Twelve years after Belgium legalized euthanasia for adults eighteen years of age or older who are terminally or irremediably ill and undergoing intolerable suffering, King Philippe signed into law a measure passed by Parliament that modifies the law to include minors: **On March, 2014, the age limit on euthanasia in Belgium was removed.** Newswires erupted with headlines depicting this decision as “Killing Children in Belgium.” Some bioethicists voiced concerns. Many in the United States, influenced by historical memories of WWII Nazi eugenics, have felt queasy over this law. But whereas in Germany, killing was not motivated by the interests of the person, in the Netherlands and Belgium, the concept of “euthanasia” comes from the Greek, eu-thanatos, meaning “good death.” Attendees of October's **Evening Ethics**, facilitated by Peggy Battin, PhD, and Jeff Botkin, MD, explored this change in Belgian law and addressed various ethical concerns provoked by it.

Traditionally in the United States, debate over Physician Assisted Dying (PAD), also called Physician Aid-in-Dying (PAID) or (AID), has turned on a distinction between passive euthanasia (“letting one die”) vs. active euthanasia (“killing.”) One might withdraw extraordinary care such as intubation, letting one die, but not actively do something to cause death. (Such as administer a lethal injection akin to what we allow for severely ill pets.) Much thought has been put into deciding the basics that babies must receive, such as fluid and nutrition, in order that the line between “letting die” and “killing” not be crossed. This distinction has fallen out of favor in recent years as the line between passively letting one die vs. actively killing someone blurs when the ultimate result (death) and frequently the intention (to have someone die), are often the same.

The Belgian government, after a twelve year trial with an adult euthanasia law that has been regarded as successful and without abuses, recognized that in some cases, the age restrictions for euthanasia were being fudged, and they wanted to be open about this situation. These practices for minors and the reasons behind them deserved to be brought out into the open.

Clinic attendees at our Evening Ethics agreed that in this country, although it isn’t advertised, and although no parents ask for active euthanasia for their extremely sick children, “hopeless” cases do arise where the distinction between passive and active euthanasia blur, when, for example, anxiety-reducing morphine that knowingly hastens death, has been requested and used, on children as well as adults.

When an adult chooses to not have a severe illness treated in the U.S., as long as that adult has medical decision-making capacity, we have come to respect that autonomous choice. Adults can legally define the limits of medical intervention. But this is not so for children. When a minor is a severely ill, even terminally, they must be medically treated. Does this seem right? Once one knows that the story is not going to end well, “more” does not necessarily equate with “better.” But where children are concerned, we appropriately become protective. Among our concerns: Who can initiate euthanasia? What about underlying treatable conditions? Is psychological suffering included for kids as it is for adults? (Should it be?) Is there no age range? Is surrogacy for minors practically worrisome?
The following are the requirements of the Netherland’s decision-making framework for allowing euthanasia for minors:

(emphasis ours)

- There is no limit of age but the notion of *discernment* is used
- A minor’s *discernment* has to be evaluated by a pediatric psychiatrist or a psychologist
- The law is only for children with a *prognosis of death in a short time*; unlike adults in Belgium, the condition must be *terminal*
- *Only for physical suffering*: unlike adults in Belgium where the suffering can be psychological
- *Only with the agreement of the parents*: this gives parents veto power over the child’s decision, unlike for adults where spouses don’t have veto power
- There is no question of anticipated declaration

We see in the Belgian euthanasia law for minors, that *discernment*—as determined by a psychiatrist or psychologist—plays a pivotal role. We are not certain what the concept of discernment entails but it seems to be understanding of a sort—although what degree of understanding remains unclear. If discernment is analogous to the capacity that we, in the U.S., require in adults for decision-making, it is assumed in adults, but assumed not to be in children. That is, one must prove that an adult does NOT have capacity; but in children, one would need to prove that a child DOES have capacity. This might set the discernment/capacity bar high, as well as make it a difficult thing to figure out. The responsibility of the professional, or professionals, to determine whether a child met the discernment standard, would likely be extremely difficult. Clearly, it would rule out babies and small children. Our Evening Ethics discussants emphasized that where teenagers are concerned, the high rate of teenage suicide would need to be considered in any analysis, although clinicians noted that often, “children” who are terminally ill gain an astounding degree of maturity. Of the five cases in the Netherlands one child was 14 years old, the other four children were 17 or 18.

It was suggested that our concern over child euthanasia may arise from a natural inclination to wish that people have reached certain milestones before we feel comfortable with their ending a life. We typically feel more comfortable with an elderly person’s passing than with a young child’s. But, as Primary Children’s Hospital Chaplain, David Pascoe, reminded us- none of us will avoid dying someday—rather than focusing on the horror over the loss of potential life, ought we to remember the concept of mercy when children are inconsolably suffering? And although it is difficult to conceive how mercy killing could be written into the law without great potential for abuse, might it be that the Belgian law removes the barrier for children to end their suffering? Framed in that way, the legitimacy of considering such requests for euthanasia, becomes more understandable. Surely, the details of each individual case will always hold deep ethical struggle, but the Belgian law opens a new direction to proceed. Ought we, in the U.S., adopt something like this?
Hospitals across the United States (and the world) are preparing for the possibility that a patient will arrive infected with Ebola. This new epidemic is raising a host of ethical issues that occur when the patient is both victim and vector. Are healthcare workers obligated to treat Ebola patients and, in turn, risk contracting the disease themselves? How should experimental medications and interventions be distributed fairly? When are quarantine, surveillance, and travel restrictions appropriate and inappropriate? And what can we learn from the effective and ineffective responses to past epidemics? As background for this session, please read “Ebola and the Epidemics of the Past.” Please join us for this discussion facilitated by infectious disease physician, and Chief, emeritus, of the Division of Medical Ethics and Humanities, Jay Jacobson, MD, and Jim Tabery, PhD.

Dr. Mary-Claire King was honored with the Lasker Koshland Special Achievement Award in Medical Science for her contributions to medical science and society, exemplified by her contributions to the discovery of the BRCA1 mutation. BRCA1 and BRCA2 mutations cause a substantial increase in risk for breast and ovarian cancer in women. In a recent article in JAMA, she advocates for population-based genetic screening of women for BRCA1 and BRCA2 mutations and suggests that such screening should be a routine part of clinical practice.

This “Genetics Hot Topics” will explore the benefits and risks of BRCA1/2 screening as part of routine healthcare for women. This informal discussion will be facilitated by Jeffrey Botkin MD, MPH, Medical Ethics and Humanities Division Chief. Background reading materials found on the DMEH website include “Population-Based Screening for BRCA1 and BRCA2: 2014 Lasker Award,” (JAMA 9/17/2014). Please join us!
Giuseppe di Lampedusa’s *The Leopard* was his only novel, and he died in 1957 while trying to get it published. The book first appeared in 1958, and it soon became the basis for a feature film by Luchino Visconti, which was released in 1963 with Burt Lancaster in the title role. (Please try to watch this film before our discussion.) *The Leopard* is a historical novel set in Sicily from 1860 to 1910, and it represents the transition from an older European aristocratic society to nationalism, capitalism, and modern representative government. The central character is Prince Don Fabrizio Salina, the Leopard, whom Lampedusa based on his own great-grandfather. The Prince takes seriously his obligations to longstanding traditions and the old social order, of which the Catholic Church is a bulwark. But he moves pragmatically to try to hold onto his high position as social and ideological changes break across the generally inert world of Sicilian life. His nephew Tancredi is his hope for the future—he regards him as far more spirited and noble than his own children—and he seeks to marry him to Angelica, the beautiful daughter of a local mayor who has become unexpectedly rich in the new commercial economy. The novel offers a subtle exploration of the Prince’s inner life and his responses to the decline of the privileged social class to which he belongs. It contrasts the emerging world of modernity, in which money will become the ruling force, with an older aristocratic society based on monarchy, a caste system, and traditional prejudices. Lampedusa’s evocation of this historical process and its consequences for individual characters is both ideologically deft and richly sensuous. Our reading of the novel will be a chance for us to consider issues of social class, inner lives, and historical change in our own country and time—and also the costs and benefits of the complicated process that produced modern society.

**December 3, 2014 LDSH Pugh Boardroom 6:00-8:30p,**
December 17, 2014 UU Hospital Large Conference Room 6:00-8:30p, **CANCELED**
Facilitated by Rachel Borup, PhD

*Billy Lynn’s Long Halftime Walk*, by Ben Fountain

The novel, *Billy Lynn’s Long Halftime Walk*, takes place on Thanksgiving Day when decorated Iraq war veterans from Bravo Squad are scheduled to appear alongside Destiny’s Child as part of the overblown spectacle at a Dallas Cowboys football game. With a satirical pen, Ben Fountain skewers Americans’ pieties about the war, our infatuation with football, our facile patriotism, and the all-too-common lack of real empathy for veterans. He also creates a winning, reluctant protagonist in Private Billy Lynn. This darkly funny novel has been called the Catch-22 of the Iraq war and was a finalist for the National Book Award in 2012.

**January 7, 2014 LDSH Pugh Boardroom 6:00-8:30p,** Facilitated by Mark Matheson, D. Phil

*My Beloved World* by Sonia Sotomayor

Justice Sonia Sotomayor is the third woman and the first Hispanic to serve on the United States Supreme Court. She began her tenure as a Justice in 2009 and published her memoir, *My Beloved World*, in 2013. Her book is a remarkably candid account of her years growing up in a Puerto Rican community in the Bronx; her education at Princeton and Yale; and her career as an attorney up to the time of her appointment as a Federal District Judge in 1992. Early in her childhood, Justice Sotomayor was diagnosed with diabetes, and dealing with this chronic disease is an important part of the personal story she relates in the text. There are some fascinating glimpses into the medical world of New York in the 1960s, and she discusses how coping with the disease has contributed to her independence and self-discipline. She also writes about a volunteer program she started at the Trenton Psychiatric Hospital during her Princeton years, her first experience in direct community service. She was moved to do this by the poverty and isolation of the patients and the shortage of Spanish speakers on the staff. While telling her story Justice Sotomayor engages with a rich variety of issues, from childhood to the workings of the criminal justice system, and as a person she emerges as both highly analytical and alert to the power of poetry.

A special note from Mark Matheson: I look forward to discussing Justice Sotomayor’s extraordinary story and achievements with you when we meet in January. The office I direct at the U, the University of Utah MUSE Project, which is dedicated to providing undergraduate students with inspiring learning opportunities, is bringing Justice Sotomayor to campus shortly after our discussion. She will speak at the Huntsman Center at noon on Wednesday, January 28th, 2015. The event is free but tickets are required. Please contact me at mark.matheson@utah.edu if you would like to obtain tickets when they become available.
### Calendar of Activities and Programs

**Evening Ethics Discussions**
- **5:30-7:00 pm**
- **RAB 117**
- Tues. Dec. 16

“Ethics and Ebola” Facilitated by Jay Jacobson, MD & Jim Tabery, PhD

**Genetics Hot Topics**
- **4:00-5:30 pm**
- **RAB 117**
- Wed. Jan. 13

“Population-Based Screening for BRCA1 and BRCA2 - Is it time to screen everyone” Facilitated by Jeffrey Botkin, MD

**Resident Ethics Conferences**
- **12:30-1:30 pm**
- Wed. Nov. 12
- Thurs. Nov. 13
- Wed. Nov. 19
- Wed. Dec. 10
- Thurs. Dec. 11
- Wed. Dec. 17
- Wed. Jan. 14
- Thurs. Jan. 15
- Wed. Jan. 21

- **Informed Consent**
  - UUMC Cartwright Conference room: Tom Schenkenberg, PhD
  - VAMC Tsagaris Conference room: Phil Bease, MD
  - IMC: Jay Jacobson, MD

- **Leaving Against Medical Advice (role play)**
  - UUMC Cartwright Conference room: Gretchen Case, PhD
  - VAMC Tsagaris Conference room: Gretchen Case, PhD
  - IMC: Jay Jacobson, MD

- **Impaired Physicians**
  - UUMC Cartwright Conference room: Jim Tabery PhD & TBD
  - VAMC Tsagaris Conference room: Leslie Francis, JD, PhD & TBD
  - IMC: Jay Jacobson, MD

**The Physicians Literature and Medicine Discussion Group**
- **6:00-8:30 pm**
- Wed. Nov. 5
- Wed. Dec. 3
- CANCELED
- Wed. Jan. 7

- **The Leopard** by Tomasi di Lampedusa Facilitated by Mark Matherson D. Phil
  - LDSH Pugh Boardroom
- **Billy Lynn’s Long Halftime Walk** by Ben Fountain, Facilitated by Rachel Borup, PhD
  - LDSH Pugh Boardroom
  - U of U Hospital large Conference room
- **My Beloved World** by Sonia Sotomayor Facilitated by Mark Matherson D. Phil
  - LDSH Pugh Boardroom

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**CME Statements**

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Ben Lewis, MD & Karly Pippit, MD co-unit directors with Gretchen Case (who is taking the photo) for the SOM Layers of Medicine course, on Halloween, of course!
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DIVISION MEMBERS ON THE ROAD AND IN PRINT

Peggy Battin's TEDMED Talk “Choosing the Least Worst Death” is now posted on the web.

Maureen Henry is joining The National Committee for Quality Assurance (NCQA) as a Research Scientist where she will address performance measurement in geriatrics and behavioral health. NCQA is a Washington, DC–based private, non-profit organization dedicated to improving healthcare quality.

Several DMEH members attended the October 2014 American Association of Bioethics and Humanities:

Jeff Botkin presented Illuminating Interprofessionalism: The Drama of DNA from Prenatal to Newborn Screening and Sequencing and participated in an ASBH/ASHG symposium: Presenting on genetic testing in children.

Gretchen Case presented a Forum Theatre workshop session with Katherine Burke.
Gretchen Case and Susan Sample participated in a Literature and Medicine Affinity group meeting, featuring a Readers’ Theater performance. Susan Sample also presented a paper on her research on physicians’ EOL narratives and participated in a panel on ethical issues for clinician writers.

Leslie Francis participated in a session on disability and Erin Rothwell had a poster presentation: A Randomized Controlled Trial of an Electronic Informed Consent Process.