

PRACTICAL BIOETHICS

ADVANCE CARE PLANNING

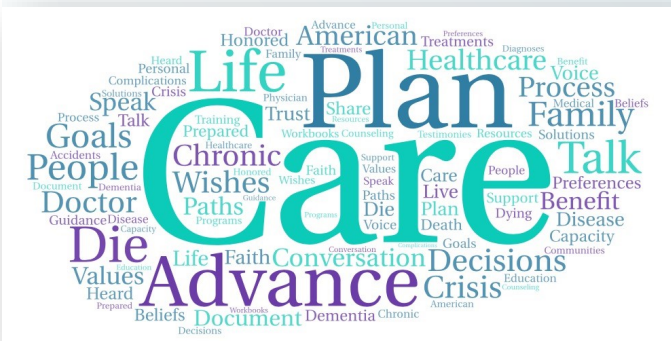
Deciding How You Want to Live

People don't like to talk about politics, religion or money. To that we would add advance care planning. Advance care planning is the process of clarifying your life goals and values, and making sure your healthcare preferences are known and honored.

Most Americans today will die from chronic illness, with slow and uncertain disease paths, affected by dementia, without capacity to make decisions.

Yet, two-thirds of Americans still leave it up to their doctors and ill-prepared family members to make decisions based on common mistaken beliefs such as:

- I'll always be able to make my own decisions.
- My family already knows my wishes.
- My doctor will know what's right.
- I've written it down so I don't need to talk about it.



Solutions Offered

The Center pioneered advance care planning in the 1980s and continues as a leader to make the patient voice heard:

- ✓ **Counseling** – Responding to calls for guidance in a personal or family healthcare crisis.
- ✓ **Resources** – Providing *Caring Conversations*® workbooks in English and Spanish.
- ✓ **Employee Benefits** – Offering advance care planning education and support through employee benefit programs.
- ✓ **Cultural Competence** – Developing curricula and holding workshops to encourage advance care planning in African American faith communities.
- ✓ **Seriously Ill Patients** – Adapting training for Missouri and Kansas providers to engage with seriously ill patients and their families about goals of care and completing medical orders.



- ✓ **MyDirectives.com** – Enabling families and providers to easily access advance care planning documents and video testimonies online.

Lessons Learned

1. **Advance care planning is for everyone.** A medical crisis could leave you too ill to make your own healthcare decisions at any age.
2. **Start with the conversation.** Share your wishes with someone you trust to speak for you if you can't speak for yourself.
3. **This is not a one-time process.** Wishes change through various life stages. Revisit your plan.

Things happen. People have accidents. Get chronic illnesses. Receive life-threatening diagnoses. Advance care planning is about living as you want, recovering when you can, and being cared for as you wish, especially in the final chapters of life.



April 16, 2020
National Healthcare Decisions Day

Founded in 2008, National Healthcare Decisions Day is a collaborative effort of national, state and community organizations to inspire, educate and empower the public and providers about the importance of advance care planning.

ETHICS COMMITTEES: The Conscience of Healthcare

Bioethics as a discipline arose from the need to address the changing face of medicine and to empower patients to share in the increasingly complex decisions that providers make in caring for them.

Hospital ethics committees arose in the mid-1970s in large part from the Karen Ann Quinlan case, which raised concerns about patient and surrogate rights to make decisions, including



decisions about foregoing medical treatment. The President's Commission for the Study of Ethics in Medicine and Biomedical and Behavioral Research addressed those concerns in the 1980s, resulting in the formation of the first hospital ethics committees.

The Center launched the Kansas City Regional Ethics Committee Consortium in 1986, which remains the oldest continuously operating consortium of its kind in the nation. In 1992, the Joint Commission began requiring hospitals to have a "clinical ethics mechanism" to receive accreditation.

The Center's longstanding work in this arena positions it as one of the nation's most authentic voices in championing ethics in healthcare across a broad spectrum of providers. Our original goals remain critical to ethics in health even today: To educate about what it means to "do ethics" well, to develop and review sound health ethics policy, and to conduct thorough consultations to address complex cases.

A Family's Journey to Peace of Mind

Jama's mom had been living in a long-term acute care facility on dialysis and a ventilator for nearly five months. Dad was by her side 24/7.

"One day, as my sister and I were walking out, I looked at her and said, 'I think Mom is dying,'" said Jama. "We started crying. Of course mom was dying, but no one had told us...or Mom."

Call the Center

Jama and her siblings began insisting that the doctors at least be honest with their dad about Mom's failing condition. Dad thought he had to seek heroic efforts because of religious beliefs. All along Mom thought she was going to get well enough to go home.



Jama Rice and her mother Henrietta Smith

... they want to ensure that the resources that helped them are there for others.



"There wasn't anyone to guide us through it," said Jama, "so I called the Center.

"The staff there helped us understand who we needed to ask for what and how to talk honestly with Dad about Mom's situation. When the doctors finally told Mom that she would live on a vent for the rest of her life, she said take it out. She died peacefully within hours.

"The work and wisdom of the Center helped move us from anguish to grief and finally peace of mind."

Monthly Giving

That was five years ago. Today, Jama and her husband Carl are monthly donors to the Center because they want to ensure that the resources that helped them are there for others.

"The Center helps people in so many personal ways," said Jama. "They focus on education and policy issues that aren't trendy or glamorous but that we, and everybody we know, will eventually face."

ANNUAL DINNER

TUESDAY, APRIL 21, 2020

RECEPTION 5:30 PM | DINNER 6:45 PM

KANSAS CITY MARRIOTT DOWNTOWN —
MUEHLEBACH TOWER



ethics champions

An evening to celebrate the people and
providers who stand up for healthcare ethics

save the date
04.21.2020



HONORARY CO-CHAIRS
**DEBBIE SOSLAND-EDELMAN
AND ALAN EDELMAN**
JOAN AND STEVE ISRAELITE



VISION TO ACTION
HONOREE
TARRIS ROSELL, DMin, PhD
Rosemary Flanagan Chair
Center for Practical Bioethics

Quality healthcare relies on ethics-rich environments. From CEOs and clinical experts to patient care volunteers, healthcare institutions need ethics champions engaged in every facet of their organizations.

Join the Center for dinner, learning and stimulating conversation about ethics in healthcare.

- * Find out how ETHICS CONSULTATION services help to avert tragic outcomes.
- * Honor ETHICS CHAMPIONS whose work ensures that our loved ones receive patient-centered care.
- * Help celebrate the 30th anniversary of the Kansas City Regional ETHICS COMMITTEE CONSORTIUM.
- * Learn how PRACTICAL bioethics seeks to resolve disparities, embrace diversity and pursue justice by addressing social determinants of health. This after-dinner conversation with one of America's foremost population health experts, Erika Blacksher, PhD, will challenge us to face the true meaning of being an ethics champion.

For sponsorship and ticket info, click "Annual Dinner" under "Events and Education" at PracticalBioethics.org or call Cindy Leyland at 816-979-1357 or cleyland@PracticalBioethics.org.



Who You Gonna Call... Clinical Ethics Service!

Imagine someone you love or your patient is in the ICU and unable to speak. The patient has an advance directive. But doctors disagree on the best course of treatment. Nurses are reluctant to discuss the situation. You're feeling something isn't right.

When a complex ethical issue arises, who should be called?

We would never send an untrained clinician to the bedside of a patient in need of critical care. Still, unfortunately, in the vast majority of hospitals across the country, a trained medical ethicist is not available.



Ryan Pferdehirt, Director of Membership and Ethics Education at the Center, discusses a case with Dr. Erin Marie Khouri, Saint Luke's Health System.



Clinical Ethics Service Benefits

- ✓ Increased patient satisfaction
- ✓ Improved employee morale
- ✓ Enhanced productivity
- ✓ Conservation of resources
- ✓ Improved accreditation reviews
- ✓ Reduced risk of lawsuits
- ✓ Corporate integrity and future

The Center collaborates with ethics-trained volunteers and professionals to fill the void. In the fall of 2019, the Center introduced the Clinical Ethics Service. Available to all healthcare providers in the Kansas City region, the service offers two options:

Ethics Direct includes ethics committee education, advance care planning and support for research.

Ethics + Plus includes Ethics Direct services plus an expert medical ethicist available to conduct inpatient consultations in real time, participate in rounds, work on policy and ethics integration, lead training and provide advisory support.

The program has been strongly embraced by our member organizations, with growing interest in the Center's ability to train and educate ethics committees. For information, contact Ryan Pferdehirt, 816-979-1350 or rpferdehirt@PracticalBioethics.org.

Bioethics on YouTube

Ethics committees in healthcare institutions address ethical issues that arise in patient care. They may also provide consultation services and policy guidance.

The Center presents eight educational webinars a year for members of the Kansas City Regional Ethics Committee Consortium. You can learn more about the kinds of issues ethics committees tackle at [YouTube/PracticalBioethics](https://www.youtube.com/channel/UCPracticalBioethics).

Check YouTube regularly for new titles. Call Matthew Pjecha at 816-979-1366 to learn more about the Ethics Committee Consortium.

Selected Topics

Professionalism in Medicine
Autonomy and Informed Consent
Introduction to Hospital Ethics
Brain Death and Jahi McMath
Artificial Intelligence in Healthcare
Landmark Cases: Nancy Cruzan and Karen Ann Quinlan
Kansas/Missouri TPOPP Update
Unrepresented Patients
Suspension of DNR for Surgery



THE GENE: AN INTIMATE HISTORY



THE GENE: An Intimate History, a documentary series on the quest to decipher the master code of instructions that defines humans, will air on KCPT Channel 19 from 8:00 to 10:00 p.m. on April 7 and 14. The two-part documentary presented by Ken Burns will bookend *THE GENE: A KC Town Hall* at 7:30 p.m. on April 9.

Key moments in the documentary include the birth of genetics, discovery of the structure of DNA, identification of the first genes that cause human illnesses, the excesses of eugenics in Germany and the United States, recent attempts to change the genetic material of human embryos, and breakthroughs in our understanding of how genes impact heredity, disease and behavior.

At the Town Hall, leaders and ethicists from the Center for Practical Bioethics along with local researchers, medical students and patients will examine Kansas City's role in genetic research. Moderated by Nick Haines, participants will explore the ethics and nagging questions over who benefits from genetic research and who is left behind.

The GENE: A KC Town Hall

You can join us for the Town Hall recording on March 31, 5:30 p.m., at Kansas City University of Medicine and Biosciences. Register at PracticalBioethics.org. Click "Events Calendar" under "Events and Education."

PAIN POLICY CONGRESS

Numerous yet inconsistent policies and guidelines affect pain management, while solutions to the nation's opioid misuse and overdose epidemic have left few treatment options for many people who live with chronic pain.

On **May 13-14**, more than 125 leaders from 75 organizations will gather in Kansas City for the third annual Pain Policy Congress. The Congress,

co-sponsored by the Center, is hosted by the Alliance to Advance Comprehensive Integrative Pain Management and continues work begun by the PAINS Project and the Academy of Integrative Pain Management to improve access to comprehensive integrative pain management. Participants will develop recommendations and create educational materials to address access to quality comprehensive care.

TALIA'S VOICE

Talia Goldenberg died at age 23 because her doctors, nurses and support staff failed to listen when Talia, her physician father and her mother repeatedly told them that Talia couldn't breathe. Talia's parents founded Talia's Voice: Projects for Patient Safety to change the culture in medicine so that nobody else's child dies because people in charge won't listen.

You can hear Talia's parents, Dr. Jeff Goldenberg and Ms. Naomi Kirtner, present *Talia's Voice: Listening to Patients and Their Families*, on **August 17, 2020**.

13th Annual Joan Berkley Bioethics Symposium

8:30 – 11:30 a.m.

Kansas City University of Medicine and Biosciences (KCU)
1750 Independence Avenue, Kansas City, MO
Academic Center AC200

9:00 a.m. lecture followed by panel discussion moderated by
KCU Bioethics Department Chair David Sine, PhD

26th Annual Rosemary Flanigan Lecture

7:00 – 8:30 p.m.

Jewish Community Center of Greater Kansas City
5801 West 115th Street, Overland Park, KS
Social Hall



YOUR HELP IS NEEDED NOW BECAUSE...

- ✓ Families facing health crises need consultation and advocacy.
- ✓ Current and future healthcare professionals need to learn how to address ethical issues.
- ✓ Healthcare leaders need resources and guidance to make informed decisions.
- ✓ Science and technology in medicine present new ethical challenges every day.
- ✓ And most Americans still avoid preparing for the inevitable challenges of illness, disability and mortality.



YOU CAN INVEST IN OUR PROJECTS



ETHICS EDUCATION

The Center trains students, volunteers and professionals to use ethics skills to protect patients' rights, assess benefits and burdens, choose treatments and embrace patient-centered care. We also help consumers navigate healthcare crises and assist policymakers seeking to better understand implications of health legislation and regulation.



ETHICAL.AI

The Center, with Cerner Corporation, is convening multi-disciplinary experts to develop recommendations for incorporating fairness, inclusion, accountability, transparency, data privacy and security, and reliability and safety into AI development and implementation.



ETHICS DISPATCH

The Ethics Dispatch, published monthly, provides curricula for Ethics Committees, with online discussion for committee members to engage in more robust exploration of the topic.



Learn more about these special projects under "Make a Donation" at PracticalBioethics.org.

With your help, more people can receive the healthcare they want when it counts the most.

Name _____ Email _____

Address _____ Phone _____

CC Number _____ Expiration _____ Code _____

Please make checks payable to the Center for Practical Bioethics or donate at PracticalBioethics.org.

_____ My employer has a "Gift Match" program.

_____ Please make this a monthly recurring gift.

_____ Please tell me more about special projects.

_____ Please send me information about a legacy gift.