

Medical Ethics and Humanities in Utah

Winter 2019

Being White in Healthcare - How Privilege, Bias and Racism Affect Outcomes

By Amy Cowan, MD

Amy Cowan, MD, led an interactive discussion about white privilege healthcare at our September 2019 Evening Ethics. She has shared here her reflective thoughts from that session. If you missed this eye-opening Evening Ethics, Dr. Cowan has been invited to present it again at both Pediatric Grand Rounds and Internal Medicine Grand Rounds in 2020.



1. **Biases or prejudice:** with very little information I make up a story or a narrative about another group. Be curious and ask why. How did we get to where we are now? Who benefits from the way things have been set up? Have people of color been set up to succeed for decades in the same way as whites? How do I benefit from racism? In what ways do I contribute to racism?

2. **Get close to the problem.** Learn about American history from black scholars. Look things up and cross reference. Figure out your cognitive style and find a medium that challenges you. Podcasts and audio books are a great way to learn while cooking, cleaning, exercising or just relaxing. Listening with a friend offers a shared experience and a chance to process thoughts and emotions.

3. **Be willing to be uncomfortable.** By working to develop your capacity to self-reflect, the discomfort often leads to growth. Call on your courage and speak up when you notice no people of color on a committee, at a boardroom meeting or in leadership roles. Look honestly at your own practice and identify ways you provide biased care: Opioid replacement, HCV treatment, PrEP for HIV, when someone needs a translator or when I see someone as poor and black did I assume they are also disinterested in their health care? If I am not mentoring learners or faculty of color, why not?

From the work of Dr. Ibram X. Kendi, it is not enough to not be a racist, we have to be antiracist. "I'm not a racist," is a term of denial; it doesn't have any other meaning. We must be proactive. "Antiracist" is clear and actionable. It's someone who has expressed ideas of racial equality or supports antiracist policy that leads to racial equity. We get to deconstruct this and choose differently. It's daily work that leads to connection and community. This I would argue is the work that matters most.



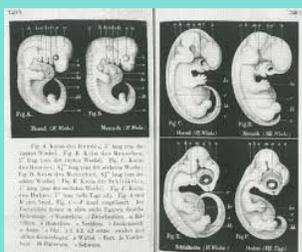
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Evening Ethics Discussions



These informal, multidisciplinary discussions about current issues in medical ethics take place approximately bi-monthly or as ethical issues arise. A PMEH member facilitates discussion. Guided by the topic, we invite people with relevant expertise and experience and informed opinions to join us. Generally about 15-40 people from a variety of disciplines, including healthcare, public policy, philosophy, law, and business attend. We distribute short, timely articles from the nation's most thoughtful newspapers, journals, and magazines to the group in advance of our discussions. CME and light refreshments are offered.



A Genetics Hot Topic:

Polygenic Risk Scores for Embryo Selection: Making a Healthier Human, or a False Promise?

With Erica B. Johnstone, MD & Erin Rothwell, PhD

Tuesday October 29, 2019
5:00pm-6:30pm
SJ Quinney College of Law
Room # 6623

Polygenic risk scores have been developed from genome-wide association studies, and incorporate data on numerous genetic polymorphisms to predict the chances that an individual will develop a given disease. The original goal of this tool was to enable early intervention for individuals at high risk of disease, in the hopes of preventing illness or mitigating its consequences. This technology can now be applied to human embryos. Will this technology offer parents the opportunity to prevent disease in their children, in the vein of preimplantation genetic diagnosis for Mendelian disorders such as spinal muscular atrophy? Or are children placed at risk by premature adoption of an intervention with uncertain outcomes? When and how should polygenic risk scores for embryo selection be offered? How should this innovation be evaluated before making it clinically available?

Background Reading: <https://www.biorxiv.org/content/biorxiv/early/2019/05/05/626846.full.pdf>

Genetics Hot Topics are collaborative Evening Ethics with UCEER (Utah Center for Excellence in Ethical, Legal and Social Implications)



Caring—How can we work together to address drug shortages and drug costs?

With Erin Fox, PharmD, BCPS, FASHP & Jim Ruble, PharmD, JD

Tuesday November 12, 2019
5:30pm-7pm
Research Administration
Building , Room #117

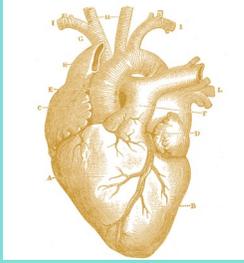
Drug shortages and high drug prices can both affect patient access to critically needed medications. Medications cannot be effective, if patients can't obtain needed treatments. In some cases, shortages and high prices lead to rationing, as well as tension in patient-provider relationships. Our discussion will focus on some of the ongoing actions to improve drug shortages and high prices. We will also provide some information about how patients can lower their drug costs, and communication tips for dialogue between clinicians and their patients.

Recommended background readings for this discussion:

For an overview on shortages: [https://www.mayoclinicproceedings.org/article/S0025-6196\(13\)01043-4/abstract](https://www.mayoclinicproceedings.org/article/S0025-6196(13)01043-4/abstract)

For the most current stats on shortages: <https://www.ashp.org/Drug-Shortages/Shortage-Resources/DrugShortages-Statistics>

For an overview on drug pricing: <https://hbr.org/2017/04/how-pharma-companies-game-the-system-to-keep-drugs-expensive>



HEALTHCARE: STORIES OF REBELLION

**Thu, Nov 21, 2019 7pm
Kingsbury Hall
1395 President's Circle, SLC**

Following last season's powerful performance, our healthcare-themed storytelling event returns this year with the first of two new topics. **Healthcare: Stories of Rebellion** will highlight how we navigate illness, treatment, and the "way it's always been done." With some storytellers selected from the audience, the evening will include prepared and impromptu true stories about making different choices, pushing back, going against the grain, and finding our own way.

This is a UtahPresents event that is co-sponsored with the Program in Medical Ethics and Humanities and the University of Utah Health's Resiliency Center. This event requires tickets.



**"Patients, Parents, and Professionals:
Ethical Issues in the Treatment of Trans
Adolescents"**

With Armand H. Matheny Antommara, MD, PhD, FAAP
2019-20 David Green Memorial
Speaker

**Wednesday December 4, 2019
5:30pm-7pm
Research Admin Bldg. Rm #117**

Armand H. Matheny Antommara, MD, PhD, FAAP, Director, Ethics Center, Lee Ault Carter Chair of Pediatric Ethics, Cincinnati Children's Hospital, Attending Physician, Division of Hospital Medicine, Associate Professor, University of Cincinnati Department of Pediatrics, will be our 23rd Annual David Green Lecturer.

Medical treatment of trans adolescents is controversial. Proponents of hormonal and surgical treatment emphasize the high rates of depression and suicide in this population. Opponents contend that evidence supporting the current standard of care is lacking and highlight individuals who regret their treatment. Our discussion will focus on ethical issues such as the following: What are the potential benefits, risks, and alternatives to treatment with puberty blockers and gender affirming hormonal and surgical treatment? What does reversibility mean in this context and what role should it play in the ethical analysis? May health care professionals refuse to treat trans patients and what constitutes medical neglect in this domain? For background readings before this discussion, please contact linda.carrlee@hsc.utah.edu



**STUMPED: An extraordinary
journey through tragedy, comedy and
restoration**

A Film screening & and Q & A discussion with
Will Lautzenheizer

**Thursday, December 12, 2019
5:00pm-7pm, EHSL, Lower Level**

Will Lautzenheizer, after losing his arms and legs to a deadly infection, became the third patient to undergo a double-arm transplantation at the Brigham and Women's Hospital in Boston. The documentary, *STUMPED*, chronicles how Will copes with the loss of his filmmaking career by pursuing stand-up comedy, how he navigates personal relationships, and how he transforms, physically and spiritually, with newly transplanted arms. *STUMPED* was filmed over four years. Natalia Washington, PhD will facilitate discussion of the many ethical issues faced in this journey of pioneering medicine. Will Lautzenheizer will skype in to join us for this discussion and to answer questions.

This Evening Ethics is a collaboration with University of Utah's Burn Center and the Eccles Health Sciences Library.

Wednesday, November 13, 2019

University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Mark Matheson, D.Phil.

Why We Revolt: A patient revolution for careful & kind care by Victor Montori

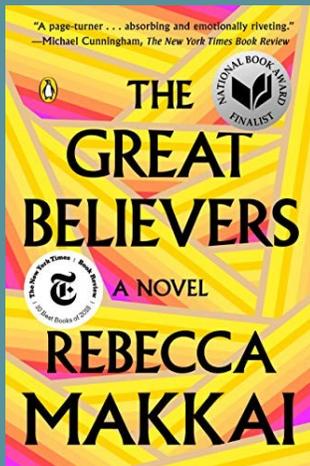


Victor Montori is an endocrinologist who grew up and trained in Peru and who now practices at the Mayo Clinic. In November we'll discuss his book *Why We Revolt: A Patient Revolution for Careful and Kind Care* (2017). The title is somewhat misleading about the book's content and tone. Montori offers a meditative analysis of what he describes as the current "healthcare industry" and of how its functioning degrades the clinician-patient relationship. And he makes the point that this system damages not only patients but also doctors and other healthcare providers. Genuine care is "co-created" by the patient and the clinician through a process of listening, imparting, and shared decision-making that Montori likens to a creative dance. But this kind of dancing is increasingly rare in the factory-like conditions of present-day healthcare. Montori's diagnosis of systemic problems in modern medicine will be familiar, but he makes some thoughtful points about possible remedies, including a new emphasis not just on efficiency but on the "elegance" of care, as well as on building a culture of "solidarity" between patient and doctor. He believes that real change is both desirable and possible, though he acknowledges that it will take time, just as building a cathedral is the work of many generations. We look forward to hearing your responses to Montori's specific claims and to his overall vision for healthcare—and you'll even find a reference to Hubert Humphrey!

Wednesday, December 11, 2019

University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Rachel Borup, PhD

The Great Believers by Rebecca Makkai



The 1980s AIDS crisis in Chicago is the setting for Rebecca Makkai's award-winning novel, *The Great Believers*. The narrative is split between the extended social circle of Yale Tishman, a young gay man living in Chicago in 1985, and the survivors of that social circle in the year 2015. Makkai's research and interviews with people who lived through the early AIDS crisis give the story a strong quality of authenticity and realism. The novel beautifully evokes not just the fear and frustration that abounded at that time, but the massive sense of loss we are still left with.

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Wednesday, January 8, 2020

University of Utah Hospital Large Conference Room #W1220
6:00-8:30pm, Facilitated by Mark Matheson, D.Phil.

Book Selection TBD

The 2019 Schedule of Readings can be found on [our website](#)

2018-19 David Green Memorial Speakership



Armand H. Matheny Antommara, MD, PhD, FAAP, Director, Ethics Center, Lee Ault Carter Chair of Pediatric Ethics, Cincinnati Children's Hospital, Attending Physician, Division of Hospital Medicine, Associate Professor, University of Cincinnati Department of Pediatrics, will be our 23rd Annual David Green Lecturer. Please join us for:

- **"Patients, Parents, and Professionals: Ethical Issues in the Treatment of Trans Adolescents"** (Wed, December 4, 2019, 5:30pm-7pm, Evening Ethics Discussion, Research Administration Building, Room #117)
- **"Establishing Goals of Care and Ethically Limiting Treatment,"** (Thurs, Dec. 5, 2019, 8am, Pediatric Grand Rounds, David Green Lectureship, Primary Children's Hospital, 3rd floor Aud.)

PMEH Calendar of Events

<p>*The Physicians Literature and Medicine Discussion Group 6:00-8:00 pm U of U Hospital Large Conference Room #W1220</p> <p>Why We Revolt : A patient revolution for careful and kind care by Victor Montori Facilitated by Mark Matheson, D.Phil.</p> <p>The Great Believers by Rebecca Makkai, Facilitated by Rachel Borup, PhD TBD, Facilitated by Mark Matheson, D.Phil.</p>	<p>Wed. Nov. 13</p> <p>Wed. Dec. 11</p> <p>Wed. Jan . 8</p>
<p>Resident Ethics Conferences 12:30-1:15 pm</p> <p>When Patients Change their Minds—Medical Futility & Code status VAMC: 2nd floor Tsagaris Rm: Susan Sample, PhD, MFA, and Samuel Brown, MD UUHosp 4th floor SOM, Cartwright Rm: Susan Sample, PhD, MFA, Timothy Fuller, MD, and Sean Bernfeld, MD</p> <p>Treating your friends and relatives VAMC: 2nd floor Tsagaris Rm: Brent Kious, MD, PhD UUHosp 4th floor SOM, Cartwright Rm: Brent Kious, MD, PhD</p>	<p>Tues. Nov. 5</p> <p>Tues. Nov. 20</p> <p>Wed. Jan. 8</p> <p>Wed. Jan 15</p>
<p>*Evening Ethics</p> <p>A Genetics Hot Topics: Polygenic Risk Scores for Embryo Selection: Making a Healthier Human, or a False Promise? With Erica B. Johnstone, MD & Erin Rothwell, PhD, 5:00pm-6:30pm, SJ Quinney College of Law, Room #6623</p> <p>Caring—How can we work together to address drug shortages and drug costs? With Erin Fox, PharmD, BCPS, FASHP & Jim Ruble, PharmD, 5:30pm-7pm, RAB Rm. #117</p> <p>UtahPresents: Healthcare: Stories of Rebellion, 7pm, Kingsbury Hall</p> <p>Patients, Parents, and Professionals: Ethical Issues in the Treatment of Trans Adolescents With Armand H. Matheny Antommara, MD, PhD, FAAP, 201920 David Green Speaker, 5:30-7pm, RAB Rm. #117</p> <p>Screening of Documentary Film, Stumped, and Q& A with Will Lautzenheizer 5:00-7:00pm, Eccles Health Sciences Library, Lower Level</p>	<p>Tues, Oct. 29</p> <p>Tues, Nov. 12</p> <p>Thurs, Nov. 21</p> <p>Wed, Dec. 4</p> <p>Thurs, Dec. 12</p>
<p>David Green Memorial Lectureship Grand Rounds 8-9am Primary Childrens Hospital, 3rd floor auditorium</p> <p>Establishing Goals of Care and Ethically Limiting Treatment With Armand H. Matheny Antommara, MD, PhD, FAAP, 2019-20 David Green Memorial Speaker</p>	<p>Thurs, Dec. 5</p>



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Program Members on the Road and In Print

Peggy Battin will give a plenary lecture at the American Society for Bioethics and Humanities (ASBH) meeting in Pittsburgh, October 26, 2019, "*Death and Sex: Thought Experiments with Normative Force*"; she will participate in a working group from the Hastings Center on "*Dementia and the Ethics of Choosing When to Die*," New York, November 7-8, 2019.

Brent Kious and **Peggy Battin** published Kious, B. M., & Battin, M. (2019). [Physician aid-in-dying and suicide prevention in psychiatry: A moral crisis?](#) The American Journal of Bioethics, 19(10), 29-39, and Kious, B. M., & Battin, M. P. (2019). [Response to Open Peer Commentaries on "Physician Aid-in-Dying and Suicide Prevention in Psychiatry"](#). The American Journal of Bioethics, 19(10), W14-W17.

Teneille Brown will give a talk at ASBH on detecting incest and regions of homozygosity in clinical and research genetics, and the legal and ethical obligations of laboratories and providers. This is part of a larger project--as a member of the Working Group on revising the ACMG guidelines on returning a finding of possible incest. This summer, she presented June 12, 2019 at the University of Utah Psychiatric Update, on "*How the Law Exacerbates the Stigma of Addiction*" ; July 7, 2019 (with Markus Kneer), at the Experimental Jurisprudence Workshop, Luzern, Switzerland, on "*Empirical Evidence: of Bias in Imposing Duties to Warn*," and July 26, 2019, at the International Association of Law and Mental Health on "*Addiction as Character Evidence*." She also recently spoke at the prison on advance directives for prisoners.

Susan Sample will present "*Integrating a Writer-in-Residence Program into a Cancer Research Hospital: Program Development and Best Practice Guidelines from the University of Utah's Huntsman Cancer Institute*" at the 16th International Conference of the Society for Integrative Oncology in New York City Oct. 20. She also held a writing workshop for Physical Medicine and Rehabilitation residents as part of their day-long retreat in Salt Lake City September 12.