3rd Annual
Paul M. Schyve, MD
Center for Bioethics Conference
Family Matters/Families Matter:
Ethical Considerations in Patient Decision Making

Sponsored by:
THE PAUL M. SCHYVE, MD
CENTER FOR BIOETHICS

UNIVERSITY OF ROCHESTER
SCHOOL OF NURSING

THE DEPARTMENT OF
HEALTH HUMANITIES & BIOETHICS

In Collaboration with:

Alden March Bioethics Institute at
Albany Medical College

Center For Bioethics & Humanities at
SUNY Upstate Medical University

Friday & Saturday
May 2-3, 2025

Saunders Research Building & School of Nursing
University of Rochester

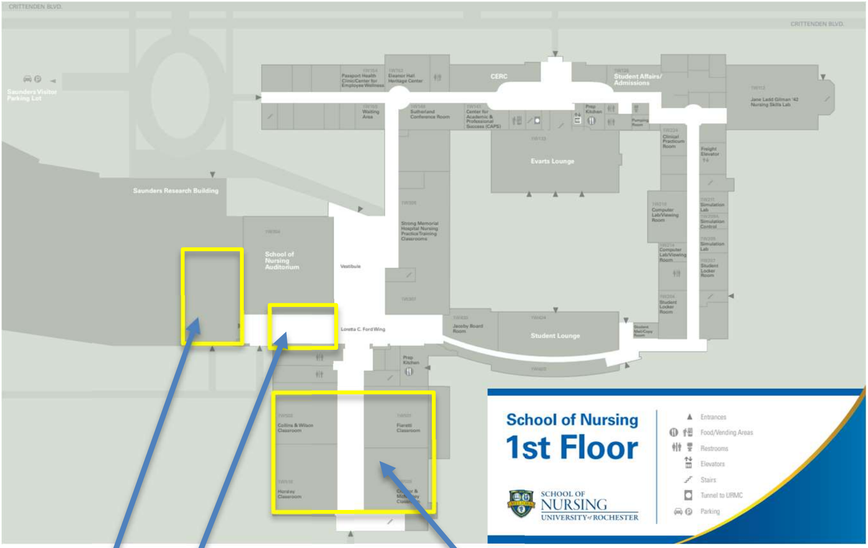
About the Conference:

This regional conference is dedicated to advancing education, collaboration, and dialogue on ethical issues central to healthcare and clinical practice. One of our primary objectives is to provide interdisciplinary learning opportunities that address a wide range of ethical challenges relevant to today's healthcare environment.

Through focused workshops and facilitated discussions, we aim to engage professionals across the spectrum of healthcare disciplines—fostering active learning, shared perspectives, and practical application. These sessions are designed not only to enhance ethical awareness, but also to promote meaningful engagement with complex, real-world issues.

Serving participants from across New York State and the surrounding region, this conference also seeks to strengthen connections among institutions, improve community outreach, and support a broader conversation about the role of ethics in clinical care, policy development, and public health.

Map of Events:



Saunder's Research Building Atrium -Poster Session

Helen Wood Hall Auditorium – Keynote & Panel

School of Nursing Classrooms
1st & 4th Floors – Workshops

3rd Annual Paul M. Schyve, MD Center for Bioethics Conference

Friday, May 2, 2025. 8:30 a.m. – 4:45 p.m.

8:30 - 9:00 a.m. Registration, Poster set-up, Continental Breakfast

9:00 - 9:15 a.m.
LAINIE ROSS, MD, PhD:
Director, Paul M. Schyve MD Center for Bioethics –
WELCOME AND INTRODUCTION
Helen Wood Hall Auditorium

9:15 - 10:15 a.m.
AMY CARUSO BROWN, MD, MSc, MSCS
SUNY Upstate Medical University
KEYNOTE SEMINAR
Family-Centered Care in the Time of Workplace Violence:
The Role of Clinical Ethics in Rebuilding Trust
Helen Wood Hall Auditorium

10:15 – 10:25 a.m. Coffee Break

10:30 a.m. - 12:00 p.m.
Workshop Sessions

Navigating Adolescent Refusal of Life-Saving Reproductive Health Treatments **Presenters:** Liz Bowen, PhD Tricia Huguelet, MD Edward McArdle, JD, HEC-C Karen Teelin, MD, MSED 1W-510	**Dammit Jim, I'm a Doctor, not a Televangelist: Why Should Clinicians Talk About Religion in the First Place?** **Presenter:** Kevin Boyd, M.Div. 4W-507	**Family Interests as Individual Interests: Why Incorporating Third Party Risks into Informed Consent is Required for Autonomous Choice** **Presenter:** Stephanie Solomon Cargill, PhD, MSPH 1W-502
Behavior Contracts as Reponses to Disruptive Behavior in Hospitals: A Knowledge-Sharing Workshop **Presenters:** Rachel Fabi, PhD, HEC-C L. Syd Johnson, PhD, HEC-C 1W-509	**Understanding Ethical Dilemmas in Family Caregiving: A Case-Based Approach** **Presenter:** Nicholas Mercado, DrPH, MS, MCHES, HEC-C 4W-506	

12:00 – 1:30 p.m.
Lunch & Poster Viewing

1:30 – 3:00 p.m.
Workshop Sessions

Advanced Communication Training (ACT) – Navigating Challenging Conversations **Presenter:** Thomas Carroll, MD, PhD 1W-509	**Bestowed Worth and the Meaningfulness of Continuing Treatments for Children with Neurologic Devastation or the End-of-Life** **Presenters:** Daniel Kim, PhD, MPH Xiang Yu, PhD, HEC-C 1W-510	**The Process Prior to the Signature: Informed Consent and Models of Medical Decision Making** **Presenter:** Ashley Labodda, MA 4W-506
Am I My Sibling's Keeper? **Presenter:** Lainie Ross, MD, PhD 4W-508	**Ethics Consult: Navigating Conflicts Between Patient & Parental Rights** **Presenter:** L. Syd Johnson, PhD Sarah Reckess, JD 4W-507	**When is it Withdrawing Therapy and When is it Suicide?** **Presenter:** Chris Reynolds, MD, HEC-C 1W-502

3:00 – 3:10 p.m. *Coffee Break*

3:15 – 4:30 p.m.
PANEL DISCUSSION
Two Hats, One Heart:
Clinicians' Stories About Parental Illness & Medical Decision-Making
JANE GREENLAW, RN, MS, JD, University of Rochester
DAVID KAUFMAN, MD, University of Rochester
BERNARD SUSSMAN, MD, University of Rochester
Moderators: Bryanna Moore, PhD, HEC-C & Erik Larsen, PhD
Helen Wood Hall Auditorium

4:30 – 4:45 p.m.
LAINIE ROSS, MD, PhD - *CLOSING REMARKS & POSTER AWARDS*
Helen Wood Hall Auditorium

3^{rd} Annual Paul M. Schyve, MD Center for Bioethics Conference

Saturday, May 3, 2025. 8:30 a.m. – 12:00 p.m.

8:30 - 9:00 a.m. REGISTRATION, Continental Breakfast

9:00 - 9:05 a.m.
BRYANNA MOORE, PhD, HEC-C - *WELCOME AND INTRODUCTION*
Helen Wood Hall Auditorium

9:05 - 9:45 a.m.
AMY CARUSO BROWN, MD, MSc, MSCS, SUNY Upstate Medical University
Do Reasons Matter?
Helen Wood Hall Auditorium

9:45 – 9:55 a.m. Coffee Break

9:55 - 10:55 a.m.
Breakout Discussions

10:55 – 11:05 a.m. Coffee Break

11:05 - 11:50 a.m.
Debrief Discussion
Helen Wood Hall Auditorium

11:50 a.m. - 12:00 p.m.
LAINIE ROSS, MD, PhD - *CLOSING REMARKS*
Helen Wood Hall Auditorium

10:30 a.m. - 12:00 p.m.

Navigating Adolescent Refusal of Life-Saving Reproductive Health Treatments

Presenters:
Liz Bowen
Tricia Huguelet
Edward McArdle
Karen Teelin
Location: 1W-510

What should a provider do when an adolescent refuses a treatment that might save their life? What if the proposed treatment is in the realm of reproductive health care, which demands heightened attention to autonomy and confidentiality? This interactive workshop will invite participants to work through a case in which a 16-year-old patient refused treatment for an ectopic pregnancy, a potentially life-threatening condition, raising difficult questions about whether a clinician should ever override the treatment decisions of a minor patient with legal authority to make her own decisions or breach medical confidentiality by notifying her parents. While most states give minors with decision-making capacity the legal right to make their own reproductive health decisions, are there circumstances when clinicians should treat a minor's refusal differently from an adult's refusal? If so, how can ethical and professional duties to ensure the health and well-being of adolescent patients be reconciled with the obligation to respect their reproductive autonomy and privacy?

This interactive workshop will ask participants to consider these questions from three perspectives—medical, legal, and ethical—guided by practitioners in each area. Two specialists in adolescent medicine and pediatric gynecology and obstetrics, respectively, will discuss the clinical dimensions of the case that inform ethical decision-making. An attorney and clinical ethics consultant will contextualize the case in relation to New York state's legal protections for adolescent confidentiality in reproductive health care, as well as the complex legal landscape nationwide. Finally, a health humanities scholar and clinical ethics consultant will identify relevant ethical frameworks for balancing the realities of adolescent decision-making in high-stakes, high-stress situations with the strong duty to protect adolescents' reproductive autonomy. Participants will be invited to think through the case in conversation with the presenters and introduce examples and insights from their own practices.

10:30 a.m. - 12:00 p.m.

Dammit Jim, I'm a Doctor, Not a Televangelist: Why Should Clinicians Talk About Religion in the First Place?

Presenter:
Kevin Boyd
Location: 4W-507

Nearly fifty years after George Engel and John Romano published their seminal paper in the journal *Science* advocating for what we now call the biopsychosocial model, the inclusion of certain relevant pieces of that model are still routinely disregarded in the regular charting practices of clinicians throughout medical systems. We are now more keenly aware of various social determinants of health (SDOH), as evidenced by their inclusion in electronic health records like EPIC. However, the Social History portion of many of the H&P notes found on inpatients is little more than a record of their history of smoking and alcohol intake. In this session we will explore the significant role that religion plays in the clinical decision-making processes of patients and families, and why a basic understanding of that can be an important component of working towards collaborative decision-making. Given that religion is often a fraught topic we will explore strategies for how to talk about the relationship between a patient's religious worldview and their medical decisions. My hope it to demonstrate ways in which we might hold productive, process driven discussions about how decisions are made and avoid potential disagreement or argument about content driven theological or epistemological claims.

The session will make use of additional role-play and creative writing experiences to further demonstrate ways that health care team members can productively interact with those who hold to belief systems that are different, sometimes even at odds with their own personal views. This session will rely upon active engagement and participation from its members.

10:30 a.m. - 12:00 p.m.

Family Interests as Individual Interests: Why Incorporating Third Party Risks Into Informed Consent is Required for Autonomous Choice

Presenter:
Stephanie Solomon Cargill
Location: 1W-502

Bioethics and medical communities widely recognize that patients care about how their decisions impact their family members and close contacts, yet the full implications of this fact are rarely borne out. While we continue to incorporate shared decision-making into the process of *choosing* based on provided information, the nature of that provided information has not been challenged on the same basis. The risks and concerns disclosed in the consent form and process remain focused on those that impact the individual, such as medical risks of allergic reactions or financial concerns around compensation for injury or payment. Except in the notable exception of potential risks to embryos or fetuses, the required elements of consent do not require disclosure of the potential risks or concerns that directly impact a patient's familiars. Just as decision-making is rarely confined to the individual patient, the risks and concerns surrounding treatment or research are rarely confined to the individual. I will argue that a "reasonable person" would both want and deserve to know what these risks are to make an informed decision. As a result, I will argue that reasonably known direct risks to identifiable close contacts of patients/researchers should be disclosed in the consent form. This disclosure is importantly NOT being justified by the duty of healthcare providers or researchers to protect third parties (which remains under debate), but rather is justified by the noncontroversial duty to provide adequate information for a patient or participant to make a reasonable choice in the healthcare context. I will demonstrate this obligation with two examples: risks of gene therapy to close contacts, and risks of observational research in shared settings.

10:30 a.m. - 12:00 p.m.

Behavior Contracts as Reponses to Disruptive Behavior in Hospitals: A Knowledge-Sharing Workshop

Presenters:
Rachel Fabi
L. Syd Johnson
Location: 1W-509

Workplace violence in healthcare settings has been on the rise. One contributing factor to workplace violence and subsequent provider burnout is a troubling upward trend in aggressive and abusive behaviors in hospitals, exhibited by patients and their families, as well as by hospital staff. A common mechanism for addressing these behaviors is the behavior contract, also known as a behavioral agreement, used in clinical contexts in response to patient or family behaviors that the care team deems disruptive, offensive, threatening, or otherwise unacceptable. Behavior contracts typically list the behaviors that the team finds unacceptable and propose consequences that may be invoked if the behaviors continue.

This workshop will explore the ethical, legal, and clinical implications of the use of in-patient behavior contracts through an institutional case study. We will examine empirical evidence for efficacy, concerns about unjust implementation and violations of patient moral and legal rights, and the ethical and practical pitfalls of behavior contracts. We will then invite participants into a moderated discussion that will provide an opportunity for the audience to share their own experiences with behavior contracts and brainstorm potential alternative approaches to protecting hospital staff from workplace violence and verbal abuse.

10:30 a.m. - 12:00 p.m.

Understanding Ethical Dilemmas in Family Caregiving: A Case-Based Approach

Presenter:
Nicholas Mercado
Location: 4W-506

Former First Lady of the United States Rosalynn Carter said, “There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers”. Family caregivers are a highly utilized resource in the healthcare system. Approximately 53 million people provide family care in the United States. Modern clinical ethics focuses on patient-centered care and decision-making which, at times, excludes the perspectives and needs of the family caregiver. However, there are several ethical concerns that are unique to people who are, or are deciding to become, family caregivers. These ethical issues include the absence of boundaries, informed decision-making, relational autonomy, care power dynamics, and relations with the professional care sectors. There are several practical responses to the ethical issues in family caregiving that health professionals can consider when faced with these dilemmas. This 75-minute workshop will include a brief didactic presentation framing the session and small group clinical case discussions that center on the ethical issues in family caregiving.

1:30 - 3:00 p.m.
Am I My Sibling's Keeper?

Presenter:
Lainie Ross
Location: 4W-508

The aims of the workshop are: 1) to explore the limits of the "best interest" standard, the moral boundaries of parental decision-making, and the factors that influence the need for the child's assent in pediatric decision-making; and 2) to explore whether we have obligations to our adult siblings, and how to balance responsibilities to our childhood families versus our families of choice.

In this workshop, we will discuss the ethical issues raised by pediatric siblings and adult siblings. In the first part, the presenter will begin with a short didactic about what it means for parents to act in their child's "best interest". We will next explore how parents should act when what is best for one child is not best for his or her sibling? Specifically, we will examine how parents ought to make health decisions for one child when the decision may have a negative impact on the health interests or other interests of their siblings. In small groups, we will then consider several cases involving pediatric siblings. The second part will begin with a short didactic by the presenter about moral relationships and moral obligations between adult siblings. In small groups, we will then explore several cases involving adult siblings.

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1:30 – 3:00 p.m.

Advanced Communication Training (ACT) – Navigating Challenging Conversations

Presenter:
Thomas Carroll
Location: 1W-509

This workshop will begin with a didactic presentation (~20 min) of the MVP communication model and how it can be utilized to help navigate ethically challenging conversations, including when speaking with surrogate decision makers, families, etc. We will spend the remainder of the workshop, with the help of a patient-actor, demonstrating and practicing communication skills using a variety of ethically challenging clinical scenarios.

1:30 – 3:00 p.m.

Bestowed Worth and the Meaningfulness of Continuing Treatment for Children with Neurologic Devastation or the End-of-Life

Presenters:
Daniel Kim
Xiang Yu
Location: 1W-510

When parents request life-sustaining treatments for children with neurologic devastation or at the end of life, the typical ethics advice for clinicians is to accommodate. The duty in pediatrics is to serve the patient's best interests, but in such cases, it is often unclear what interests, if any, the child has: the child just lies there, uncomprehending, suffering no pain, and neither horrified nor depressed by their plight. Unable to assess the child's interests, the tendency is to let parents continue treatments if the associated pain can be palliated. But then, how are these vulnerable children not being used as means to satisfy others' interests? How, if at all, can clinicians experience their participation in the situation as worthwhile, meaningful?

Two articles in major journals have recently proposed a "relational potential standard" to make sense of the accommodation, arguing that the parent-child relationship has an "inherent value" that clinicians have an obligation to preserve. But the proposal either assumes that the relationship is in the child's interests or bites the bullet on keeping the child alive for the relationship's sake. Either way, it seems problematic.

We therefore propose an alternative explanation by appealing to Nicholas Wolterstorff's notion of "bestowed worth." We argue that a certain mode of parental "love as attachment" can impart a distinctive worth that inheres in the child. The worth is the child's, and the duty is to respect the worth of the child's life as an end and not a means. Building on this insight, we propose a "meaningfulness standard" for clinician decision making: would prolonging this child's life (1) serve their interests or capacities or (2) be properly expressive of the worth of their life? We consider its practical implications and the meaningfulness of the clinician's obligations within a shared decision-making model.

1:30 – 3:00 p.m.

The Process Prior to the Signature: Informed Consent and Models of Medical Decision Making

Presenter:
Ashley Labodda
Location: 4W-506

This was a preliminary study aiming to determine how different models of patient and family medical decision-making appear in patient-family-medical professional dynamics in the United States, specifically in plan of care and informed consent conversations. With an understanding that, in the United States, the standard model of medical decision-making is patient-centered and individualist, this research and corresponding study considered two additional models practiced globally that call for more familial involvement and communal styles of decision making, familialist and Confucian models. With the understanding that many patient populations come from various cultural and geographical backgrounds, a secondary aim of this study was to discern to what extent medical professionals are open to family involvement and collective styles of medical decision-making in their practice.

In addition to a philosophical analysis of these three models, qualitative interviews of medical professionals from different specialties (N = 5) were conducted to gather information on their experiences in their practices with medical decision-making. They provided responses to a set list of questions about informed consent and family involvement in medical decision-making as well as their thoughts on various case studies. These responses were analyzed for content that aligned with the philosophical commitments and practices within each model. As anticipated, the results showed that the medical professionals held strong commitments to individualism; however, several endorsed philosophical commitments and practices of the other two models potentially indicating a less rigid commitment to individualism. Several professionals spoke to the benefit to patient outcomes due to family involvement and shared decision-making. While acknowledging the small sample population, I argue these preliminary results support current work on developing a place and role for family in medical decision-making within the United States medical system. As such, further work aims to expand the sample size of the study in the hopes of more significant results.

1:30 – 3:00 p.m.

Ethics Consult:
Navigating Conflicts Between Patient & Parental Rights

Presenters:
L. Syd Johnson
Sarah Reckess
Location: 4W-507

Goals of care conflicts can arise between parents and child patients in settings where children are developmentally mature enough to understand and have strong preferences about their treatment options. This session concerns an ethics consult involving Ms. S, a 13 year old girl with end-stage Spinal Muscular Atrophy who was admitted to our children's hospital with respiratory distress, and failure to thrive, and who experienced a cardiac arrest believed to have been partly stress-induced. Her parents, non-English speaking conservative Muslim immigrants, were focused on prolonging her life. They resisted including Ms. S in any discussions of her care, believing it upset and frightened her. They asked the care team not to disclose any information to her. A 13 year old would typically be included in medical discussions, and her assent or dissent would be sought. The care team experienced moral distress and was concerned that Ms. S was nearing the end of her life without understanding her condition and without being able to meaningfully participate in treatment decisions.

This session will address and include opportunities for attendee discussion of several key questions and issues:

- Is it ethical to withhold information and actively exclude older children from decision making?
- Legal rights of patients and families regarding disclosure, and the right to be informed, or not informed
- Parental obligations to act in the child's best interests, and considerations of the patient's quality of life and the burdens of treatment
- When should treatment of a child be considered objectionably coercive?
- Sensitively managing spiritual and cultural conflicts in settings where parental beliefs conflict with the core principles of medical ethics
- Balancing patient autonomy and family interests
- How to effectively utilize interdisciplinary teams to address complex social, ethical, and medical conflicts

1:30 – 3:00 p.m.

When is it Withdrawing Therapy and When is it Suicide?

Presenter:
Chris Reynolds
Location: 1W-502

Most clinical ethicists argue that withholding and withdrawing life-sustaining therapies are ethically equivalent and that withdrawing a life-sustaining intervention is not an act of suicide. The understanding is that a patient does not die from the act of removing the life-prolonging intervention (e.g., the ventilator), the patient dies of the disease (e.g., respiratory failure).

However, some medical technologies "feel" like they become part of who the patient is. This is especially true for front-line clinicians with less experience or exposure to ethical theory. This workshop will unpack a few recent cases where at least one care team member expressed concern that withdrawing a medical intervention was morally blameworthy. When a clinician *feels* like s/he/they have committed a morally blameworthy act, how should other care team members respond? The first case involves a patient hospitalized for two years. Hemiparetic, bedbound with a chronic metal (non-cuffed) tracheostomy following a stormy COVID hospitalization in 2021, this 49 year old man was stable but unable to be discharged because he needed frequent suctioning. Depressed (not suicidal), he eventually convinced his children. Sunday: his quality of life was unacceptable, comfortable death was his only important goal. Monday, the patient was angry he was still alive; he removed his tracheostomy. It was reinserted shortly thereafter at his request but then he removed it again 15 minutes after reinsertion, insisting, "I don't want it anymore. I'm going." He died ~30 hours later with pharmacologic therapy to palliate symptoms. Some care team members were upset: without removing his trach, he'd still be clinically stable.

We'll discuss how this case is similar or different from other cases like turning off a pacemaker or a left ventricular assist device (LVAD). Are these acts suicide, or medical aid in dying? How should ethicists respond to concerned front-line clinicians, rationally and/or emotionally?

POSTERS

Presenter(s) listed BOLD

1.	*Survey on Moral Distress Among Registered Dietitians* **Bethany Barney, RD, CCTD,** Margie Hodges Shaw, JD, PhD, MA, HEC-C Department of Health Humanities and Bioethics, University of Rochester, Rochester, NY
2.	*Capstone Project: A "what would you like to know about surgery" children's booklet* **Jan Gao, MS Student** Department of Health Humanities and Bioethics, University of Rochester, Rochester, NY
3.	*Moral Distress Among Gender-Affirming Care Providers for Transgender and Gender-Diverse Youth* Ahona Shirin[1], MPSH; Inthava Muneath[2], BA; Carley Daly[3], BA; Maya Daniello[4]; Alaap Rag[4]; **Laura Stamm, PhD**[1] [1]Department of Medicine, University of Rochester, Rochester, NY, USA [2]University at Buffalo, The State University of New York, Buffalo, NY, USA [3]University of Rochester, Rochester, NY, USA [4]School of Medicine and Dentistry, University of Rochester, Rochester, NY, USA
4.	*Miscarriage, Microaggressions, and Mistrust: An Illustrative Case Study of Black Maternal Care in the Emergency Department* **Isabelle Thenor-Louis, M.S.** Center for Bioethics and Humanities, SUNY Upstate Medical University, Syracuse, NY
5.	*Answers We Don't Want to Questions We Shouldn't Ask: Parental Decision-Making in the Absence of a Decision to be Made* **Stephanie Tom-Brophy, DO[1];** Mubasshira M. Khan, MBBS[1]; Rachel G. Clarke, MD[1,2]; Edward McArdle, JD[2]; Amy E. Caruso Brown, MD.[1,2] [1]Department of Pediatrics, SUNY Upstate Medical University, Syracuse, NY [2] Center for Bioethics and Humanities, SUNY Upstate Medical University, Syracuse, NY.