



"Science seeks to do what's good for the human being.
The Center, which emphasizes the ethical implications of healthcare, seeks to do what is good for the health of the human being.
Their end is the same."

ROSEMARY FLANIGAN, PhD

Board Chair, Center for Practical Bioethics, 1991 Program Associate, Center for Practical Bioethics, 1992-2010 Professor Emeritus, Rockhurst College, Retired

CENTER FOR PRACTICAL BIOETHICS
2019 RETROSPECTIVE • 2020 RESPONSE TO COVID-19

STANDING WITH ETHICS CHAMPIONS TO REBUILD OUR HEALTH SYSTEM

Nine months ago when we chose the Ethics Champions theme for the 2020 Annual Dinner, we could have never anticipated the significance of its meaning or impact.

Doubtless, many of the Champions that our institutional partners nominated to be honored in our original evening program consider themselves simply colleagues among a vast legion of champions who have literally and willingly placed their lives on the line daily for weeks in a way they never dreamed would be asked of them.

We honor them all in tribute to what they represent in the face of unrelenting and overwhelming adversity. We honor their courage, conviction, perseverance and spirit in responding to the greatest global health tragedy in more than a century. We honor their "doing the right thing" and their belief that in doing so something better comes of it.

Confronting Ethical Challenges

In this report you will find a summary of the Center's work in 2019 and a brief overview since the coronavirus pandemic redirected our efforts. The 2019 accomplishments are significant, and we remain grateful for your support of those programs and our eagerness to return to them in the future. This report also demonstrates the Center's ability to respond quickly to the needs of our stakeholders and constituents.

Finally, this report speaks to the importance of ethics in all our lives and livelihoods. The ethical challenges that lie ahead for this country and world are monumental and, quite frankly, a little overwhelming.

Holding Ourselves Accountable

The devastation wreaked by this tiny virus will cause a reckoning for decades to come. It has laid bare the deep divisions and fissures of inequity and injustice in our healthcare systems. We will all be held accountable, individually and collectively, for how we raise and respond to the questions of what ought we to do, as we remain vigilant and begin to rebuild.

The Center stands with its Ethics Champions – all of them everywhere – in steadfast commitment to our core value: respect for human dignity. We must rebuild a health system that recognizes the intrinsic worth of all persons, listens to the voices of every child, youth, adult and elder of every tongue, embracing all forms of ability. We must rebuild a health system, an economy and a community that measures success in terms of how the least among us is served. Justice is not a notion; it is our imperative.



John G. Carney, MEd President and CEO

Sandra R. Stites, MD Chair of the Board



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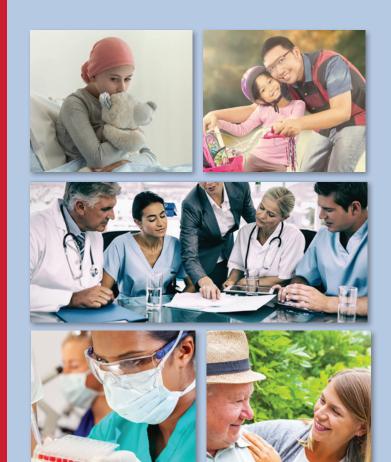
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HOW WE DO ETHICS

As science, technology and engineering expand what we can do in medicine, questions about what we should do grow more complex and consequential. The Center for Practical Bioethics has been "doing ethics" by raising and responding to ethical issues in health and healthcare since 1984.

PERSONAL | Providing guidance for patients, families and clinicians struggling with ethically complex issues in medicine and research.

PROFESSIONAL Teaching bioethics to healthcare providers, students, clinicians and consumers.

POLICY | Creating guidelines, developing programs, publishing resources and advising decision makers.



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ETHICS IN THE TIME OF COVID-19

Since the emergence of Covid-19, the Center for Practical Bioethics has been on the front lines of our region's response, providing unique guidance on the ethical implications of the choices we are making and the actions we may have to take.

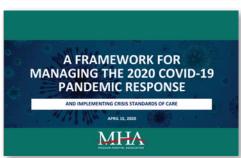
Never has the need for PRACTICAL solutions to ethical dilemmas in healthcare been greater in volume and complexity. Never have the stakes been higher in physical, social, emotional and economic impact. In the context of Covid-19, the Center is working 24/7 to provide guidance and crisis solutions to patients, families, clinicians, institutional leaders and policy makers at all levels of government, including public health and elected officials.

In less than a month, the Center has completely reoriented and redesigned its resources and programming to focus on what our region and nation need most—ethical guidance through the unprecedented Covid-19 pandemic.

We expect these activities to evolve and expand as the pandemic progresses. The following summarizes key activities and accomplishments from mid-March to mid-April.









For Institutions and Healthcare Professionals

- Responding to urgent requests from hospitals and long-term care facilities for ethics consultations on care for critically ill Covid-19 patients and related policy determinations.
- Coordinating the regional effort, with leaders from Missouri Hospital Association and Mid-America Regional Council (MARC) Health Care Coalition, to encourage all metro area jurisdictions to adopt model public health Crisis Standards of Care.
- Continuously providing and updating resources for more than 40 metro area healthcare ethics committees.
- Providing Covid-19 ethics training for national organizations, such as Consumer Voice (a national association for ombudsmen) and the National Nursing Home Social Work Network.
- Guiding policy makers on the impact of proposed local, state and national legislation (e.g., suspension of requirement for face-to-face patient visits).
- Publishing regular COVID ETHICS UPDATES on YouTube addressing ethical dimensions of the pandemic, with 740 subscribers as of April 24, 2020.
- Producing a weekly Covid-19 webinar series. Titles so far include Ethics in a Pandemic, Duties to Care in a Coronavirus Pandemic, Ethical Dimensions of Quarantine and Isolation, Crisis Standards of Care in a Pandemic, and Advance Care Planning During the Covid-19 Pandemic. More than 100 attendees required us to expand Zoom "room" size.

For the General Community

- Enhancing advance care planning training to meet urgent need for individuals to name an agent to speak for them if they can't speak for themselves (especially for people at risk and to ensure easy access to documents/videos online).
- Educating the public to understand and accept Crisis Standards of Care (i.e., the transition from clinical to public health ethics), including collaboration with KCUR 89.3 and KCPT Channel 19.
- Encouraging appreciation for the courage and commitment of healthcare workers and how citizens can support their efforts.



Vicky Burnett, RN, MS, Clinical Nurse Specialist, Visiting Nurse Association

Ethics in a book is one thing. But in the real world it's a whole other ballgame. The Ethics Committee Consortium made that very clear. We learned that everybody has a perspective and everybody has a background.

George Flanagan, DMin, MA, Chaplain and Ethics Consultant, Retired

At the Consortium, just hearing people talk about issues, how they would approach them, what the pitfalls are and how we can avoid them, to keep learning from other people's experiences...that's a phenomenon that we would not have if it weren't for the Center's presence in Kansas City.

Dr. Barbara Bollier, Kansas State Senator

Both as a physician and as a public policy maker, the Center is able to make a very specific difference in people's outcomes and in the care that they can and will receive.

Jerry Wilmes, MD, Medical Director, Hospice and Palliative Medicine, Mosaic Life Care

Serving on ethics committees, in my opinion, makes you a better clinician because it helps you think about situations from a more comprehensive and compassionate perspective. Ethics committees have been instrumental in the development and growth of our palliative care program and in helping the healthcare system navigate difficult situations.

FTHICS COMMITTEES: The Conscience of Healthcare

Bioethics arose 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 developed 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.

DOING ETHICS

Ethics committee members apply reasoned analysis and discourse to support clinicians, patients and families through clinical and organizational stress points. The process typically includes these steps:

- 1. Gather facts.
- 2. Clarify ethical issues.
- What values are in conflict?
- What are the differences of opinion about the consequences of different actions?
- 3. Discuss stakeholders' interests: Who has interests? What are those interests?
- 4. Decide on one or more alternatives with justification for each.
- 5. Implement recommendations and respond to policy implications.
- 6. Evaluate outcomes.

High functioning ethics committees provide educational opportunities for their members and hold regular reviews and updates of hospital policies that involve ethical considerations.

AUTHENTIC VOICE

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 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.



Quality healthcare relies on ethics-rich environments. Ethics-rich environments rely on ethics champions. From CEOs and clinical staff to volunteers serving on ethics committees, healthcare institutions need ethics champions at all levels of their organizations.

The Center for Practical Bioethics invited healthcare providers and health systems throughout the Kansas City region to nominate such individuals. We planned to honor the 23 individuals they nominated at the 2020 Annual Dinner in April. While the emergence of the Covid-19 pandemic prevented us from holding the Dinner, the leadership of ethics champions is needed now more than ever.

Cathy Boutte Overland Park Regional Medical Center, HCA Midwest Health

Kathy Davis University of Kansas Medical Center - Pediatrics

Lorraine Duncan Centerpoint Medical Center, HCA Midwest Health

Brandy Ficek Stormont Vail

Kara Hess AdventHealth Shawnee Mission
Sarah Hon North Kansas City Hospital

Ronn Huff HCA Healthcare, Brentwood, TN

Edwin T. Kraemer Truman Medical Center, Lakewood

Carmen Lile-Henley Liberty Hospital

Leslie McGrew-Kaufman Kansas City Hospice & Palliative Care

Laura Miller-Smith Children's Mercy Hospital - Hospital Hill

Sarah Oland Midwest Transplant Network

Lisa A. Osgood Truman Medical Center, Health Sciences District

Bethany Ruhl Saint Luke's Health System - Crittenton

Nancy Schroeder VNA Visiting Nurse Association

Sally Schwab Mosaic Life Care - St. Joseph

Karlie Speicher Saint Luke's Health System - Plaza

Noreen Thompson University of Kansas Medical Center

Jennifer Tieman Research Medical Center, HCA Midwest Health

Kimberly Williams Phelps Health, Rolla, MO

Jerry Wilmes Mosaic Life Care - Maryville

Cathy Wisor Saint Luke's Health System - North

Julia Woods Saint Luke's Health System - South

Read stories about Ethics Champions at https://practicalbioethics.org/ethics-champions.



WE REMEMBER RICHARD PAYNE, MD

Our colleague and friend, Dr. Richard Payne, died on January 3, 2019, from complications related to cancer. An internationally recognized expert in neurology, oncology, pain management, disparities and palliative care, Dr. Payne was in his sixth year as the John B. Francis Chair at the Center at the time of his death.

Following memorial celebrations that coincided with the 2019 Annual Dinner, the Center embarked on a months-long process to name a successor to the John B. Francis Chair. We anticipated concluding the selection process and announcing the successor at the 2020 Annual Dinner. Due to the coronavirus, plans have been temporarily delayed.



2020 ANNUAL DINNER

The 2020 Annual Dinner, to have taken place on April 21 at the Kansas City Marriott Downtown - Muehlebach Tower, was not held due to the coronavirus. It is noteworthy that Terry Rosell, the person to whom we would have presented the Vision to Action Award in person at the Dinner, is now in the forefront of action in our community responding to the ethical issues raised by the pandemic.

The Center also wishes to thank the Dinner's Honorary Co-Chairs, Joan and Steve Israelite and Debbie Sosland-Edelman and Alan Edelman, for their time, effort and commitment to ensuring the event's virtual success.



VISION TO ACTION HONOREE

Tarris Rosell, PhD, DMin | Dr. Rosell joined the Center in 2004 where he has held the Rosemary Flanigan Chair since 2006. On behalf of the Center, he recently completed his sixth year as chair of the Department of Bioethics at Kansas City University of Medicine and Biosciences and eleventh year providing ethics consultation for The University of Kansas Health System, where he directs the ethics consultation service and teaches at the University of Kansas School of Medicine.

Dr. Rosell publishes frequently in addition to teaching and lecturing internationally. He is also a Professor of Pastoral Theology at Central Baptist Theological Seminary, Shawnee, Kansas. He holds doctoral degrees in Pastoral Theology from Colgate-Rochester Divinity School and in Ethics and Society from Vanderbilt University.

Terry makes pottery for art's sake and for three orphaned kids in Kenya, to whom all proceeds are donated. He and his wife, the Reverend Dr. Ruth Rosell, have four children and recently delighted in becoming grandparents.



HONORARY CO-CHAIRS

Deborah Sosland-Edelman and Alan Edelman | Debbie is the Executive Director of the Sosland Foundation, where she administers grants to social welfare, education, health-related, civic, cultural arts and Jewish organizations in the Kansas City area. She earned her doctoral degree in developmental and child psychology from the University of Kansas and her undergraduate degree from Smith College.

Alan is the former Director of Engagement and Leadership Development for the Jewish Federation of Greater Kansas City. He earned his Master's Degree in Jewish Education from the Jewish Theological Seminary, New York City. He also holds a Master's Degree in Education Policy and Leadership from the University of Kansas. In addition to serving on the board of the Center for Practical Bioethics, Alan's volunteer efforts focus on inter-faith and multi-cultural programming, including guest theologian for many churches, universities and seminaries.

Combined, Alan and Debbie serve or have served on more than 35 local, regional, national and international boards and committees. They are the proud parents of three children and two grandchildren.



Joan and Steve Israelite | Joan was the founding President and CEO of the Arts Council of Metropolitan Kansas City from 1999 to 2009. Currently, she assists the Kauffman Center for the Performing Arts' fundraising efforts. Prior to leading the Arts Council, she served as development director for several Kansas City arts, youth and family nonprofit organizations. She earned her nursing degree from St. Francis School of Nursing in Evanston, Illinois, and bachelor of arts from St. Francis College in Joliet, Illinois.

Steve graduated from the University of Illinois School of Pharmacy. He and Joan served in the Peace Corps together shortly after they were married in 1964. They have two sons and six grandchildren. Steve's consistent focus as an official in the U.S. Department of Housing and Urban Development, as founding executive director of the Jewish Heritage Foundation from 1994 to 2015, and since retirement has been social justice.

Four years ago, Steve was seriously injured crossing 63rd Street in Brookside, followed shortly by a stroke. Steve credits his remarkable recovery to God, Joan, his family and the many doctors, nurses and therapists who cared for him.

2019 HEALTH ETHICS IMPACT REPORT



The object of philosophy is the logical clarification of thoughts. Philosophy is not a theory but an activity." — Ludwig Wittgenstein Hot Topic The Ethics of Allowing Patients to Make Bad Decisions Challenging patient discharges are common events with strong ethical implications. They present in many officers from. Each is unique to the particular plantar, and each require knowledge and neglector skills they applicate plantar, and each require knowledge and neglector skills they represent the patients of the strong they are the are they are







THANK YOU FOR MAKING HEALTH ETHICS MATTER.

From providers in clinical practice to patients and families making difficult choices for themselves and loved ones, your support helps thousands each year.

We hope you take pride in the values you advance through the accomplishments described in this report.

ETHICS EDUCATION AND CONSULTATION

PROFESSIONAL MEDICAL EDUCATION

Kansas City Regional Ethics Committee Consortium

Launched webinars and workshops for more than 300 individual Consortium members representing three dozen providers. Provided prompt response to requests for resources to address critical, time-sensitive cases and issues.

Health Ethics Dispatch

Began publishing a monthly resource addressing issues and needs identified by ethics committees. In 2020, we will expand the Dispatch's reach to students, educators and administrators and introduce an online discussion opportunity.

Clinical Ethics Service

Introduced new "Ethics Direct" model for providing member organizations with ethics education, consultation and support that the Center has offered for nearly 30 years, as well as more intensive and individualized consultation and training through Ethics+.

Medical Student Education

Chaired the Bioethics Department at Kansas City University of Medicine and Biosciences (KCU) and provided bioethics instruction to 860 students, including 130 enrolled in KCU's dual degree medicine/bioethics program.

Faculty Services

For The University of Kansas Health System (TUKHS), oversaw more than 100 ethics consultations. Provided ethics consultations for the Heart Transplant program and Blood and Marrow Transplant team. Co-chaired the Hospital Ethics Committee. Served as ethics faculty for student, residency and fellowship case conferences.

CONSUMER GUIDANCE

Helped more than 100 patients, families and practitioners who called the Center for guidance in a health crisis to:

- Advocate and sort through options
- Obtain advance care planning documents and properly execute them
- Ask for ethics and palliative care consultations
- Clarify how to present concerns to family members and providers
- Articulate ethical concerns regarding quality and access to care

COMMUNITY EDUCATION

Current Issues in Bioethics Lecture Series

With Kansas City University School of Medicine and Biosciences, presented 5 lectures by speakers of national stature to 430 KCU medical students and hundreds of others online.

Flanigan Lecture

The 25th annual lecture, *America's Obsession: Having It All Without Paying the Price*, at the Jewish Community Center of Greater Kansas City featured Jonathan Moreno. PhD.

Berkley Symposium

The 12th annual symposium explored *Perspectives on the Ethics of Genetic Engineering*, with panelists Jason Glenn, PhD, George Gotto, PhD, and Carla Keirns, MD, PhD, with Jonathan Moreno, PhD, moderating.

Staff Presentations and Publications

Presented more than 70 professional education lectures, conferences, workshops, discussion groups and community talks. Published articles for peer-reviewed and mass media outlets. Appeared in 6 local TV/radio stories.

Stakeholder Communications

- PracticalBioethics.org, which provides free access to 3,000+ resources, received 509,200 pageviews in 2019.
- 10,000 people subscribe to our monthly e-newsletter.
- 1,000 supporters receive our print newsletter, *Practical Bioethics*, in the mail.
- Thousands keep up to date with the Center on Facebook and Twitter.











MAKI HEALTHCARE WISH



Advance Care Planning in African American Faith Communities

Completed comprehensive literature review of best practices to improve African American participation in advance care planning. End-of-life academic researchers and faith-based organizations planned five regional events for 2020.

Caring Conversations® Program and Resources

Connected more than 17,000 people with Caring Conversations® advance care planning resources, including 5,200 printed workbooks and 21,000 other resources including *Introduction to Caring Conversations®*, *Caring Conversations® Starter and Caring Conversations®*...Continued.

Bi-State Transportable Physician Orders for Patient Preferences (TPOPP) Initiative

Presented 7 onsite/webinar trainings, published a new *Clinical Guidebook for Healthcare Providers in Kansas and Missouri*, and approved guidance documents for out-of-hospital Do Not Resuscitate rules. More than 62 reams of TPOPP forms and 75 *Guidebooks* were purchased by Kansas and Missouri providers, demonstrating growing adoption of standardized medical order sets for seriously ill persons living with life-limiting illnesses.

Art of the Wish

Marn Jensen and Andy Newcom began translating the wisdom of older adults into works of art for an exhibition that was originally planned to open in Fall 2020. The artists are also designing a presentation based on the exhibition for student healthcare professionals to convey the importance of listening to their patients.



KENTER EST PRACTICA





EMERGING ISSUES AND SYSTEMS CHANGE

Artificial Intelligence in Healthcare

The Center, in collaboration with Cerner, gathered 60 healthcare innovators and thought leaders to address ethical considerations raised by AI and its potential to produce biased predictions. Participants identified 360 elements of AI development and implementation needed to ensure fairness, inclusion, accountability, transparency, data privacy and security, and reliability and safety. The Center and Cerner are analyzing these elements and producing a report. The workshop model will be repeated for another group in Atlanta in October.

Chronic Pain

The Center provided technical assistance to obtain funding from the Lovell Foundation to support the formation of the Alliance to Advance Comprehensive Integrative Pain Management. The AACIPM will host the Pain Policy Congress in 2020 to advance evidence-based, person-centered pain care.



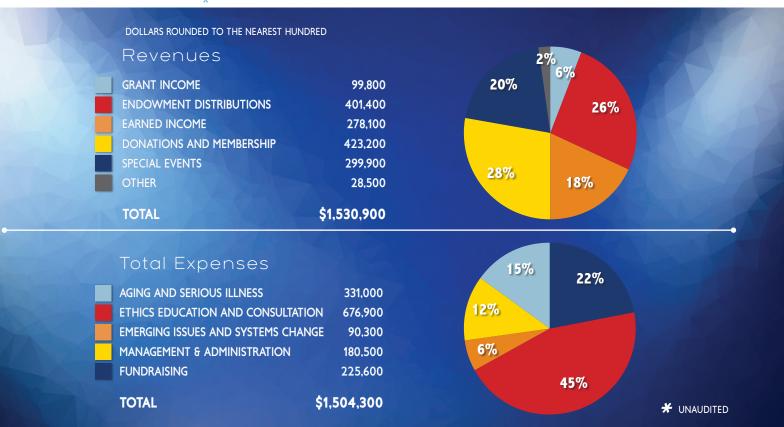


PAINS-KC

PAINS-KC provides a voice through education and advocacy for those who live with pain. PAINS-KC Citizen Leaders serve as patient instructors for some of the American Academy of Family Physicians continuing medical education courses.



2019 FINANCIALS,



LEGACY SOCIETY

The Legacy Society was established in 2009 as a way for individuals to make provisions for the Center for Practical Bioethics in their estate plans.

Judith S. and James M. Beck

Joan* and Bert Berkley

Mary Beth Blake

Donna K. Blackwood*

Drs. Barbara and Rene Bollier

Dianne and John Carney

Myra and Truman Christopher

Kelley and Bill Colby

Karen Cox

Karren King Crouch and **Dr. Thomas Crouch**

Helen C. Emmott

Jo Ann Field

J. Scott Francis

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Tarris Rosell

Mary M. and David L. Sallee

Dianne C. Shumaker

Hans W. Uffelman*

Linda D. Ward and Terrence R. Ward

For information about joining the Legacy Society, contact Linda Ward at 816-979-1362 or lward@PracticalBioethics.org.

*Deceased

CIRCLE OF FRIENDS We are thankful for the generous support of donors to the Center for Practical Bioethics from January 1, 2019 - April 10, 2020. We sincerely regret any errors or omissions.

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