




CENTER FOR PRACTICAL  
BIOETHICS

Guidance at  
the crossroads  
of decision

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The Center  
for Practical  
Bioethics raises  
and responds  
to ethical issues  
in health and  
healthcare.

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# The Organization





*When* Mary Beth Blake was a young lawyer representing the University of Kansas Medical Center in the early 1980s, she often found herself in the hospital rooms of dying patients.

Court orders to permit removal of a ventilator or other life-sustaining intervention were often needed in cases where benefits of the intervention had been exhausted or were creating additional burden. Mary Beth's call to the judge in Wyandotte County, Kansas, prompted a court reporter to be sent to the hospital to take testimony. "There might be some assessment of the patient's wishes," recalls Mary Beth. "Then the judge would issue an order that it was okay to withdraw ventilation."

She concluded, along with her physician colleague Karen Ritchie, that there had to be a better way. And so together with Dr. Hans Uffelmann, Professor of Philosophy and Medicine at the University of Missouri-Kansas City, they co-founded the Center for Practical Bioethics in 1984, **raising and responding to ethical issues in healthcare** by challenging the status quo and addressing the practical needs of patients to improve health outcomes.






## The Issues Multiply

The Center's mission then and now remains the same. However, the issues and avenues for responding to them have changed dramatically. In its first two decades, the work of the Center focused on the goals of its founders and founding executive director Myra Christopher.

- To help establish and train hospital **ethics committees**
- To improve how communities **care for those with terminal illness**
- To ensure through **advance care planning** that the care patients receive matches their wishes





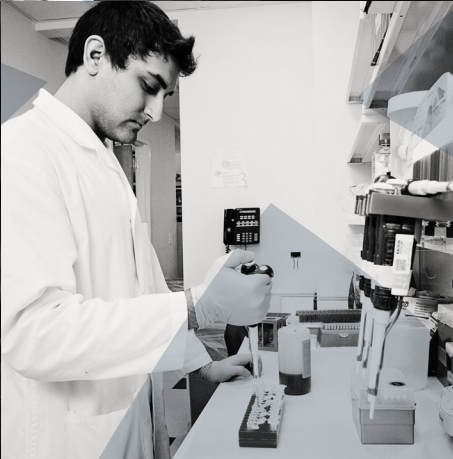
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Over the next decade,  
the Center added  
additional challenges:

- To expand **bioethics education, consultation and resources** for students, healthcare professionals and the public
  - To develop a regional response to the challenges and opportunities presented by the Kansas City region's growing **older adult population**
  - To provide ethical guidance in response to **emergencies and national disasters**
  - To change the way people who live with **chronic pain** are perceived, judged and treated
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And most recently:

- To protect diversity and inclusion while reducing risk for bias in the application of **artificial intelligence** in healthcare
- To expand the Center's longstanding commitment to justice and equity in healthcare through **community-based democratic deliberations**
- To update and provide timely resources for clinicians, administrators and policymakers in responding to ethical dimensions of pandemic





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## People Served

The Center's work impacts diverse constituencies, including patients, families and all kinds of health professionals, from aspiring students to life-long learners in mid- and encore careers. We target colleagues in public health, nonprofit, civic and private sector leadership roles. Ethics issues impact all of us every day. Specific programs often target communities of color, e.g., African Americans and LatinX populations. Though primarily English-speaking, our constituencies include persons of all ages, socioeconomic levels, genders and physical ability. Most recently we have added staff capacity for bilingual (Spanish) services.

Geographically, the Center's activities take place primarily in the Greater Kansas City region and the states of Kansas and Missouri. Due to growing widespread adoption of video conferencing and private broadcasting, the audience for our webinars and other educational resources has grown significantly. In 2020, more than 4,000 reports, guidelines, policy briefs, program resources, audio and video recordings and webinars from the late 1980s to present at PracticalBioethics.org attracted more than 750,000 pageviews. Registrations for several webinars exceeded 700 each.

## Impact on Health and Healthcare

The Center, through its unique model of *practical* bioethics, provides leadership and expertise to address myriad ethical dimensions of care facing individuals in crises to public health issues involving structural and systemic injustice.

# The Need

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## Practical Bioethics

The Center for Practical Bioethics was originally founded as Midwest Bioethics Center in 1984. The incentive to change our name in 2004 to the Center for Practical Bioethics arose for two reasons.

First, as more and more academic medical institutions established bioethics centers based on philosophical and theoretical foundations, the Center's distinction in emphasizing practical applied bioethics grew. A search for synonyms for "practical" yields words like realistic, doable, functional, constructive and serviceable. The Center, unlike nearly all other bioethics organizations, applies the principles and tools of bioethics to real-world, in-the-moment crises and lived experiences of the people we serve.

Second, the new name recognized the Center's increasingly national impact, as exemplified by management from 1999 to 2006 of the Robert Wood Johnson Foundation multi-million dollar, Community-State Partnerships Project to Improve End-of-Life Care.



## A Three-Dimensional Response

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The Center's work encompasses  
three dimensions.

### PERSONAL

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Patients, families and  
clinicians need help  
responding to ethically  
fraught issues in  
medicine, healthcare  
and research  
every day.



## PROFESSIONAL

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Providers, students, clinicians and caregivers need to understand and apply sound ethical principles and decision making to uphold their duties when caring for others and themselves.

## POLICY

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Elected and appointed civic leaders need guidance and resources to apply just and equitable standards for the common good.



# Program Areas

A close-up photograph of a laboratory instrument, likely a liquid handling robot, with four metal tips positioned over a multi-well plate containing numerous small vials. The text "Program Areas" is overlaid in white serif font. The tips are metallic and have black tubes attached. The vials are arranged in rows, and some have labels with barcodes. The background is blurred, showing more of the instrument and the plate.



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# ETHICS EDUCATION AND CONSULTATION

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## Professional Education and Clinical Services

Ethics consultation and support for ethics committees demand much of the Center's time. Ethics consultations aren't planned but require timely and sometimes immediate response. Ethics requires critical skills in listening and the ability to apply abstract concepts in concrete situations. Whether perplexed or in need of a helping hand to sort through a thorny situation, bioethics can ease anxiety and keep everyone focused on what's in the patient's best interest. It matters to us because those who consult know that it matters to them and those they serve.

A recent study found that bioethics education and training in consultations can lead to increased patient satisfaction, improved employee morale, enhanced productivity, conservation of resources, improved accreditation reviews, reduced ethics violations and risk of lawsuits, and sustained corporate integrity, thus safeguarding the organization's future.









## Ethics Direct/Ethics+

The Center enters into formal agreements with providers and health systems to support and improve performance of ethics committees and clinical staff.

**Ethics Direct and Ethics+** agreements address an array of training, resources and other services for organizational ethics committees and individual clinicians, ranging from advance care planning and medical decision-making to policy development, human subjects research/protectations and crisis guidance.

Our **Ethics+** agreements include credentialed ethics consultants working directly with clinicians and staff, demonstrating ethics consultation skills in real time as well as advisory support (e.g., mediation, counseling, moral distress) and participation in grand rounds.



*Word has gotten around that the Center's presence has been invaluable in the ICU, helping staff reframe how they perceive their role and understand the difference they're making, even if they can't change the outcome.*

**SARAH J. HON, DO, FAAN**

Meritas Health Neurology/North Kansas City Hospital  
Kansas City, Missouri



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*Being a part of the Ethics Committee Consortium has helped our hospital grow in our ethical awareness and refine our ethical lens so that staff increasingly identify and address moral distress, feel more empowered to ask ethical questions, and to see ethics as part of the healing environment, rather than a punitive process. It's reassuring to know the ECC is there as we all learn from each other and grow together.*

**REV. DR. CARMEN L. LILE-HENLEY, DMIN, OSL, CT, BCC**  
Chaplaincy Services Manager  
Liberty Hospital



## Kansas City Regional Ethics Committee Consortium (ECC)

The ECC, founded in 1986, is one of the nation's oldest continuously operating groups of its kind. Currently we serve about 40 institutions involving more than 500 individuals. ECC services, including workshops and monthly webinars, are open to all Ethics Direct/ Ethics+ affiliates. ECC members also receive the monthly *Ethics Dispatch*, an online resource offering timely ethical guidance on hot topics. The *Dispatch* is used by many affiliates as a resource for ethics committee agendas and trainings.

## Medical Student Education

*As a dual degree medical student in the Bioethics Master's program, my bioethics training has provided me with the tools to more easily consider the ethical, spiritual, equitable dimensions of patient care as a part of my routine assessment and plan.*

**SIERRA MILLER**

Fourth Year Medical Student  
Kansas City University

The Center has long-term working relationships with area medical schools in training students. Both the **University of Kansas Medical Center** and **Kansas City University** contract with the Center for teaching faculty through lectures, courses and master's program work.

The Center serves in leadership at The University of Kansas Health System, providing oversight of the hospital's clinical ethics consultation service and its ethics committee. Fellowship direction and mentoring are also provided. More than 850 students at Kansas City University campuses (in Kansas City and Joplin, Missouri) benefit from our staff's skills.

The Center also offers **Medical Ethics One-Day Workshops**, enabling participants to customize in-house clinical ethics training to improve ethics skills and enhance an ethics-rich culture.



# Community Education & Engagement

The Center's vision that ethical discourse and action advance the health and dignity of all persons requires community engagement in many and meaningful ways.

## Lectures and Symposia

The Center's lectures and symposia throughout its history have engaged the public and stakeholders in its visionary work. The annual **Flanigan Lecture**, introduced in 1995, honors Sister Rosemary Flanigan, PhD, a former board chair and veteran staff member of 18 years. Her passion for developing and educating hospital ethics committees across the country is renowned. The annual **Berkley Symposium**, launched in 2008, honors Joan Berkley, also a board chair and devoted advocate for advance care planning. The Center also honors its founding executive, Myra Christopher, by the recently established **Christopher Forum**. And, since 1992, the Center's **Annual Event** fundraiser has featured a keynote lecture by a prominent leader in health and healthcare.

Attendance at Center-sponsored programs mushroomed in response to requests during the pandemic and growing demand to reach remote participants. It is now common to see event registrations top 800.

## Workshops

The Center offers more intense and intimate learning experiences through educational workshops that focus on building ethics competencies and skills development for professionals and consumers.

- Half-day sessions for Kansas City Regional Ethics Committee Consortium members
- Advance Care Planning for company employees and consumers
- Accelerated Advance Care Planning for long-term care facilities
- Transportable Physician Orders for Patient Preferences training for community and provider coalitions
- Customized ethics workshops for Ethics Direct and Ethics+ affiliates
- Medical Ethics One-Day workshops for health professionals and organizations

*I am grateful to you,  
all the speakers and  
anyone else involved. It  
was great to have an ethics  
presentation focused solely  
on long-term care. That  
happens so infrequently.*

**SISTER NANCY SURMA, OSF**

VP Mission Integration  
CHI Living Communities,  
Toledo, Ohio







*As a community-based nonprofit, we found ourselves struggling mightily — in the midst of the pandemic — to help a family (single Spanish-speaking mother with two teenaged-daughters) obtain appropriate medical care for her severe heart condition. Our healthcare system is extraordinarily complicated even for those with good health insurance, who are English-speaking and self-reliant. This was not the case in this instance.*

*Center staff helped us think through the related medical and ethical issues on relatively short notice and with a thoughtfulness and compassion that otherwise had not been evident in our efforts to be an ardent advocate for this family facing life-threatening choices and whose needs and medical condition went unheard.*

**BRENT SCHONDELMAYER**

Deputy Director

Local Investment Commission (LINC)

Kansas City, Missouri

## Policy & Consumer Guidance

The Center responds to calls for help daily. They come from patients and family members at the bedside not sure what to do in a healthcare crisis. From organizations struggling to navigate healthcare needs for their clients. And from policymakers seeking background and guidance on delicate ethical matters to consider in formulating protocols, standards, executive orders, regulations and legislation.

This time-consuming work reflects our commitment to promote and protect the interests of those whose voices have not been heard or heeded, to education and to the equitable and just delivery of healthcare.



## Educational Resources in Bioethics

Thousands of students and other users rely on our archived resources annually. More than 4,000 reports, guidelines, policy briefs, case studies and audio/video recordings of interviews from the late 1980s to present are freely available. Recent additions include more than 50 webinars to our video collection. Our pageviews exceed more than three quarters of a million annually, with robust growth every year. We routinely receive organizational requests for permission to reuse and repurpose these resources.

# ADVANCE CARE PLANNING

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Building on its legacy work in advance care planning, the Center's national involvement in end-of-life care emphasizes our growing commitment to diverse communities' participation and the need to respond effectively to emergent high stress situations in medical decision making, as was evident during the height of the pandemic.

The need is great and growing. A recent (2020) study of 9,000 participants (published in the Journal of Palliative Medicine) found that, while nearly 90% reported awareness of advance care planning and considered it important, less than 40% had named a proxy or completed a written document. Lower participation rates among minority communities can be attributed to structural racism, longstanding distrust of the healthcare system and cultural barriers. The Center's noteworthy accomplishments working with African American faith communities has contributed to the field in numerous ways, resulting in a major initiative now underway with Duke University and significant resource development for local congregations throughout the country.

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*Thanks to the Center for the opportunity to participate in this very valuable and informative conversation. These are hard decisions and even harder conversations for families. Thanks for providing the information and guidance.*

**PEGGY L. JOHNSON**

Executive Director

Wichita Medical Research  
& Education Foundation



## Caring Conversations® Community Education

The first edition of the Center’s Caring Conversations® advance care planning workbook in 2001 set the stage for millions distributed over the next two decades. Electronic versions are now routinely downloaded by consumers or purchased in bulk by providers and distributed by the Center at workshops in the community. In 2010, the Center introduced the opportunity for companies to provide advance care planning workshops, personal consultation and advocacy as an employee benefit. Virtual Caring Conversations® workshops are now open to everyone online.

## Transportable Physician Orders for Patient Preferences (TPOPP)

TPOPP is the Kansas/Missouri version of POLST (Physician Orders for Life-Sustaining Treatment). POLST is a voluntary national program that seeks to align treatment plans with the goals and values of seriously ill patients living with life-limiting illness. The Kansas/Missouri POLST initiative, sponsored by the Center, is the country’s only bi-state initiative. The Center trains providers at various stages of development of TPOPP, requiring extensive coordination among and between providers and across care settings.

*No other organization has been more effective than the Center at unifying healthcare professionals across the state in advocating for the patient’s right to decide what medical care they want and don’t want.*

**PATRICK WHITE, MD, HMDC, FACP, FAAHPM**

Washington University School of Medicine  
and BJC Home Care  
St. Louis, Missouri

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## EMERGING ISSUES AND SYSTEMS CHANGE

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Issues emerge in health and healthcare all the time, while the need for change in systems of organizing and delivering care persists throughout American society. The Center works proactively to shine light and respond to these issues by:

- Using the tools of ethics based on principles of philosophy
- Seizing opportunities to advance awareness of issues and causes
- Bringing diverse, inclusive, multi-disciplinary groups together to work collaboratively
- Creating, curating and disseminating resources

*The importance of having an organization firmly focused on the moral and ethical implications and trade-offs for our work can't be overstated. KC Digital Drive's work centers on the social impact of emerging technology. During the pandemic, information was rapidly changing. The Center provides hands-on expertise in navigating the tradeoffs between the need to move quickly and decisively without sacrificing an underlying commitment to equity and justice. The Center's participation in the regional vaccine workgroup and assistance in developing a local vulnerability index were key assets in our work.*

**AARON DEACON**

Managing Director

KC Digital Drive

## Emerging Issues

### COVID-19

In March 2020, the Center completely reoriented programmatic resources to focus on the ethical issues arising from the coronavirus pandemic. Over the next 12 months, this pivot translated into:

- More than 50 educational webinars offered to thousands of attendees
- Collaboration with more than 25 local, regional and national entities to advocate for embedding ethical principles into pandemic policies and plans
- Responding to dozens of media requests for ethics guidance and analyses on crisis standards, treatment protocols and equitable vaccine allocation

Another pandemic is only a matter of time. The Center continues this work building on lessons learned with emphasis on equity and justice.



## Artificial Intelligence in Healthcare

The positive and negative implications of AI in healthcare pose incredible promise and massive risk. Potential harms resulting from implicit bias will influence access to care, treatment and health outcomes.

The Center launched the **Ethical AI Project** in collaboration with leading healthcare organizations regionally in 2019. The goal to develop recommendations and best practices for improving adherence to an ethics framework in the development, dissemination and use of AI systems will be met by engaging diverse leaders in a community-based participatory research model.



## Systems Change

## Democratic Deliberation and Population Health

Deliberative engagement has been increasingly used over the past two decades to bring informed public perspectives into policy debates. The approach has been shown to increase knowledge, impact reasoning and demonstrate value, particularly among members of ethnically diverse groups and those with high school education.

Recent design and implementation of deliberative engagements for NIH studies proved helpful in public deliberations on vaccine distribution. Research on questions of responsibility and justice raised by health inequalities and democratic deliberation have become increasingly important in addressing public health concerns about the value of science. Population health ethics and civic engagement through research, strategic alliances, and creating a foundation for a community-based “health and opportunity for all” will remain central to the Center’s work in the coming years.

## Chronic Pain

Living with chronic pain extracts personal tolls unlike other conditions, so much so that the risk of suicide is up to four times greater for individuals. For more than a decade through PAINS-KC, the Center has supported and sustained community engagement efforts to give voice to citizen leaders as they work to educate, raise awareness and advocate to change the way chronic pain is perceived, judged and treated.

“ I had not been heard before. I doubted myself, and my depression kept getting worse. But in PAINS-KC, I’m heard, believed, loved and respected. I don’t feel like I have to hide my emotions. All of this together impacts my pain level and intensity positively. I am grateful for PAINS-KC.

Citizen Leader  
PAINS-KC

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*AI has tremendous potential to improve the quality and efficiency of healthcare. Reluctance to use AI could pose harm by avoiding these benefits. However, AI in healthcare is still emergent and includes unique risks. These include the potential to introduce or amplify bias and undetectable errors in algorithms introduced by flaws in source data that's used to train the system. The Ethical AI initiative provides a venue to discuss both the risks and benefits of AI and to identify potential safeguards to seek appropriate balance.*

**MARK HOFFMAN, PHD**

Chief Research Information Officer  
Children's Mercy Research Institute  
Children's Mercy Kansas City

# Evaluation & Impact

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The Center's logic model captures quantitative data for program services and community initiatives, as permitted by patient private protections. We also use qualitative data and process measures to report on performance, goal attainment and critical evaluation. For example:

- To measure the impact of webinars, we survey participants periodically and retrospectively to assess perceived and actual skill development.
- To measure the impact of Caring Conversations® workshops, we seek feedback and contact information from participants for follow up. These efforts assist in improving program offerings over time.
- Goals directed at cultural change take time and expense. One evaluation effort conducted by the Center evaluated improvements in end-of-life services that looked back 10 years. We rely heavily on social science research and participate with colleagues in these areas serving as co-authors and principal investigators.



Despite challenges facing Center staff engaged in changing health outcomes over time, the efficacy of our programs and services is supported by normative and theoretical study and, more and more, by research methodologies that employ social science techniques and more sophisticated frameworks, such as by observing practice and studying provider networks and practitioner clusters, as well as other mixed methods beyond standardized clinical trials. For example:

- The beneficial impact of **Clinical Ethics Consultation** on length of stay, resolving conflicts and family and provider satisfaction has been demonstrated in studies reported by JAMA (2003), BMC Medical Ethics (2014), and Critical Care Medicine (2018).
- **Advance Care Planning** studies by The Pew Charitable Trusts (2015) and Stanford University (2018) show that end-of-life conversations with non-clinical workers bring patient satisfaction and lower costs.
- **Democratic Deliberations** in New York City on the equitable distribution of COVID-19 vaccines found broad consensus on priority factors, which were incorporated into the City's update of its vaccination effort with a focus on equity.
- The problem of bias in **Artificial Intelligence** algorithms used to predict outcomes was documented by Pro Publica in 2016. Ethical implications for AI in healthcare are the subject on ongoing exploration in numerous publications.

# Our Team

**John G. Carney, MEd**, became the Center's second President and CEO in December 2011, after serving as Vice President from 2004 to 2010. John devoted his early career to the development of hospice and palliative care throughout the Midwest, with policy and advocacy work in aging, advanced illness and advance care planning at the state and national association levels. John holds an undergraduate degree in philosophy from Newman University in Wichita, Kansas and a Master's from Wichita State University.

**Tarris Rosell, DMin, PhD**, was named as the Rosemary Flanigan Chair at the Center in 2009. He provides ethics consultation for The University of Kansas Health System, where he co-chairs the Ethics Committee and directs the Ethics Consultation Service and the Clendening Summer Fellowship program. He is also a Professor of Pastoral Theology at Central Baptist Theological Seminary in Shawnee, Kansas. Dr. Rosell earned a PhD in Pastoral Theology from Colgate-Rochester Divinity School and a PhD in Ethics and Society from Vanderbilt University, followed by a fellowship at Vanderbilt in Clinical Ethics.

**Erika Blacksher, PhD**, appointed the fourth John B. Francis Chair at the Center in September 2020, 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. Her current work focuses on questions raised by mortality trends in low-education white people and related issues. She holds master's and doctoral degrees from the University of Virginia's bioethics program. Prior to joining the Center, Dr. Blacksher was a tenured Associate Professor and Director of Undergraduate Studies at the University of Washington in Seattle, Washington.

**Ryan Pferdehirt, D. Bioethics, HEC-C**, Director of Membership and Ethics Education, joined the Center in 2019 after serving as the Department Chair and Bioethicist for MultiCare Health System in Seattle/Tacoma, Washington. In addition to directing the clinical ethics consultation service and conducting hundreds of ethics consultations, he served on or chaired multiple hospital ethics committees and IRBs, and he taught at the University of Puget Sound in the Religious Studies and Bioethics Department. Dr. Pferdehirt received his undergraduate degree from the University of Pittsburgh, master's from Creighton University and doctorate from Loyola University in Chicago.



**Polo Camacho, PhD**, Program Manager and Health Ethics Education Promoter, manages Transportable Physician Orders for Patient Preferences (TPOPP), the Ethical AI Project and Ethics Committee Consortium and works with healthcare organizations to promote the Center's health ethics education services. He holds a PhD in Philosophy from the University of Kansas.

**Cindy Leyland, BCPA**, joined the Center in 2005 and was named Vice President of Operations and Fund Development in 2020. She oversees creation, implementation and management of administrative, financial and operational systems, as well as resource development. She also leads the PAINS-KC Citizen Leaders group. She is a graduate of Benedictine College's graduate MBA program.

**Jan Evans, CPA**, Controller and Finance Officer, is responsible for all facets of the Center's financial operations. She joined the Center in 2011 and holds a B.A. in Business Education from Avila University and an MBA from Rockhurst University.

**Trudi Galblum, MPS**, Director of Marketing and Communications, has helped the Center to develop strategy and implement tactics to build awareness and philanthropic support, including grantwriting, since 2013. She holds a Master of Policy Sciences degree from the University of Maryland, Baltimore County, and a B.A. in English from the University of Maryland, College Park.

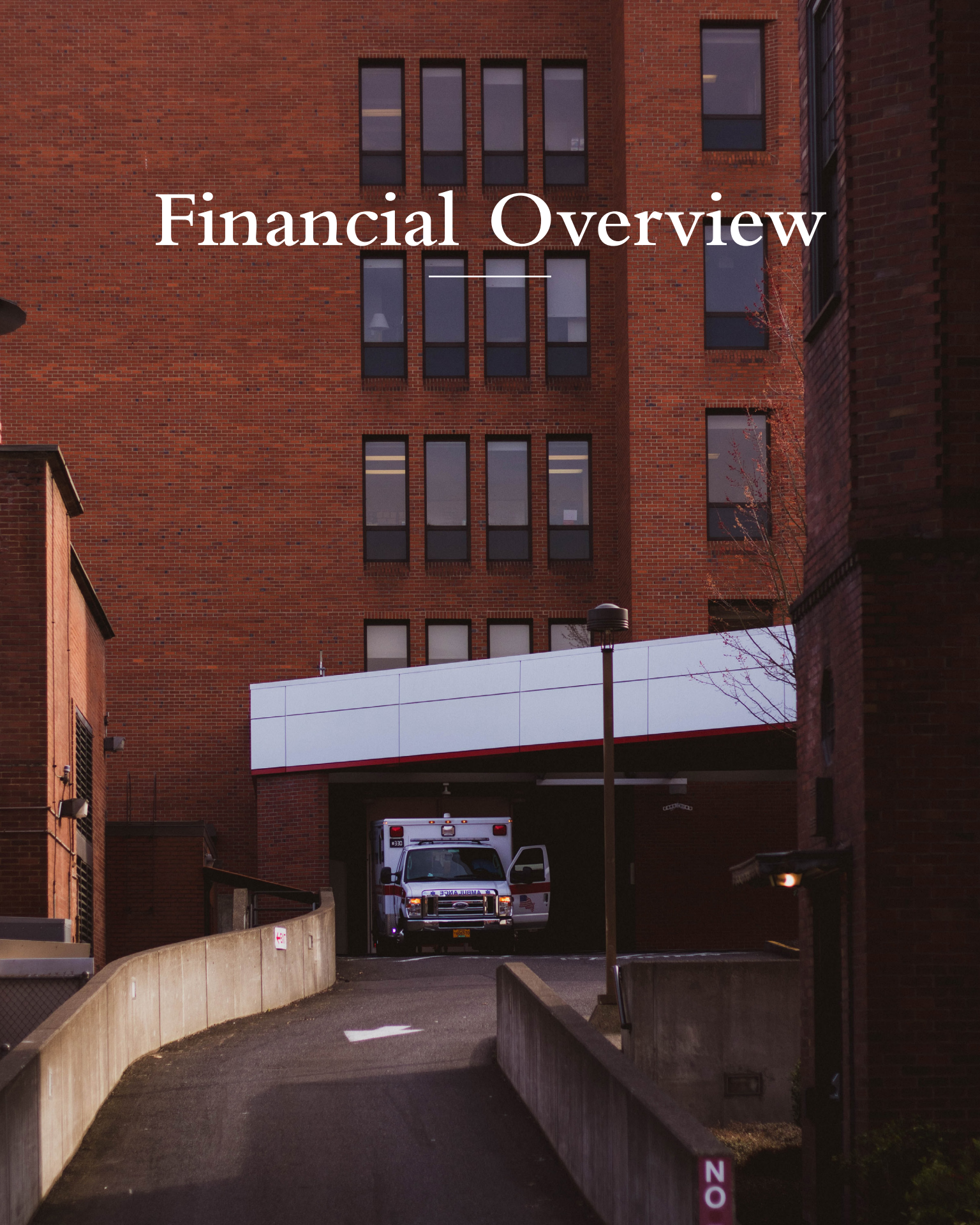
**Monica Delles**, Administrative and Communications Manager, joined the Center in 2016. She graduated with honors from Christopher Newport University with a B.A. in English.

**Quet Sledge**, Operations and Data Management Assistant, maintains and updates customer relationship management systems and databases and provides clerical/administrative support.



# Financial Overview

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Since its founding in 1984, the Center has committed to professional integrity in the conduct of its business and in its relationships with all those with whom it works. As a freestanding, independent, community-based nonprofit corporation, the Center strives to preserve and maintain its autonomy and independence at all times and in all respects.

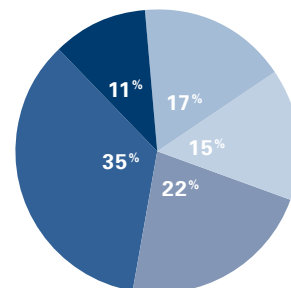
An engaged and knowledgeable Board of Directors sets the strategic vision and oversees the mission of the organization, relying on skilled, competent professional staff in execution of its goals. Those goals incorporate financial discipline and integrity to support the financial needs required to serve our stakeholders. The Center's balanced approach to revenue generation, including earned income, promises future sustainability for the organization.

From the many perplexing issues in healthcare, we strategically choose where best to focus our limited resources. That focus is represented in fiscally responsible expense allocations, including reasonable Fundraising and General Administration in alignment with nonprofit standards.

More information on recent financial and program performance is available at [PracticalBioethics.org](http://PracticalBioethics.org).

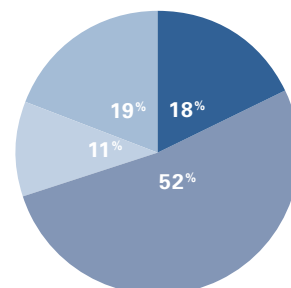
## 2020 REVENUES

- Grant Income
- Endowment Distributions and Earnings
- Earned Income
- Donations and Membership\*\*
- Special Events



## 2020 EXPENSES

- Advance Care Planning
- Ethics Education and Consultation
- Emerging Issues and Systems Change
- Fundraising and General Administration



### REVENUES (IN THOUSANDS)

Grant Income	248.00
Endowment Distributions and Earnings	215.52
Earned Income	311.46
Donations and Membership**	505.15
Special Events	166.01
<b>Total</b>	<b>1,446.14</b>

### EXPENSES (IN THOUSANDS)

Advance Care Planning	242.95
Ethics Education and Consultation	713.00
Emerging Issues and Systems Change	155.67
Fundraising & General Admin.	258.10
<b>Total</b>	<b>1,369.71</b>



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**[PracticalBioethics.org](http://PracticalBioethics.org)**