

PRACTICAL BIOETHICS

Art OF THE Wish

What would you wish for the world? Can you imagine what your grandmother or grandfather might wish?

That's the question two Kansas City artists, Andy Newcom and Marn Jensen, asked older adults across the country. The 50 works of art that they created from those conversations will be exhibited at the Leedy-Voulkos Art Center in the Kansas City Crossroads from March 4 through May 27, 2022.

The idea to create an exhibit based on wishes grew out of Newcom and Jensen's very personal experiences in caring for elderly parents. They spent time with a wide-ranging group of wishers, including an anthropologist, social worker, educator, librarian, musician, inventor, artist, clergy, homemakers, doctors, administrators, nurses, attorneys and military, representing diverse ethnicities, socioeconomic levels, genders, sexual orientations, religions and geography.

The overwhelming response to a private exhibition at Hallmark in 2017 inspired Newcom and Jensen to continue their work. The result is *Art of the Wish*.





"I wish everyone had a good dry martini within reach." — Harriet Mixed media collage, found objects, paper, ink Marn Jensen

"I wish our most vulnerable were cared for." —Lynn Old wire fence, jute string Andy Newcom

An exhibit celebrating stories that matter and wishes that change lives

> "One of the Center's core values," said CEO John Carney, "is to promote and protect the interests of those whose voices have not been heard or heeded. Marn and Andy's works of art and the stories that accompany each piece convey this value in a more impactful way than I have ever experienced. We



"I wish for meaningful connections, it makes one feel validated, it makes one feel whole." —Terri Wood panel, acrylic paint, tinker toys Andy Newcom

knew we had to work with Marn and Andy to make the exhibition accessible to the community.

"Our hope for everyone who experiences *Art of the Wish* is twofold. First, that they come away with a deeper appreciation for the wisdom of people who have lived long lives and the value of human connection. And second, that they turn those feelings into acts of listening, caring and kindness."

You're Invited
Art of the Wish Benefiting the Center for Practical Bioethics
Thursday, May 12, 2022
Choose your session: 5:30 – 7:00 p.m. – Appetizers 7:30 – 9:00 p.m. – Dessert
Leedy-Voulkos Art Center 2012 Baltimore, Kansas City, MO
Tickets & Sponsorships: Starting at \$100 www.PracticalBioethics.org 816-221-1100

Equitable Treatment and Care Ethical AI Initiative Poised to Test Recommendations

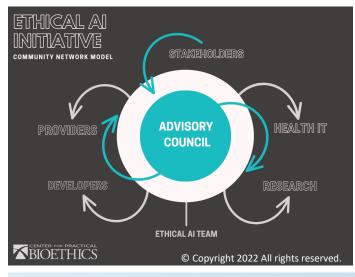
There is broad agreement about the need to address ethical problems in the development and use of artificial intelligence systems in healthcare. The Center for Practical Bioethics is tackling the challenge of how to go about it using a novel approach that's inviting widespread interest and buy-in.

Drawing on community-based participatory methodologies long used in public health promotion and services to improve health outcomes, the Ethical AI Initiative – led by Lindsey Jarrett, PhD, Principal Investigator and Program Director at the Center – is convening leaders primarily in the Kansas City region to provide practical interventions on ethical problems that arise at various stages throughout AI's lifecycle in healthcare.

Community Leadership

By putting community members in leadership and decisionmaking positions, the Initiative works to reduce potential harms due to systemic biases that negatively impact marginalized members of the community.

Initiative stakeholders have tasked themselves with building a framework that requires an educational curriculum, diverse



Remembering Liza

Sarah Rowland Townsend, a member of our Board of Directors, died at her home in Kansas City, Missouri on November 26.

After earning her law degree in 1993, Liza devoted 18 years to raising three children and volunteering in the community. During that time, family illnesses sparked her desire to learn more about what she could do to improve our healthcare system.

She explained, "People who lack resources, or meaningful access to resources, how do they do this? I began to focus on



2. Leverage industry know-how, academic expertise, and community-based local knowledge to design, pilot and disseminate interventions that address these ethical problems and risks.

3. Develop a sustainable model for ongoing development and support of interventions.

partnerships, best practices standards, and validation of tools to address inequities, biases and potential harms, particularly to marginalized communities.

With first and second year funding from the Sunderland Foundation, the Initiative is now poised to implement educational programming and test recommendations identified by collaborators. The Initiative has formal support from BioNexus KC, Children's Mercy Research Institute, Cerner Charitable Foundation, KC Digital Drive and The University of Kansas Health System.

2022 Pilot

In 2022 the Initiative plans to:

- Expand Advisory Council membership to incorporate community members who identify as community advocates and who represent vulnerable populations that regularly utilize healthcare services in their communities; and
- Develop and implement a pilot program with The University of Kansas Health System.

"Overall success of the Initiative depends on interrelationships between and among key stakeholders focused on equitable treatment and care for vulnerable persons in the deployment of AI in healthcare," said Jarrett. "With that in mind, we are always seeking additional community partners, students, researchers and other to help us push this important topic forward."

the ways policy might impact more positive interactions with the healthcare system that would lead to better health outcomes."

In lieu of flowers, Liza's family generously asked that donations be made to the Center. We are humbled and grateful.



BRIAN CARTER, MD Vision to Action Award Goes to Pioneer in Pediatric Palliative Medicine and Ethics

When Brian Carter enrolled in the U.S. Coast Guard Academy, he had hopes of becoming an oceanographer but discovered that only two percent of the class was allowed to pursue that major. Born in San Diego and living in the Netherlands where his father was based in the Navy until he was two, he made the hard choice to leave the Coast Guard and return to Nashville, Tenn., where he spent time as a teenager. It was a choice that ultimately led to neonatology, pediatric palliative care, Children's Mercy Kansas City, and the Center for Practical



Bioethics.

Carter became interested in medicine while majoring in biology on scholarship at David Lipscomb College in Nashville and working part-time as a pharmacy technician. A U.S. Army Health Professions Scholarship enabled him to attend the University of Tennessee College of Medicine in Memphis.

Critical Newborns

"I became enthralled with care for the critically ill newborn," said Carter of his decision to pursue a residency in pediatrics at Fitzsimons Army Medical Center outside of Denver, Colorado, and later a fellowship in Neonatal-Perinatal Medicine at the University of Colorado, where he served on the hospital's inaugural ethics committee.

He was also influenced by personal crises.

"My wife and I experienced a stillbirth and a year later the live birth of my son at 34 weeks," said Carter, "the same gestation as President Kennedy's infant son, Patrick, who died in 1963 with respiratory distress syndrome, invigorating the field of neonatology."

He Wrote the Book

Carter published a paper on ethical and professional conduct issues he observed as a Medical Company Commander in the 1991 Gulf War in Iraq. Commended for meritorious service with a Bronze Star, he resigned his commission in 1996 and joined the faculty of the Medical College of Georgia.

According to Carter, the majority of children who die in ICUs are less than a year of age. His work in pediatric palliative care puts him among a very small group of clinicians in the early 2000s advocating for better care for these children and families.

Carter and Dr. Marcia Levetown published the first textbook on pediatric palliative medicine – *Palliative Care for Infants, Children and Adolescents* – in 2004 during Carter's 13year tenure on the faculty at Vanderbilt University Medical Center.

Coming to Kansas City

In 2005, Carter led the first of three conferences presented by the Kansas City Partnership to Advance Pediatric Palliative Care, organized by the Center to ensure growing commitment to palliative care for children. Carter's talk explored the needs of critically ill children and their families.

In 2012, with his wife Angel having completed her doctorate and their children graduated from high

school, Carter accepted the invitation from Children's Mercy to join its Pediatric Bioethics Center where he serves as co-director for its Certificate in Pediatric Bioethics. He also joined the faculty of the University of Missouri Kansas City School of Medicine in 2012 to work with medical students, and in 2018 became the Sirridge Endowed Professor of Medical Humanities and Bioethics. In 2020 he became the Department Chairman for the Department of Medical Humanities and Bioethics. This year he became the Interim Director of the Children's Mercy Bioethics Center.

Practical Bioethics Leadership

Since coming to Kansas City, Carter has served many times as faculty for the Center for Practical Bioethics' Ethics Committee Consortium, helped to expand development of ethics committee competencies, facilitated collaborations with Children's Mercy, provided testimony and advocacy on ethics issues addressed by the Center, and supported the development of the Center's Ethical Al Initiative. He recently retired after three years serving on the Center's Board of Directors.

A former marathon runner, avid reader and lover of jazz, he and Angel have adopted fly fishing as their most recent hobby. Carter looks forward to continuing to teach, write and speak about perinatal and neonatal ethics.

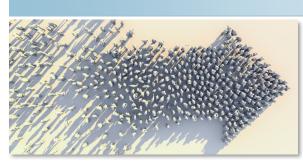
Flanigan Lecture

Talia Goldenberg died at age 23 because her doctors, nurses and support staff failed to listen when Talia, her physician father and mother repeatedly told them that Talia couldn't breathe.

The 15th annual Flanigan Lecture will feature Talia's parents, founders of Talia's Voice, speaking about the importance of listening to

patients and their families. If you don't already subscribe to our monthly *Bioethics Bulletin*, sign up now at the bottom of our home page, <u>PracticalBioethics.org</u>, for details about the lecture.





The Center's John B. Francis Chair, Erika Blacksher, PhD, studies ethical and policy questions raised by health inequalities in the U.S. and the role of civic engagement in advancing health equity and social justice.

Under Dr. Blacksher's leadership in collaboration with a seasoned research team and guided by a 15-member committee of local, regional and national experts in population health sciences, democratic deliberation, intersectionality and health justice, the Center's new project, *Civic Learning, Dialogue and Connection to Advance Health Equity Project – A Deliberative Approach*, is building a democratic deliberative toolkit to convene racially, socioeconomically and geographically diverse Kansans and

Pathways to Health Equity through Civic Engagement

Missourians in a bi-state initiative to learn, discuss and weigh in on pressing population health challenges.

The first phase of this multi-year initiative is focused on building the deliberative toolkit. The toolkit will include:

- a deliberative model designed to address diversity, structural inequities and power imbalances;
- ✓ balanced, inclusive plain language briefing materials and case studies; and
- metrics that gauge knowledge, deliberative and civic gains attributable to the process.

Foundational funding for the project was provided in September 2021 by County Health Rankings & Roadmaps, a program directed by the University of Wisconsin Population Health Institute with support from the Robert Wood Johnson Foundation.

SHORT TAKES

Bioethics Case Studies

Curious about the issues that our clinical ethicists are called upon to help resolve? The Center's recently redesigned website contains one of the nation's most extensive and downloaded libraries of bioethics case studies. Check out all the brand new website features at PracticalBioethics.org.

Sustainers Council

Recurring donors create a reliable source of funding to raise and respond to ethical issues in health and healthcare.

Recurring donors increase their impact by spreading their support over time.

As a recurring donor – along with our deep gratitude – you receive the quarterly Sustainers Council Update newsletter. Join the Sustainers Council now at <u>PracticalBioethics.org/</u> <u>support</u>.



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Living Organ Donor

Many might wonder what motivates a person to donate an organ to a recipient with whom they have no familial or close relationship. Lindsey Jarret's answer is complicated, rooted in her values and the life experiences that shaped them.

Three weeks post-surgery, Lindsey was back at her desk at the Center where she is principal investigator and program director of the Ethical AI (Artificial Intelligence) Initiative, which seeks to identify ethical problems, risks and potential harms associated with the unexamined use of AI in health and healthcare.

Read Lindsey's organ donation story, a path to recovery and meaning, under In the News at <u>PracticalBioethics.org</u>.

Dr. Richard Payne Palliative Care Leadership Award

The Hastings Center in collaboration with the Cunniff-Dixon Foundation announced the first year of a \$25,000 award in honor of our late beloved John B. Francis Chair, Dr. Richard Payne, whom we lost a little over two years ago.

This new award, made every other year, is for physicians who have built palliative care for marginalized and underserved communities.

Nominations were due January 31; the winner will be announced this spring.

