

## PRACTICAL BIOETHICS TODAY

CELEBRATING OUR
35th ANNIVERSARY



GENETIC ENGINEERING AND THE FUTURE OF HUMANITY

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 may face such choices? Would they be okay with editing for intelligence or personality?

Dinner keynote speaker Jamie Metzl believes these choices and more are not only on the horizon. Many are already happening.

"I urge everyone planning to attend the Annual Dinner to invite younger colleagues and family members to join you," said John Carney, President

JAMIE METZL

and CEO of the Center. "Jamie's keynote will show us how the genetic revolution will transform our healthcare in the short term, how we make babies and the nature of babies in the medium term, and how it will transform our species' evolutionary trajectory long term. This is a unique opportunity to prepare for these massive changes."

Guests will receive a complimentary copies of Jamie's new book, *Hacking Darwin: Genetic Engineering and the Future of Humanity*, scheduled for release April 23.

### ANNUAL DINNER

April 9, 2019

Reception 5:30 pm Dinner and Program 6:45 - 9:00 pm

Marriott Muehlebach Hotel 12<sup>th</sup> & Wyandotte Kansas City, Missouri

### **JAMIE METZL**

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. Currently a senior fellow at the Atlantic Council, he has previously served as a member of the U.S. National Security Council, State Department and Senate Foreign Relations Committee. He was a Human Rights Officer for the United Nations in Cambodia, advised the government of North Korea, and was an election monitor in Afghanistan and the Philippines. The author of five books and a syndicated columnist, Jamie is also an athlete. He has raced in 30 marathons, 13 Ironman triathlons and 12 ultramarathons.

**INSIDE:** Annual Dinner Continued

### **2019 Annual Dinner**





HONORARY
CO-CHAIRS
Wayne and
Julie Carter

Wayne Carter, DVM, PhD, recently stepped down as CEO of BioNexus KC to move to Atlanta, where his wife, Julie Carter, JD, joined St. Mary's Health Care System as vice president of mission services. A veterinarian by training, Wayne led BioNexus KC for more than six years. Julie was previously a mission leader intern at Via Christi Hospital in Manhattan, Kansas.



VISION TO ACTION AWARD James and Lisa Spigarelli

As President and CEO of MRI Global, Jim Spigarelli, PhD, was responsible for all aspects

of managing, operating, and developing the Institute. Jim joined the Center's board in 2011 and served as Board Chair in 2013 and 2014. "After experiencing the death of my daughter from cancer," he said, "the Center's long history of helping families with the most difficult medical decisions became personal."

### **ARTS ENCOUNTER**

Artists are creating custom pieces you can acquire at the dinner.



Robyn Nichols

Silversmith Robyn Nichols' handcrafted jewelry, tableware and sculpture are collected and displayed in worldrenowned museums, including the Smithsonian and Nelson-Atkins. This year, in addition to her signature argentium sterling silver gingko leaf brooch, Robyn is creating a custom piece.



Marn Jensen and Andy Newcom

Marn has been with Hallmark for over 30 years. A mixed-media artist, she often incorporates found or antique objects to add texture and story to her work. Andy has been creating art since his debut as the youngest exhibitor in the Plaza Art Fair. At Hallmark, he has been a Senior Photo Stylist for the past 20 years and enjoys teaching macramé workshops. 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.



### **BOARD MEMBER PROFILE**

### Liza Townsend, JD, MSW

Landon Rowland used to send his daughter Liza articles from the Hastings Center Report, British Medical Journal and JAMA. She devoured them. If the C in biology at Smith College

hadn't discouraged her, she would have applied to medical school.

Liza graduated with a BA in art history, worked in New York City for a brokerage firm and UMB Bank in Kansas City, enrolled in law school at the University of Kansas, married Guy Townsend, and was pregnant with her first child when she passed the bar in 1993.

### **Navigating Healthcare**

She devoted the next 18 years to raising three children and volunteering. During that time, family illnesses necessitated a deep dive into the healthcare system and

sparked a desire to learn what she could do to improve it.

"As a family, we have resources," she said. "But people who lack resources, or meaningful access to resources, I wondered how do they do this? I began to focus on the ways policy might impact more positive interactions with the healthcare system that would lead to better health outcomes."

The MSW she earned from the University of Kansas in 2017 and related practicums enabled Liza to pursue this goal. At reStart, she worked with adults with chronic homelessness, substance abuse and mental health issues. "The clients face paralyzing obstacles," she said, "and yet they press on."

### **Professionalism in Healthcare**

Liza traces a direct line from her practicum at KU Family Medicine to participation on the

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Center's task force to review methods for teaching and evaluating medical students' professional behavior and likelihood to succeed as doctors. At the KU Clinic, she said, "I saw what I thought good and poor healthcare looked like and the impact that communication with medical professionals has on patients and their health."

Liza and her husband Guy Townsend met in middle school. Both grew up in families where giving back to the community was a given. "It's just what you do," she said. Before joining the Center's board of directors in 2017, Liza's volunteer efforts have supported Turning Point, Child Protection Center, Voter Protection Project, ACLU, Nelson-Atkins Museum of Art, Harriman-Jewell Series, Kansas City Ballet, Planned Parenthood Great Plains, American Royal, Pembroke Hill Alumni Executive Board, St. Paul's Episcopal Day School and Smith College Club of Kansas City. In addition to the Center, she currently serves on the board of Fountain Valley School of Colorado.

### **Ethics Committees**

# Helping Patients and Providers Address Conflict and Ambiguity

Say your mom has been in the hospital for days, and things just aren't going well. You disagree with the advice you're getting and, frankly, find it hard to understand.

Or say you're a nurse. A supervisor recently implemented new procedures and you're worried they may be detrimental to patient care.

Large academic medical centers typically have clinical ethicists on staff to work through such issues. Smaller, community-based hospitals, which provide most acute healthcare in the U.S., rely – or should rely – on ethics committees.



Matthew Pjecha and Dr. Terry Rosell presented the first webinar on January 10.

In 1986, in response to ethics committees seeking opportunities to learn from each other, the Center convened the Kansas City Regional Hospital Ethics Committee Consortium. Through the years, the

Consortium published numerous guidelines archived at PracticalBioethics.org.

### **Reimagining Committees**

As times have changed, so have committee needs. Many activities once understood to be their responsibility have migrated to other hospital departments.

"Nevertheless," said Matthew Pjecha, program associate at the Center, "issues that involve customer relations or risk management or quality improvement still often have significant underlying ethical implications."

Recognizing the need to improve the accessibility of education and resources for ethics committees, the Center is offering eight lunch-hour webinars and two half-day workshops.

#### Webinars and Workshops

The first workshop will be held on April 11 featuring Brian Carter, codirector of Children's Mercy Hospital's Certificate in Bioethics, on conducting a family meeting. The next webinar is scheduled for March 14.

For information about these programs, contact Matthew Pjecha at <a href="mailto:mpjecha@PracticalBioethics.org">mpjecha@PracticalBioethics.org</a> or 816-979-1366.

# ¿Algunos de Sus Pacientes Hablan Español? Do Some of Your Patients Speak Spanish?

We now offer our advance care planning materials in Spanish.



#### To Order Online:

www.practicalbioethics.org/ resources/caring-conversations/ order-prints.html

### **Ethics Committees: Save These Dates**

- ✓ March 14 Webinar: Intro to Ethics Committees
- ✓ April 11 Workshop: Conducting a Family Meeting



Harzfeld Building 1111 Main Street, Suite 500 Kansas City, MO 64105-2116

www.PracticalBioethics.org 816.221.1100 1.800.344.3829











# IN MEMORIAM Richard Payne, MD

It was with profound sadness that we announced that our colleague and friend Dr. Richard Payne, 67, died on January 3 from complications related to a recent cancer diagnosis. Richard had just completed his sixth year as the John B. Francis Chair at the Center. A neurologist, he was also an international expert in palliative care, pain management and care near the end of life.

Richard's association with the Center began in the mid-90s, working on projects to improve end-of-life care and designing outreach efforts to engage

clinicians of diverse backgrounds in caring for underserved and disaffected populations.

Richard leaves his wife Terrie Payne, son Richard Jr., daughter Susan Oziogu, their spouses, four beloved grandchildren and many grieving colleagues around the world. A graduate of Yale College and Harvard Medical School and Professor Emeritus of Medicine and Divinity at Duke University Divinity School, you can read more about his remarkable accomplishments at PracticalBioethics.org under "About Us."

### **SAVE THE DATE**

Richard Payne Memorial Service in Kansas City April 10, 2019 at 10 am Community Christian Church 4601 Main St, Kansas City, MO

### **Board of Directors**

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