In 2019, the Treuman Katz Center for Pediatric Bioethics sponsored its 15th annual conference on Defining Moments in Pediatric Bioethics: Future Insights from Past Controversies. There were a record 272 participants from around the U.S. in attendance. Doug Diekema, Aaron Wightman and Hannah Lewis co-edited a supplement to Pediatrics in August 2020 which included papers written by the annual conference presenters.

Our clinical bioethics consultation service began a partnership with Seattle Children’s Center for Diversity and Health Equity to collaborate on responding to consultation requests for concerns about equitable care and how best to address these concerns within the organization. This partnership supplements our existing clinical ethics, nursing ethics, and research ethics consultation services, and is a model for how our Center collaborates with other important and ethically relevant initiatives at Seattle Children’s.

This Year in Review illustrates the publications, presentations, grants, and leadership of our faculty and staff. It also highlights the research of Stephanie Kraft, a faculty member who is deepening our understanding of a core concept in ethics: respect. In this report you will read about her interviews with research participants from diverse communities who describe what it means to be respected in a clinical study. The knowledge learned by Ms. Kraft and her research team can impact how researchers engage with participants in many contexts.

I hope that you enjoy reading about the efforts of the faculty, staff, and fellows to achieve our mission.

Benjamin S. Wilfond, Director
Treuman Katz Center for Pediatric Bioethics
MISSION: Improve the well-being of children, their families and communities by facilitating deliberation about ethical issues in pediatric healthcare and research

GENERATING SCHOLARSHIP about emerging issues in pediatric bioethics

ENGAGING with professional organizations, government agencies and community groups to improve policies and practices related to critical bioethics issues

EDUCATING our bioethics fellows, the Seattle Children’s community, and the broader professional and public communities about the unique issues in pediatric bioethics

ADVISING families, clinicians, and leaders at Seattle Children’s who face challenging bioethics issues

MISSION: Improve the well-being of children, their families and communities by facilitating deliberation about ethical issues in pediatric healthcare and research

FACULTY
Emily Berkman, MD, MA
Jori Bogetz, MD
Jonna Clark, MD, MA
Douglas Diekema, MD, MPH
Nanibaa’ Garrison, PhD
Katherine Gentry, MD, MA
Ross Hays, MD
Stephanie Kraft, JD
Mithya Lewis-Newby, MD, MPH
Douglas Opel, MD, MPH
Amy Trowbridge, MD
Elliott Weiss, MD, MSME
Aaron Wightman, MD, MA
Benjamin Wilfond, MD
Joon-Ho Yu, PhD, MPH

AFFILIATES
Denise Dudzinski, PhD, MTS
Kristi Klee, DNP, MSN, MA
Leah Kroon, MN, MA
Jeff Sconyers, JD

STAFF
Devan Duenas, MA
Nicolas Dundas, MPH
Hannah Lewis, BA
Katie Porter, JD, MPH
Jennifer Scott, MHA, PMP
Kelly Shipman, MS
Sharee Smith, BA
Heather Spielvogle, PhD
Diana Wells, BA
Scholarship

**39 presentations**, including **11** at national and international meetings, plus others at Seattle Children’s, the University of Washington and in the community.

**57 publications**, including **43** peer-reviewed papers and professional organizational statements and **14** commentaries, editorials, and book chapters.

**SELECTED PUBLICATIONS:**


PRESENTATION HIGHLIGHTS

Elliott Weiss:
Strategies to Improve Surrogate Decision-Making in Intensive Care
American Society for Bioethics and Humanities Annual Meeting, Pittsburgh, PA; October 2019.

Aaron Wightman:
Delivery of Care for the Disabled and Developmentally Delayed
American Society of Pediatric Nephrology Annual Meeting, Pediatric Academic Society, Baltimore, MD; April 2019

Benjamin Wilfond:
The Value of Genetic Information: Patients Matter
American Society for Bioethics and Humanities Annual Meeting, Pittsburgh, PA; October 2019.

National Leadership

SELECTED HIGHLIGHTS:

• Jori Bogetz, Co-Author/Course Designer, Talking About Serious Illness, EQIPP MOC Course, American Academy of Pediatrics

• Doug Diekema, Director at Large, American Society of Bioethics and Humanities

• Nanibaa Garrison, Advisory Committee to the Director’s Working Group on Diversity, National Institutes of Health

• Doug Opel, Committee on Bioethics, American Academy of Pediatrics

• Kathryn Porter, Chair, Clinical Research Ethics Consultation Affinity Group, American Society for Bioethics & Humanities

• Aaron Wightman, Ethics Committee, United Network for Organ Sharing

• Benjamin Wilfond, Planning Committee, An Examination of Emerging Issues in Biomedical Research Workshop, National Academy of Medicine
Funded Research Projects

7 new projects (16 submitted)

SELECTED HIGHLIGHTS:

• Jori Bogetz, *Development of a Communication Tool for Relationship-Building Between Clinicians and Parents of Children with Severe Neurological Impairment*
  CRSP — Center for Clinical and Translational Research, Seattle Children’s Research Institute

• Nanibaa’ Garrison, *Center on American Indian and Alaska Native Genomic Research*
  Supplement — National Human Genome Research Institute

• Doug Opel, *King County Child Health Improvement Partnership*
  Best Starts for Kids

• Benjamin Wilfond, *‘What it Means for our Family’ — Video Decision Supports for Parents Considering Pediatric Home Mechanical Ventilation’*
  National Palliative Care Research Center

Grant Applications 2015 – 2019
Consultation

Our clinical ethics consultants completed 51 consults in 2019.

- Most common topics:
  treatment decisions (16), informed consent/parental permission (9), benefit/harm assessment (8), limitation of life sustaining treatment (5), disclosure of results/information (3), other — moral distress (3), end of life care (2)

- Most frequent requesting services:
  inpatient medicine (22), outpatient medicine (11), intensive care (8), non-Children’s (4), surgery (3), hematology/oncology (2)

Our research ethics consultants completed 12 consults in 2019.

- Most common topics:
  benefit/harm assessment (4), conflict of interest (2), confidentiality/privacy (1), data & safety monitoring (1), informed consent/parental permission (1), legal/regulatory (1), other — deception (1), recruitment/incentives (1)

- Requesting services include:
  Institutional Review Board, Rheumatology; Seattle Children’s Hospital and Research Institute.
  Harborview Injury Prevention & Research Center, Epidemiology, Neurosurgery, Occupational Therapy, Pathology, Psychiatry & Behavioral Sciences; University of Washington.
  Cystic Fibrosis Foundation, Bethesda, MD
  Johns Hopkins University, Baltimore, MD
  Pacific Northwest University of Health Sciences, Yakima, WA
  PATH, Seattle, WA
  St. Luke’s Health Systems, Boise, ID
In 2019, 272 clinicians and scholars from the U.S. and worldwide attended *Defining Moments in Pediatric Bioethics: Future Insights from Past Controversies*

**QUESTIONS DISCUSSED AT THE CONFERENCE INCLUDED:**
- Are children with disabilities less deserving of life-saving treatments?
- Can a teen refuse life-sustaining interventions?
- How do we assess suffering in an infant?
- Should disability affect candidacy for a transplant?
Bioethics Fellows

2019 – present
Kate MacDuffie, PhD, is a licensed clinical psychologist in her first year of the bioethics fellowship program. Her research focuses on the ethical implications of emerging technologies in neuroscience.

2018 – present
Kim Sawyer, MD, is a pediatric palliative care physician in her second year of the bioethics fellowship program. Her research focuses on evaluating bioethics education and training.

2018 – present
Jenny Kingsley, MD, is a pediatric critical care medicine fellow who is concurrently in her second year of the bioethics fellowship program. Her research focuses on death and dying in the critical care setting.
Demonstrating ‘Respect for Persons’ in Clinical Research: Asking diverse voices to define respectful behaviors

Respect is critical in expanding research to underrepresented populations
Recognizing the importance of respect for research participants is a necessary first step for academic medical centers to become trustworthy enterprises. Though foundational from an ethics perspective, researchers and academic medical centers have not always prioritized respecting participants in a meaningful way. Current research practices designed to protect the rights of research participants are a direct reaction to unethical activities in the past, many of which were directed at people of color and people from marginalized communities. Despite current regulatory protections, ongoing inequities and structural racism in healthcare and research systems contribute to a lack of diversity in clinical research, which contributes to inequities in the implementation and generalizability of research findings.

In order to expand research to include underrepresented groups, it is imperative that researchers think critically about how they respect participants. To date, efforts to demonstrate respect in research have predominantly focused on autonomy, each individual’s right to make their own informed decision about whether or not to participate in a study. Yet respect has broader though less well understood implications including participants’ needs, interests and values. Feeling respected is inherently subjective and likely to vary across individuals, communities and cultures. It is therefore necessary to understand what behaviors demonstrate respect from the perspective of a wide range of potential participants.

Listening to research participants: Respect in their own words
Treuman Katz faculty member Stephanie Kraft, a lawyer and bioethicist, wants to shed light on what respect means from the research participant’s point-of-view. Kraft explains that experiencing respect is critically important given the nature of the relationship between participant and researcher. “There is a heightened obligation to show respect in the clinical research setting because researchers are asking people to take on risks and burdens for the benefit of others,” says Kraft.

To address the gap in understanding what respect means to research participants, Kraft and her team conducted interviews with a diverse group of people who were participating in a research study implementing genomics testing-based services. Interviews focused on actions perceived as conveying respect, or a lack thereof, in research. Kraft’s team identified four key domains that researchers should attend to in order to demonstrate respect.

1. Personal study team interactions
2. Study communication processes
3. Inclusion
4. Consent and authorization
Interactions with members of the study team were perceived as respectful, particularly when recruitment staff explained the study thoroughly, checked for understanding and provided the opportunity to answer questions. Kindness, patience, and interest in participant perspectives are also vital. Kraft’s earlier work has demonstrated that many individuals make decisions about participating in research before they even read the consent form, further highlighting the critical role played by research staff in recruitment and the importance of respectful interactions throughout the process.

Offering multiple ways for participants to get in touch with the study team, having a designated point of contact to answer questions, and sharing study results were ways that the study’s communication processes could demonstrate respect. Taking steps to ensure that language, disabilities, and location were not barriers to participation were seen as inclusive and respectful practices.

Finally, the consent process is important, and participants see thoroughness, neutral descriptions, privacy protections, time to make a decision, and choices about level of participation as respectful. Kraft’s newest project will augment these findings by using a survey-based consensus-building technique to identify approaches to demonstrating respect that are most important to patients who would potentially be eligible for, but are not currently enrolled in, genomics research.

“ If we are asking patients and participants to place their trust in clinicians and researchers, we first and foremost must make sure we are holding up our end of the bargain and are deserving of the trust that we are asking people to place in us.”

Implications for the future
Kraft says that the impact of the research teams’ interactions with participants illustrates the importance of building a culture of respect among members of the team and identifying opportunities to strengthen and support their innate abilities. To understand how to leverage this observation, Kraft, along with her co-PI Elliott Weiss and Research Scientist Katie Porter, are currently conducting interviews with research coordinators about how they seek to build relationships with patients and their families in the recruitment and consent processes.

With regard to the longer-term implications of her work, Kraft believes that strategies to effectively demonstrate respect must become a focus at the system and institutional levels with an eye toward ensuring equity, inclusivity, and positive health outcomes for all people.