Scientists can now use gene-editing technology to alter ecosystems. Should they? An interdisciplinary group of faculty, staff, and students gathered on Tuesday, December 5 at the University of Utah to assess precisely that question. The gathering, hosted by the Division of Medical Ethics and Humanities and the Utah Center for Excellence in ELSI Research (UCEER), considered the emerging field of research on gene drives. The concept of a gene drive is not new; it refers to any process where a genetic element is capable of being transmitted to future generations in ways that defy the normal rules of Mendelian inheritance, and there are a number of known cases of gene drives that occur naturally. But the recent emergence of gene-editing technologies, especially inexpensive and relatively easy versions like the CRISPR-Cas9 system, have opened the door to human-engineered gene drives. The technology works like this: a population of organisms is engineered in a lab such that all those organisms have a drive gene that both codes for some desirable trait and contains the molecular machinery to promote gene editing. Those organisms are then released to interbreed with naturally occurring versions of those organisms (the “wild type”). Normally, when the lab organisms breed with the wild type organisms, the desirable trait would have a 50% chance of occurring in the progeny. But the gene drive alters those odds. During embryonic development, the drive gene on the lab organism’s chromosome, when it encounters the chromosome of the wild type organism hacks the wild type genome to copy the drive gene onto the other chromosome. As a result, all the progeny get two copies of the drive gene, ensuring they will carry the desirable trait forward. And when those progeny mate with other wild type organisms, their progeny will only have the desirable trait. And so on. The idea with a gene drive is that eventually an entire population could be genetically engineered to contain the drive gene.

Scientists have proposed using the ecosystem-altering potential of gene drives to combat threats to both humans and wildlife. For example, a gene drive that alters the gut of mosquitoes so that they cannot carry malaria has been proposed; malaria kills upwards of 400,000 people/year (mostly children in Africa), and so the promise of a tool that could eliminate the threat is exciting. A gene drive to alter the fertility of rodents has also been proposed; the natural wildlife on islands across the globe have been decimated by invasive rats and weasels, so the idea here would be to try using a gene drive on an island in order to eliminate the invasive species.

While the potential advantages of certain gene drives are alluring, scholars have also drawn attention to the risks associated with the technology, and much of the discussion among the University of Utah community members focused on those risks. Altering the gut of mosquitoes to eliminate their ability to carry malaria is desirable, but genes are known to move from one species to another (a process called “horizontal gene transfer”). It’s unclear what would happen if the drive gene inserted into one species of mosquito jumps to another species of mosquito, or a different organism entirely like bees. So a gene drive designed to combat malaria could potentially alter another species not targeted at all. Likewise, the elimination of invasive rats and weasels on islands may be desirable, but modeling work has also indicated that the naturally occurring rodent populations on main lands could be quickly overtaken by a gene drive if even a small number of the genetically altered organisms found their way off the island. So a gene drive designed to combat island weasels could decimate weasel populations generally, leading to all sorts of unforeseeable ecological alterations.

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Challenges to treating drug addiction in our Homeless

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The University of Utah faculty, staff, and students drew attention to how little is currently known about gene drives, which makes the risk-benefit calculus of evaluating them so difficult. While it’s easy to imagine a better world with fewer people dying of malaria and island ecosystems restored to their pre-invasive species state, the risks are harder to judge because the technology is still in its infancy, and so the scientific and public communities are still learning. One inferential resource in these scenarios with emerging technologies is analogical reasoning—looking to cases that bear relevant similarities to the emerging technology so as to consider how the similarity in question plays out in the analogue case. Horizontal gene transfer, for example, is a well-known biological phenomenon, and so research on the naturally occurring process can shed light on the real risks of a drive gene jumping from mosquitos to bees and the real impact of that species jump. Similarly, concerns about human-caused extinctions due to gene drives can be gauged against known cases from history where humans intentionally caused a species to go (virtually) extinct like smallpox, and known cases from history where humans unintentionally caused a species to go extinct like the dodo. The law also offers resources. Questions about who would bear responsibility for a gene drive that goes awry and how compensation would be assessed might look similar to who bears responsibility when an oil spill occurs and how compensation is handled in that ecological disaster.

Gene drives facilitated by cheap and efficient gene-altering technologies are on the horizon. New Zealand, for example, is already planning to try eradicating all marsupial and mammalian introduced predators from their islands by 2050, and gene drives targeting those species are one method being considered. It remains to be seen what the impact of gene drives will be when they’re released into the wild. Since the scientific and public communities are learning as this process unfolds, there is a very real sense in which we are all “student drivers” when it comes to gene drives. Proceed with caution.

Our 2018 David Green Memorial Speaker is Douglas S. Diekema, MD, MPH, Professor of Pediatrics, University of Washington School of Medicine, and Director of Education, Treuman Katz Center for Pediatric Bioethics, Seattle Children's Research Institute. Dr. Diekema is board certified in general pediatrics and pediatric emergency medicine. His teaching responsibilities include education in the emergency department, monthly pediatric ethics conferences and several education committees. He is past-chair of the Committee on Bioethics of the American Academy of Pediatrics and serves on the Ethics Committee of the American Board of Pediatrics. His research interests include pediatric bioethics and pediatric wilderness medicine. Dr. Diekema's extensive bibliography includes *Clinical Ethics in Pediatrics: A Case-Based Textbook*, Cambridge University Press, 2011.

There will be two opportunities to see Dr. Diekema:

- **Evening Ethics:**
  “OMG, What R They Thinking: Adolescent Refusals of Important Medical Care”
  Wednesday, January 31, 2018, 5:30pm-7:00pm, Research Administration Building, 1st floor conference room (room #117).

- **Pediatric Grand Rounds, David Green Memorial Lectureship:**
  "When Parents and Providers Disagree: Understanding and Responding to Conflicts in the Care of Children"
  Thursday, February 1, 2018, 8am-9am, 3rd floor Primary Children's Hospital Auditorium.
**The Bright Hour: A Memoir of Living and Dying by Nina Riggs**

Nina Riggs found inspiration for the title of her book, *The Bright Hour: A Memoir of Living and Dying*, in a passage from her great-great-great-grandfather, Ralph Waldo Emerson. Each morning, he would "cease for a bright hour to be a prisoner of this sickly body and to become as large as the World." Riggs does exactly that in her poignant memoir. In short chapters, some just one page, she writes with lyricism, humor, candor, and wisdom about fully living life, knowing it will end too soon. Diagnosed at age 37 with breast cancer, Riggs was told it could be easily treated. A year later, the former teacher and poet learns the cancer had metastasized. What began as a blog about her experiences as a wife and mother of two young sons grew into an essay in The New York Times and finally, the memoir, published last summer five months after her death. Yet, as she told an interviewer, "I really hope the book I wrote will make you feel much more joy than anything else"; "Even the scary parts are deeply intertwined with all the bits of life we cherish most." As you read, note both, the chapters you found heart-rending and joyful.

**Lab Girl by Hope Jahren**

*Lab Girl* is a best-selling memoir by geobiologist Hope Jahren. The book alternates between fascinating descriptions of the secret lives of plants and frank and funny accounts of her life as a research scientist, including the thrill of discovery, the desperation for funding, and the tedium of grunt work. Jahren has often been compared to Stephen Jay Gould and Oliver Sacks and, like these two, uses her personal knowledge and experience as a scientist to ask broader philosophical questions about the human condition.

**Memory's Last Breath: Field Notes on My Dementia, by Gerda Saunders**

Gerda Saunders, Ph.D., may be familiar to many of you. She retired as associate director of gender studies at the University of Utah in 2011. The reason: a diagnosis of microvascular disease, the second leading cause of dementia. Her colleagues gave her a journal, which Saunders, then 60, used to "report my descent into the post-cerebral realm for which I am headed. No whimpering, no whining, no despair. Just the facts." Her book does present a dispassionate self-analysis as Saunders courageously examines her condition as both subject and impartial observer. An erudite researcher, she quotes sources ranging from Albert Einstein to Marcel Proust, Don Quixote to neuroscience texts. Yet, *Memory's Last Breath* is equally personal—what her mother called "heartsoreness"—as Saunders writes about her childhood in South Africa, her marriage and family life. Interspersed with her lyrical prose are family photos and cartoons, scientific diagrams and news clippings, rendering her book not only imaginative but unique and indeed memorable.

The 2018 Schedule of Readings is posted on our website at:

[http://medicine.utah.edu/internalmedicine/medicaledics/](http://medicine.utah.edu/internalmedicine/medicaledics/)
In recent years, several cases involving adolescent patients refusing life-saving treatment (blood transfusions, cancer treatment) have been covered by national media outlets, raising questions about the role of the adolescent in medical decision-making. Should adolescents be allowed to refuse life-saving medical treatment? Does it matter whether their parents agree or disagree with their decision? Does the age of the adolescent matter? Using several case studies, we will discuss whether adolescents, as a rule, possess capacity of sufficient quality that their decisions should be respected even in the case of life-altering medical decisions. This session will touch on the traditional approach to determining when adolescents should have their decisions respected (including what the American Academy of Pediatrics Committee on Bioethics has said), the evolving understanding of adolescent brain development, and the implications of that “brain science” for how we should understand adolescent decision-making capacity.

Please contact linda.carrlee@hsc.utah.edu for a pdf of the background reading for this event, “Adolescent Refusal of Lifesaving Treatment: Are We Asking the Right Questions?” by Douglas Diekema, MD, MPH. (Adolec Med 022 (2011) 213-228)

### Evening Ethics

**A Terror Way Beyond Falling: Suffering, Suicide, and Physician Aid-In-Dying**

Facilitated by Peggy Battin, MFA, PhD and Brent Kious, MD, PhD

**Thursday, February 22, 2018, 5:30pm-7pm, Research Administration Building #117**

“The so-called ‘psychotically depressed’ person who tries to kill herself doesn’t do so out of quote ‘hopelessness’ or any abstract conviction that life’s assets and debits do not square. And surely not because death seems suddenly appealing. The person in whom Its invisible agony reaches a certain undurable level will kill herself the same way a trapped person will eventually jump from the window of a burning high-rise. Make no mistake about people who leap from burning windows. Their terror of falling from a great height is still just as great as it would be for you or me standing speculatively at the same window just checking out the view; i.e. the fear of falling remains a constant. The variable here is the other terror, the fire’s flames: when the flames get close enough, falling to death becomes the slightly less terrible of two terrors. It’s not desiring the fall, it’s terror of the flames. And yet nobody down on the sidewalk, looking up and yelling ‘Don’t!’ and ‘Hang on!’ can understand the jump. Not really. You’d have to have personally been trapped and felt flames to really understand a terror way beyond falling.” –David Foster Wallace (2009), Infinite Jest, pg. 696.

In late 2016 the American Psychiatric Association (APA) stated that psychiatrists ought not participate in physician aid in dying (PAD) or euthanasia for non-terminal illnesses. This practice already occurs in some European countries. As Mark Komrad, a psychiatrist on the APA’s national ethics committee, explained, the organization was concerned about this practice for multiple reasons: that it communicates that there is no hope for persons with severe suffering due to psychiatric illness, that persons with psychiatric illness have impaired decision-making capacity, and that judgments about whether suffering is interminable depend upon patients’ assessments of whether treatments like ECT are acceptable, even though these assessments could be controversial or misinformed. In effect, Komrad and the APA have opposed this practice because they are concerned that vulnerable psychiatric patients whose suffering might be treatable could instead receive aid in dying.

It would undoubtedly be a bad thing if that worry came to fruition. Still, we’re concerned that the APA’s opposition to PAD for non-terminal psychiatric illness is too facile. We’ll argue that the central justifications for PAD in cases of terminal illness also apply to some cases where people suffer only from non-terminal psychiatric illness. Moreover, we argue that the APA’s reasons for excluding persons with non-terminal illness from PAD are not compelling.

On the other hand, we are also sensitive to the APA’s concerns about PAD and euthanasia, and agree that many persons with psychiatric illness who suffer from suicidal ideation should not have access to PAD. Furthermore, we regard psychiatric practices like involuntary civil commitment and involuntary medication to prevent suicide as generally justifiable even though they are, as we will argue, deeply at odds with the rationale for PAD for non-terminal, psychiatric illness.

The result, we think, is a serious dilemma: how do we reconcile the idea that medicine should be empowered to prevent persons from attempting suicide with the idea that severe and intractable suffering, even when it is due to a non-terminal illness, can make death seem a reasonable option?

There are 3 short background readings: (contact linda.carrlee@hsc.utah.edu for copies) • http://www.psychiatrytimes.com/suicide/apad-position-medical-euthanasia • “Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands” by S.N. Dorenberg, et.al. (Psychosomatics2016:57:556–565) •“Psychiatric evaluations for individuals requesting assisted death in Washington and Oregon should not be mandatory” by Linda Ganzini, MD, MPH (General Hospital Psychiatry 36 (2014) 10–12)
From the 1930s to the 1970s, more than 7000 people were sterilized, often against their wishes and without their knowledge, by the state of North Carolina. While not the only state to use official government channels to promote procure “eugenic sterilizations” for people deemed unworthy of reproducing, North Carolina has one of the best documented histories of the practice and subsequent attempts at reparations. This 80-minute documentary film portrays the lives and struggles of the people and families wronged, and now seeking justice. There will be no background reading for this session, but it will be one-half hour longer than our typical Evening Ethics program in order to have adequate time for the panel-led discussion after we view the film.
PROGRAM OF MEDICAL ETHICS AND HUMANITIES

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Peggy Battin lectured at Cornell Medical, “Thinking All Wrong About How We Die,” on December 7, 2017. She will be presenting March 15, 2017, at the 12th Annual Professional Hospice & Palliative Care Conference hosted by the Central Utah Hospice & Palliative Care Coalition at the Provo City Library. This keynote talk will be at 12:15 on death with dignity issues "Thinking All Wrong About How We Die."


Susan Sample was a guest panelist Nov. 21 at the University’s Service House monthly dialogue series, held in conjunction with the Bennion Center. She joined a community pharmacist and social worker to talk about ethical issues in health care.

Brent Kious has been selected as a 2018 VPCAT Scholar. (Vice President’s Clinical Translational Research Scholars at UHealth)