday, March 8, 2019: Cowan Memorial Public Lecture, “Responding to requests for futile or potentially inappropriate treatment” noon, HSEB 2120)**
Wednesday, February 13, 2019
University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Susan Sample, PhD, MFA

The Two Kinds of Decay: A Memoir by Sarah Manguso
Sarah Manguso begins with an unusual disclaimer for a memoir: “The disease has been in remission seven years. Now I can try to remember what happened. Not understand. Just remember.” In short, spare chapters, she recounts vivid memories from her nine-year experience with chronic idiopathic demyelinating polyradiculoneuropathy, a very rare condition “something like a chronic form of Guillain-Barre syndrome but not exactly…there isn’t a proper name for it yet.” What emerges is an exploration of language—how physicians use it; how she as a patient uses it—to describe and cope with illness. Manguso’s writing is precise, concise, and emotionally honest, so that by the book’s conclusion, we do come to an understanding of empathy.

Wednesday, March 13, 2019
University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Jenny Cochrane, MA

From Here to Eternity by Caitlin Doughty
Sir Bentley Purchase, Coroner of London from 1930-1958, was once described as a man who found every aspect of death incredibly amusing; in her book From Here to Eternity, mortician Caitlin Doughty follows in his shoes. Full of gallows humor and perceptive, humane, and intriguing insights into humankind’s customs surrounding death, Doughty takes us on a journey throughout the United States and around the world on a cultural quest to find “the good death.” She explores the idea of what it means to treat the dead with dignity and how the way we tend to our dead impacts on individual feelings about death, mortality, and the way we expect our own body to exit this life. Warning: reading this book may cause you to rethink your own funeral plans and perhaps opt to be mummified and kept in your family home, or possibly become a grant-wishing human skull in Bolivia.

Wednesday, April 10, 2019
University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Susan Sample, PhD, MFA

Mend: Poems (Contemporary Poetry and Prose) by Kwoya Fagin Maples
Mend is a stunning contribution to an ethical debate that has been ongoing for decades, if not a century. J. Marion Sims was a renowned surgeon who practiced in the early 19th century in Alabama and New York. He invented the speculum and pioneered surgical treatment for fistulas, a condition resulting from lengthy births that leaves women incontinent. What has been called into question is whether Sims, lauded as the “father of gynecology,” obtained consent from and provided anesthesia to his patients, enslaved black women. The issue continues to be debated in professional journals ranging from Female Pelvic Medical Reconstructive Surgery to the Journal of Medical Ethics to Ethnic Health as well as in the popular press, including The Atlantic and The Washington Post last year. Mend adds a unique voice, literally. The book is a collection of poems written in the voices of the only three black women whose names are known: Anarcha, Betsey, and Lucy. Interspersed with their harrowing yet tender narratives are excerpts from Sims’ autobiography and references to the author’s own medical experiences. The juxtaposition not only humanizes abstract ethical issues; it challenges us as readers to reconsider history and the role poetry can play in fully imagining the past.

The 2019 Schedule of Readings can be found on our website at:
http://medicine.utah.edu/internalmedicine/medicaethics/activities/literature/
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<th>Event Type</th>
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<tr>
<td>Evening Ethics</td>
<td>Thurs. Jan. 24</td>
<td>5:30-7:00p</td>
<td>U of U RAB #117</td>
<td>“Is It Ethical for Physicians to Strategically Lie to Third-Party Payers On Behalf of Their Patients?” With Saundra Buys, MD and Susan Sample, PhD, MFA</td>
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<td>The Physicians Literature and Medicine Discussion Group</td>
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<tr>
<td>Resident Ethics Conferences</td>
<td>Wed. Mar. 13</td>
<td>12:30-1:15 pm</td>
<td>U of U Hospital Large Conference Room #W1220</td>
<td>Legal and ethical perspectives: Current Issues VAMC: Jim Ruble, PharmD, JD UUMC Cartwright Conference room: Teneille Brown, JD Withholding/Withdrawing life prolonging treatment VAMC: Paige Patterson, MD &amp; Peggy Battin, PhD, MFA UUMC Cartwright Conference room: Holli Martinez, FNP-BC, ACHPN, FPCN &amp; Susan Sample, PhD, MFA When Clinicians Disagree: How to speak up when there is a power differential VAMC: Jeffrey Botkin, MD, MPH &amp; Jim Ruble, PharmD, JD</td>
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<td>David Green Memorial Speakership with Jeffrey Botkin, MD, MPH</td>
<td>Wed. Mar. 26</td>
<td>12:30-1:15 pm</td>
<td>U of U Hospital Large Conference Room #W1220</td>
<td>“Informed consent: enduring challenges and opportunities” Research Administration Building, 1st floor large conference room (Rm #117) 5:30pm-7:00pm Pediatric Grand Rounds: David Green Memorial Lecture: “Biobanking Newborn Bloodspots: Henrietta Lacks Revisited” Primary Children’s Hospital Auditorium 3rd floor 8:00am-9:00a</td>
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<td>Cowan Memorial Public Lecture, “Responding to requests for futile or potentially inappropriate treatment” (noon, HSEB 2120)</td>
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Jeff Botkin and Teneille Brown received the Eccles award for teaching in Ethics. The announcement is here: https://eccles.utah.edu/news/daniels-fund-ethics-initiative-leadership-in-education-awards-announced/

Peggy Battin will be speaking at the third International Conference on End of Life Law, Ethics, Policy and Practice (ICEL3) in Ghent, Belgium, March 8, 2019, and participating in two working groups on genetics and infectious disease at the Berman Institute of Bioethics at Johns Hopkins the following week March 11-14.

Susan Sample's new collection of poetry about the end of life, Some Unsayable Blue, has been accepted for publication by Finishing Line Press later this summer.