

hacking darwin



CENTER FOR PRACTICAL BIOETHICS
ANNUAL DINNER
APRIL 9, 2019

RECEPTION 5:30 PM • DINNER 6:45 PM
KANSAS CITY MARRIOTT DOWNTOWN – MUEHLEBACH TOWER

JOIN US IN CELEBRATING OUR 35TH YEAR
ASKING HARD QUESTIONS...WORKING TOGETHER TO DETERMINE A FITTING RESPONSE

In today's fast-paced world of science and medicine, we rarely question the value of advances in technology or the contributions of scientific research. Nor do we spend much time reflecting on the connection between those advances and the larger question of human flourishing. For a long time now, we've pretty much assumed that scientific progress is a good that we can rely on – a good that allows us to overcome, achieve, expand and accomplish.

But can we continue in that vein? If we reach a stage where discoveries and advances begin to redefine what it means to be human, do we owe it to ourselves to ask what exactly do we aspire to become? Might the technological imperative lead us somewhere we never intended to go?

Those are the some of the questions that we are asking this evening as the Center embraces this new frontier, building on our 35 years of raising and responding to ethical issues in health and healthcare. Throughout our history we have demonstrated that ethics matter in the lives of every person, every day. That ethics permeate the very definition of respect and dignity and our commitment to what it means to be fully human and cared for, regardless of how vulnerable or underserved.

We owe it to each other to ask and answer, to raise and respond, to explore, argue, challenge and commit. It's in the journey that we will discover what we are truly made of. And we are confident that we will not only benefit from the work ahead but be enriched by our common experience and solidarity.

The Center has much to be thankful for. Most of all, thank YOU for joining us this evening. Thank YOU for your faithful, ongoing support and collaboration. Thank YOU for encouraging us to ask the hard questions. And thank YOU for working with us to determine a fitting response.

John G. Carney, MEd

President and CEO

Sandra R. Stites, MD

Chair of the Board



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For many years I have been impressed by the work of the Center. It has addressed many critical areas related to bioethics and has taken that information to a local, national and international audience. I have attended a number of annual dinners and programs, and left each one more educated and inspired. When I retired, I wanted to help the Center any way I could. I was honored to be invited to serve on the board and hope to contribute to strengthening their work.

- Alan Edelman



Ethical issues arise almost daily in my life as a physician. The hard conversations are made easier with education, resources, experience and care. The Center's ability to provide all of that has enhanced how I practice medicine and, indeed, why I practice. For 35 years, the Center has maintained its focus on carrying on ethical discussions that challenge us in both theory and action. I continue to benefit from the Center's vision to have "ethical discourse and action advance health and dignity of all persons."

- Sandra Stites, MD



The Center is continually called on to answer the question, what is the right thing to do, specifically as that question relates to medicine, medical care and quality of life. CPB has opportunities to explore that question with individuals and systems and to consider how policies impact access to and delivery of meaningful health. I am glad to support the work and to be engaged with those challenges.

- Liza Townsend, JD, MSW



I first became involved with the Center when I chaired the Ethics Committee at the old Baptist-Lutheran Medical Center. I was impressed with the Center's work in educating our multidisciplinary team in the principles of bioethics and how to function as an ethics committee. Documents created by the Kansas City Regional Hospital Ethics Committee Consortium, such as "Withholding and Withdrawing Life-Sustaining Treatments," helped to frame our hospital processes, communication and decision-making in end-of-life clinical situations. As a family physician, I used the Caring Conversations® workbook to help patients understand and express their healthcare wishes.

- Stephen Salanski, MD



As a board member for the Center, I am invigorated by supporting the work of a small but mighty organization that consistently makes a national impact on issues of global importance.

- Drew Billingsley, CFA

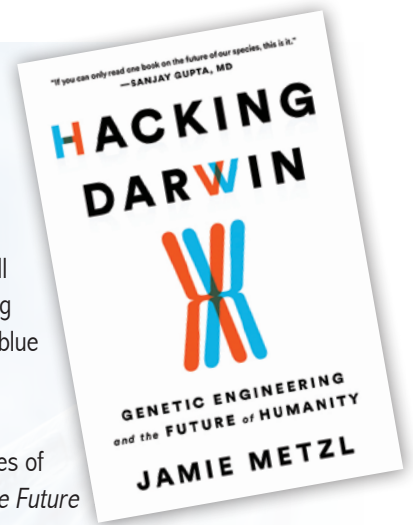


ANNUAL DINNER KEYNOTE SPEAKER

JAMIE METZL, JD, PhD

What if scientists could edit genes for depression or autism with the changes passed on to future generations? Would you be okay with that? What about your children, whose families will undoubtedly face such choices? Would they be okay with editing for intelligence or personality? What about strength, height or blue eyes? Keynote speaker Jamie Metzl believes these choices and many more are already happening.

We are pleased to provide our guests with complimentary copies of Jamie's new book, *Hacking Darwin: Genetic Engineering and the Future of Humanity*, scheduled for release April 23.



Born and raised in Kansas City, Jamie graduated from The Barstow School and holds a PhD in Asian history from Oxford University and a JD from Harvard Law School. He is currently a senior fellow at the Atlantic Council and an advisory board member of the International Center for Ethics, Justice and Public Life at Brandeis University. The author of five books and a syndicated columnist, Jamie is also an athlete having completed 30 marathons, 13 Ironman triathlons and 12 ultramarathons.

PROGRAM

WELCOME

KEYNOTE SPEAKER JAMIE METZL

DINNER

VISION TO ACTION AWARD

DIALOGUE

CLOSING

Gene editing made the news in November when a Chinese scientist announced that he had altered the genes of two baby girls when they were embryos. . . This might be the most important public debate we haven't been having widely enough.

The ethical questions are enormous. Gene editing is generating a ton of optimism for treating and curing diseases, including some that our foundation works on (though we fund work on altering crops and insects, not humans). But the technology could make inequity worse, especially if it is available only for wealthy people.

Bill Gates - GatesNotes, December 29, 2018

SAVE THE DATES!

April 10 | 10:00 a.m.

A Celebration of Life Honoring Richard Payne, MD

Community Christian Church | 4601 Main Street, Kansas City, Missouri
Please join Richard's wife Terrie Payne, children and siblings to share in tributes, reflections and spiritual thanksgiving for a life well lived.

August 13 | 7:00 p.m.

25th Annual Rosemary Flanigan Lecture

AMERICA'S OBSESSION:

HAVING IT ALL WITHOUT PAYING THE PRICE –

A CONVERSATION ABOUT HEALTHCARE, POLICY AND ETHICS

LECTURER: Jonathan Moreno, PhD, Professor of Medical Ethics and Health Policy, University of Pennsylvania Perelman School of Medicine

LOCATION: Jewish Community Center, 5801 W. 115th Street, Overland Park, Kansas

REGISTER: <https://www.practicalbioethics.org/events-education/events-calendar.html>

August 14 | 8:00 am - Noon

12th Annual Joan Berkley Bioethics Symposium

PERSPECTIVES ON ETHICS OF GENETIC ENGINEERING

FEATURING: Jonathan Moreno, PhD, Professor of Medical Ethics and Health Policy, University of Pennsylvania Perelman School of Medicine

LOCATION: Kansas City University of Medicine and Biosciences, 1750 Independence Ave., AC 200, Kansas City, Missouri

REGISTER: <https://www.practicalbioethics.org/events-education/events-calendar.html>



HONORARY CHAIRS

Wayne and Julie Carter

Wayne and Julie Carter recently relocated from Kansas City to the Atlanta area where Julie joined St. Mary's Health Care System as vice president of mission services. Wayne is the newly appointed President and CEO of TVAX Biomedical, having just completed more than six years as President and CEO of BioNexus KC, formerly Kansas City Area Life Sciences Institute. His leadership in that role greatly expanded the influence of Kansas City regionally and nationally in life sciences research and business development. Together, their civic and professional contributions demonstrate exemplary leadership and integrity in the fields of human and animal health.



VISION TO ACTION HONOREES

James and Lisa Spigarelli

Jim and Lisa Spigarelli actively support Kansas City, promoting healthy families and advancing science and research. Jim's work at Midwest Research Institute (now MRI Global) began in the 1970s, where his scientific and executive leadership helped establish the Kansas City Area Life Sciences Institute (now BioNexus KC) and contributed to many other civic and educational entities. Jim joined the Center's Board of Directors in 2011 and served as Board Chair in 2013 and 2014.

Along with Lisa's professional career in teaching and managing clinical trials, their impact is felt intimately in their raising of seven children and spoiling nine grandchildren while devoting themselves to the medical challenges that face so many. They support numerous charitable causes, including the Center for Practical Bioethics.

ARTS ENCOUNTER



Robyn Nichols

Silversmith Robyn Nichols' handcrafted jewelry, tableware and sculpture are collected and displayed in world-renowned museums, including the Smithsonian and The Nelson-Atkins Museum of Art. This year, Robyn has created a custom pendant to honor the Center's 35th anniversary, in addition to her signature argentium sterling silver gingko leaf brooch.



Marn Jensen and Andy Newcom

Marn has been part of the Hallmark creative community for over 30 years. A mixed-media artist, she often incorporates found or antique objects in her work to add texture and story within each piece. Andy has been creating art since his debut as the youngest exhibitor in the Plaza Art Fair at age 16. At Hallmark, he has been a senior photo stylist for the past 20 years and enjoys teaching macramé workshops at Hallmark and beyond. Andy and Marn shared Hallmark's 2017 Barbara Marshall Award. The result was "Wishes for the World," an exhibit inspired by conversations with more than 70 older adults and their 250 wishes for themselves, families and the world. Watch the "Wishes for the World" video on YouTube.



DR. RICHARD PAYNE REMEMBERED

August 24, 1951 – January 3, 2019

It is with profound sadness and endless gratitude that we honor the memory of our colleague and friend, Dr. Richard Payne, 67, who died on January 3 from complications related to a recent cancer diagnosis. Dr. Payne was an internationally recognized expert in neurology, oncology, pain management, palliative care, care near the end of life and bioethics. He advanced pain relief for thousands of patients and instilled in his medical trainees and colleagues around the world an appreciation for the centrality of care, the importance of trust in the doctor-patient relationship, and the relief of physical, psychosocial and spiritual suffering.

AT THE CENTER

Dr. Payne's work with the Center for Practical Bioethics began in the mid-1990s as an advisor on our Community State Partnerships project to improve end-of-life care and later in developing medical education to improve physician care for those facing serious illness. His expertise in reaching African American physicians enabled the Center's Pathways initiative to demonstrate that true success can be measured only when patients and families of all classes, races and faiths are served through a diverse, multidisciplinary, integrated community-wide approach.

Dr. Payne was named the John B. Francis Chair at the Center in January 2013. He had just completed his sixth year in that role upon his death. During his tenure, he directed projects focused on how access to care and health decision making among underserved Americans impact care delivery and patient outcomes. He also led the Center's exploration and responses in emerging ethical issues, including genetic engineering, expanded access to drug treatment, public/private partnerships, collision sports and medical professionalism.

Dr. Payne's interest in advance care planning focused on the underserved, especially the role of faith communities in providing nurturing relationships and trusted messengers among patients and families who have suffered discrimination or been ill-served by the healthcare system. His insights into how disaffected populations interact with providers in developing goals of care and making treatment decisions were informed by his extensive personal experience in dealing with those living with serious illness, pain and chronic conditions from all walks of life. He also served as medical director for the Pain Action Alliance to Implement a National Strategy (PAINS Project).

PALLIATIVE CARE AND PAIN MANAGEMENT

From 1992 to 1998, Dr. Payne served as Chief, Pain and Symptom Management Section at M.D. Anderson Cancer Center. From 1998 to 2004, he led the Memorial Sloan-Kettering Cancer Center Pain and Palliative Care Service, where he held the Anne Burnett Tandy Chair in Neurology and was Professor of Neurology and Pharmacology at Cornell University Weill Medical College. He was president of the American Pain Society from 2003 to 2004, and from 2004 to 2012 he directed the Duke Institute on Care at the End of Life, where he taught as the Esther Colliflower Professor of Medicine and Divinity at Duke University.

Dr. Payne worked to ensure access to pain relief around the world. He was chairperson of the board of directors of the Foundation for Hospices in Sub-Saharan Africa, a program of the National Hospice and Palliative Care Organization. He also served on numerous boards and committees, including at the National Academies of Science, Engineering and Medicine and at the National Institutes of Health. As a member of The Hastings Center's board of directors for the past 11 years, Dr. Payne contributed to many projects related to ethics in healthcare, including The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life, which set the standards for care of the dying now used by hospitals across the United States. He led the selection process for The Hastings Center Cunniff-Dixon Physician Award, which recognizes physicians who give excellent care to patients near the end of life.

The author of more than 275 scholarly papers and editor of four books, Dr. Payne received his B.A. in molecular biophysics and biochemistry from Yale University in 1973 and his M.D. from Harvard Medical School in 1977. He completed his postgraduate training in medicine at the Peter Bent Brigham Hospital in Boston and in neurology at The New York Hospital-Cornell Medical Center and Memorial Sloan Kettering Cancer Center in New York City.

LASTING IMPACT

The Center extends heartfelt condolences and prayers to Richard's beloved wife Terrie Payne, son Richard Payne, Jr., daughter Susan Oziogu and spouses, along with four young grandchildren – Tripp, Sloan, Justus and Zara – and loving extended family.

"Rich Payne will be missed by the thousands who knew him and were inspired by his conviction, commitment and spirit," said John Carney, President & CEO of the Center. "He will also be unknowingly missed by millions who never met him, but whose care will be better because this one man dedicated his life to all that good medicine stands for."

2018 IMPACT REPORT

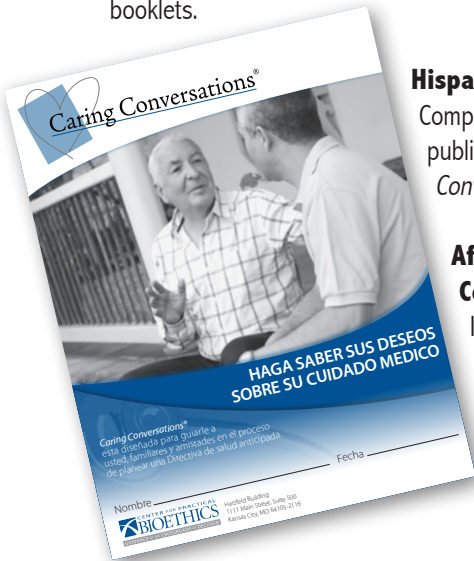
Thank you for your confidence in the Center for Practical Bioethics. Without you, these accomplishments would not be possible.

AGING AND SERIOUS ILLNESS

IMPROVING CARE AT ALL STAGES OF LIFE IN DIVERSE COMMUNITIES THROUGH ADVANCE CARE PLANNING

General Community

Distributed 10,400 *Caring Conversations*® printed and digital workbooks and 22,695 *Introduction to Caring Conversations*® booklets.



Hispanic Community

Completed translation and publication of Spanish *Caring Conversations*® resources.

African American Faith Communities

Initiated a project to develop new curriculum for underserved African American faith communities in advance care planning throughout the lifespan.

Seriously Ill and Frail Patients

Trained providers across Kansas and Missouri in a new standard of care for translating patients' goals of care into physician orders that follow patients across care settings.

Employees in the Workplace

Renewed *Caring Conversations*® in the Workplace contracts for the ninth year with Hallmark and the second year with KCP&L to provide advance care planning education and consultation as an employee benefit.



Catholic Perspectives

Co-convened "Faithful Journeys" conference on Catholic perspectives on advance care planning and palliative care with the Gerber Institute at Newman University, Ascension/Via Christi Health and the Catholic Diocese of Wichita.

MyDirectives

Formalized agreement with ADVault offering consumers a free account to upload, store and share their *Caring Conversations*® workbook and videos.



RESPONDING TO THE EPIDEMIC OF ELDER ABUSE

Assisted efforts in Johnson County, Kansas, and Jackson County, Missouri, to provide services to victims of abuse, especially in circumstances where an alleged caregiver perpetrator is removed from the home. Worked with coalitions on both sides of the state line to help raise awareness of elder abuse. Assessed current efforts in Kansas to prevent and respond to elder abuse, including funding opportunities, law enforcement and prosecution activities, and services to victims.



PROVIDING BIOETHICS EDUCATION FOR STUDENTS AND HEALTHCARE PROFESSIONALS

Kansas City University of Medicine and Biosciences (KCU)

Chaired the KCU Bioethics Department, providing instruction to 860 students at Kansas City and Joplin campuses, with 130 of those students enrolled in the dual degree medicine/bioethics program.

Kansas City Regional Hospital Ethics Committee Consortium

Developed and implemented a new training model, including webinars and half-day workshops, and continued providing resources in response to often urgent ethics committee requests.

University of Kansas Medical Center (KU)

Oversaw KU'S Clinical Ethics Service – called upon for 120 consultations in 2018 – and provided ethics consultation for the heart transplant program and Blood and Marrow Transplant Team. Co-chaired the hospital Ethics Committee. Taught ethics to medical students, residents and fellows, and directed the Clendening Summer Fellowship Program.



EDUCATING THE COMMUNITY ABOUT BIOETHICAL ISSUES AND THEIR IMPACT

Annual Dinner

Explored the five elements of improvisation that relate to practical bioethics – collaboration, structure, knowledge, confidence and creativity – and honored Myra Christopher's three-plus decades of Center leadership and Vision to Action Award recipients Mary Beth Blake and Rosemary Flanigan.

11th Annual Joan Berkley Symposium

Examined bioethics' past and present-day challenges through the lens of law, medicine and ethics, including presentations by Myra Christopher, Charles Sabatino, Richard Payne, Britt Johnson, Cynda Rushton, Matthew Pjecha, Tarris Rosell and John Carney.

24th Annual Rosemary Flanigan Lecture

Presented "Given What We Know, Ought Parents Allow Kids to Play Collision Sports," presented by Steven Miles, MD, Professor Emeritus of Medicine and Bioethics, University of Minnesota, at the Jewish Community Center of Greater Kansas City.

Current Issues in Bioethics

Hosted the fourth annual lecture series featuring national experts reaching 300 KCU medical students and hundreds more online.



Bioethics Film Series

With the Tivoli Cinemas, held Kansas City's first-ever bioethics film series featuring three award-winners: Gattaca, Big Fish and Frankenstein, followed by expert-led discussion.

Digital Bioethics Library

Nearly doubled unique visitors to PracticalBioethics.org from 72,000 in 2017 to 130,000 in 2018 and from 291,000 pageviews in 2017 to 325,000 in 2018. Most visitors sought free access to our 3,000 resources on bioethics topics and case studies developed over the Center's 35-year history.

ASSISTING CONSUMERS SEEKING GUIDANCE IN A HEALTHCARE CRISIS

Helped more than 100 callers facing complex and stressful healthcare decisions evaluate options and access resources with compassion and in strict confidence.

EMERGING ISSUES AND SYSTEMS CHANGE



RESPONDING TO DEMANDS FOR ACCELERATED ACCESS TO NEW DRUGS AND CLINICAL TRIALS

Co-sponsored a two-day conference at the National Press Club in Washington, DC, in January 2019 addressing the urgent and ongoing needs of patients facing the challenges of pre-approval access to drugs still in development in the U.S. and globally. The second day focused on the ethical dimensions facing patients and families, clinical researchers, practitioners, manufacturers, academic medicine, policy makers and entrepreneurs.

EXPLORING THE ETHICAL DIMENSIONS OF ARTIFICIAL INTELLIGENCE IN HEALTHCARE

Collaborated with Cerner social scientists to begin an in-depth exploration of the ethical implications of artificial intelligence in healthcare and to convene developers, providers and patients to articulate best practices and policy recommendations.

SUPPORTING DEVELOPMENT OF MODEL FOR EVALUATING PROFESSIONALISM IN MEDICAL STUDENTS

Established a Board Task Force to define professionalism (i.e., the likelihood for medical students to succeed as doctors) and its behavioral components, assess forces contributing to unprofessional acts, review methods for teaching and evaluating professional behavior, and identify next steps for the Center.

PROVIDING A VOICE IN RESEARCH AND TREATMENT FOR PEOPLE WHO LIVE WITH CHRONIC PAIN

Transitioned the PAINS Project, a program of the Center since 2011, to the Academy of Integrative Pain Management. Convened the sixth year of PAINS-KC, a group of people living with chronic pain who meet monthly to learn about advocacy and to partner with researchers.

MITIGATING RISKS OF YOUTH PARTICIPATION IN COLLISION SPORTS

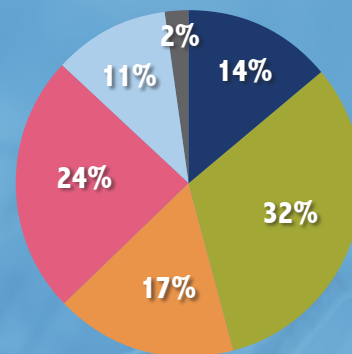
Collaborated with KU Medical Center to present invited lecture on the precautionary principle for youth participation in collision sports and presented Dr. Steven Miles, who further challenged assumptions about the promotion of football in public schools for our 24th Annual Rosemary Flanigan Lecture.

2018 FINANCIALS *

DOLLARS ROUNDED TO THE NEAREST HUNDRED

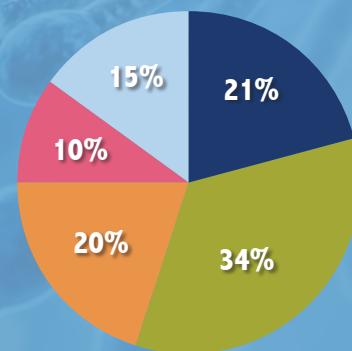
Revenues

GRANT INCOME	269,300
ENDOWMENT DISTRIBUTIONS	613,400
EARNED INCOME	335,700
DONATIONS AND MEMBERSHIP	460,700
SPECIAL EVENTS	220,500
OTHER	41,500
TOTAL	\$1,941,100



Total Expenses

AGING AND SERIOUS ILLNESS	396,500
ETHICS EDUCATION AND CONSULTATION	657,700
EMERGING ISSUES AND SYSTEMS CHANGE	380,200
MANAGEMENT & ADMINISTRATION	192,000
FUNDRAISING	288,000
TOTAL	\$1,914,400



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Contributions received through March 25, 2019. We sincerely regret any errors or omissions.

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Gloria Ramsey

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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

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Sandra Doolin Mellinger

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Paula and Clay Porsch

Andrea and E. Wynn Presson

Charles N. Romero

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.

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WE ARE THANKFUL FOR THE GENEROUS SUPPORT OF DONORS TO THE CENTER FOR PRACTICAL BIOETHICS
FROM JANUARY 1, 2018 – DECEMBER 31, 2018. WE SINCERELY REGRET ANY ERRORS OR OMISSIONS.

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