2018 was an eventful year at the Treuman Katz Center for Pediatric Bioethics because of significant organizational realignment and a number of personnel changes. The organizational realignment involved the expansion of the Division of Bioethics to become the Division of Bioethics and Palliative Care. The clinical palliative care service, under the medical leadership of Ross Hays, MD, integrated with the clinical bioethics consult service, under the medical leadership of Doug Opel, MD, MPH, to create the Palliative Care and Clinical Bioethics Program within Seattle Children’s. Arika Patneaude, MSW, who had been the palliative care supervisor, became the manager of the Palliative Care and Clinical Bioethics Program.

With this realignment, the Center’s partnership with the Department of Pediatrics evolved and the following faculty joined the Center:

- **Emily Berkman**, MD, MA, completed fellowships in pediatric critical care and bioethics. She joined the Division of Critical Care Medicine and the Center as an assistant professor. Her research focuses on the ethical implications of international patient programs.

- **Jori Bogetz**, MD, was recruited from UCSF to join the Division of Bioethics and Palliative Care and the Center as an acting assistant professor. Dr. Bogetz is a palliative care clinician whose research focuses on the healthcare experiences of families who have children with profound neurodevelopmental impairments.

- **Amy Trowbridge**, MD, was a hospitalist and palliative care clinician in the Division of Hospital Medicine and joined the Division of Bioethics and Palliative Care and the Center as an acting assistant professor. Dr. Trowbridge received an Academic Enrichment Fund award to study the experience of families with limited English proficiency during multidisciplinary care conferences.

Other personnel changes included Doug Opel, MD, becoming the associate director of the Center and the planned retirement of Kathy Fennell, RN, MPH, MBA, who served as our administrative leader for 12 years. With Kathy Fennell’s retirement, Jenn Scott, MHA, was hired as the manager of the Treuman Katz Center and administrator for the Division of Bioethics and Palliative Care. Heather Spielvogle, PhD, was hired as research staff supervisor. Kelly Shipman, MS, and Nic Dundas, MPH, were hired as research staff. Diana Wells joined our administrative team as program coordinator.

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

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
Abby Rosenberg, MD, MS, MA
Seema Shah, JD
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

Krysta Barton, PhD, MPH
Devan Duenas, MA
Nicolas Dundas, MPH
Kathy Fennell, RN, MPH, MBA
Ellen Kuwana, MS
Katie Porter, JD, MPH
Jennifer Scott, MHA
Kelly Shipman, MS
Sharee Smith, BA
Heather Spielvogle, PhD
Diana Wells, BA

seattlechildrens.org/bioethics 3
Scholarship

**51 presentations**, including **16** at national and international meetings, plus others at Seattle Children’s, the University of Washington and in the community.

**94 publications**, including **79** peer-reviewed papers and professional organizational statements and **15** commentaries, editorials and letters.

**SELECTED PUBLICATIONS:**


**PRESENTATION HIGHLIGHTS**

Krysta Barton
*Re-Imaging Ethical Genetic Research With Indigenous People: Lessons About Community Engagement and Pathways Forward*


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Nanibaa’ Garrison
*Silent Genomes: Indigenous-Led Initiatives on Addressing Equity in Genomics Health Care and Research*

American Society of Human Genetics, San Diego, CA. October 2018.

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Stephanie Kraft
*Technology, Informed Consent, and Genomic Research: Powering Scale and Adaptability*

Publications 2014 - 2018

PRESENTATION HIGHLIGHTS

Douglas Opel
*The Good News About Vaccine Communication in the Fake News Era: Evidence-Based Interventions to Address Vaccine Hesitancy*


Aaron Wightman
*Responding to Parental Requests for Life-Sustaining Treatment Utilizing a Relational Potential Standard*


Benjamin Wilfond
*Linguistic Challenges in Studying Research on Medical Practice: The Investigational Misconception*


National Leadership

SELECTION HIGHLIGHTS:

- **Douglas Diekema**, Director at Large, American Society of Bioethics & Humanities
- **Nanibaa' Garrison**, Advisory Committee to the Director’s Working Group on Diversity, National Institutes of Health
- **Douglas Opel**, Co-chair, Bioethics Interest Group, Pediatric Academic Societies
- **Kathryn Porter**, Chair, Clinical Research Ethics Consultation Affinity Group, American Society for Bioethics & Humanities
- **Abby Rosenberg**, Program Committee Co-Chair, Annual Assembly Scientific Meeting 2020, American Academy of Hospice and Palliative Medicine
- **Benjamin Wilfond**, Editorial Committee, Hastings Center Report

This should actually be 23 (green) and 46 (blue) for 2015, as fact checked in the 2015 Year in Review.
Funded Research Projects

15 new projects (20 submitted, 2 pending)

SELECTED HIGHLIGHTS:

- **Nanibaa' Garrison**, *Community-driven Deliberations to Inform a Navajo Genetics Research Policy Supplement* - National Human Genome Research Institute

- **Stephanie Kraft**, *Respect for Persons in the Genomics Research Enrollment Process: Incorporating Diverse Experiences and Attitudes*  
  K01 – National Human Genome Research Institute

- **Doug Opel**, *Evaluation of the Presumptively Initiating Vaccines and Optimizing Talk with Motivational Interviewing (PIVOT with MI Intervention)*  
  R01 – National Institute of Child Health & Human Development

- **Abby Rosenberg**, *The Promoting Resilience in Stress Management (PRISM) Intervention: A Multi-Site Randomized Controlled Trial for Adolescents and Young Adults Receiving Hematopoietic Cell Transplantation*  
  R01 – National Cancer Institute

- **Abby Rosenberg**, *The Promoting Resilience in Stress Management (PRISM) Intervention: A Multi-Site Randomized Controlled Trial for Adolescents and Young Adults with Advanced Cancer*  
  R01 – National Cancer Institute

- **Amy Trowbridge**, *High Stakes Communication for Patients and Families with Low English Proficiency*  
  Academic Enrichment Fund, Center for Clinical and Translational Research

- **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 2014 - 2018
Consultation

Our **clinical** ethics consultants completed **44 consults** in 2018.

- Most common topics: treatment decisions (14), informed consent/parental permission (8), disclosure of results/information (5), limitation of life-sustaining treatment (5), benefit/harm assessment (3), resource allocation (3)

- Most frequent requesting services: PICU (5), hematology/oncology (4), pediatrics (3), infectious disease (2), medically complex child (2), NICU (4), nursing (2), palliative care (2), pastoral care (2), psychiatry and behavioral medicine unit (2)

Our **research** ethics consultants completed **15 consults** in 2018.

- Most common topics: community considerations (3), benefit/harm assessment (2), confidentiality/privacy (2), conflict of interest (2), data & safety monitoring (2), informed consent/parental permission (2)

- Requesting services include: Seattle Children’s Hospital and Research Institute: Biochemical Genetics, Center for Integrative Brain Research, Center for Global Infection Disease Research, Center for Developmental Biology and Regenerative Medicine. University of Washington: Harborview Injury Prevention & Research Center (2), Epidemiology, Family Medicine, Neurology, Urology.

14th Annual Conference

**When Cultures Clash:**
Navigating Ethical Disagreements Related to Diversity

14th Annual Pediatric Bioethics Conference

In 2018, **265 clinicians and scholars** from the U.S. and worldwide attended *When Cultures Clash: Navigating Ethical Disagreements Related to Diversity.*

**QUESTIONS DISCUSSED AT THE CONFERENCE INCLUDED:**

- What factors should be considered in deciding whether to respect a parent’s refusal to consent to important medical treatment?

- When is it appropriate to withhold a diagnosis from a child or adolescent at the parent’s request?

- Should a family’s request to see a healthcare provider of a different gender or race be respected?

- Should cultural practices that cause small amounts of pain or harm to children be tolerated or reported as child abuse?
**Bioethics Fellows**

**2016-2018 Emily Berkman, MD, MA**, completed the bioethics fellowship, concurrently with a fellowship in pediatric critical care. She joined the Division of Critical Care Medicine and the Division of Bioethics and Palliative Care, University of Washington School of Medicine as an assistant professor.

**2016-2018 Jessica Jeavons, JD, MA**, completed the bioethics fellowship and is the Director for Policy and Planning for adult mental health at the Department of Health and Mental Hygiene, New York City.

**2016-2018 Jeanne Krick, MD, MA**, completed the bioethics fellowship and is an attending neonatologist and Deputy Chair of the Ethics Board at Madigan Army Medical Center, Tacoma, WA.
2017– present Kim Sawyer, MD, is a pediatric palliative care physician in her first year of the bioethics fellowship program. Her research focuses on evaluating bioethics education and training.

2017– present Jenny Kingsley, MD, is a pediatric critical care medicine fellow who is concurrently in her first year of the bioethics fellowship program. Her research focuses on death and dying in the critical care setting.
Spotlight on Research

Developing a Communication Tool for Parents of Children with Severe Neurological Impairment: Connecting Clinicians and Parents on a Deeper Level

Clinicians often view fixing problems as their job, but this is not easy in the case of medically complex children, especially those with severe neurological impairment. Because of their underlying central nervous system disease, these children have problems with feeding, respiratory infections and mobility. They require a lot of care from their families, presenting challenges and stressors as parents implement extensive, technology-based medical regimens at home. Treating these children is also challenging for clinicians who may feel a lack of control over medical outcomes that is at odds with their professional identity as “fixers.” They often miss the mark in meeting important needs for the children and their families related to spirituality and values. This mismatch of priorities can lead parents to report poor communication and even conflict with clinicians during times in which they must make critical decisions for their children.

Treuman Katz Center faculty and palliative care physician Jori Bogetz wants to change this through her research, which focuses on training clinicians to better connect with parents in order to meet not just the medical needs of the patient, but the family’s quality of life needs as well. During her fellowship at Stanford, she discovered that communication skills are critical to meeting the needs of families and she learned which aspects of communication are most important and what clinicians miss in their training. She found that being able to “sit” with unsolvable problems, listen to people tell their stories, and talk about quality of life considerations are the important details absent from many clinical conversations and that these skills are fundamental to building effective therapeutic

Jori Bogetz’s research focuses on enhancing communication and building clinician-family relationships to improve care for children with severe neurological impairment.
relationships with families. Relationship-building is the key ingredient that allows families to feel that they are part of making decisions, that their child’s life is valued and that they have made good medical choices for their child.

“How do we change the questions that we ask to facilitate quick, efficient and effective downloading of the family’s values and perspectives?”
— Jori Bogetz

In her current research, Bogetz is exploring both parent and clinician perspectives on relationship-building. For example, she asks parents how they know when they have developed a relationship with a clinician or when they trust that a clinician really understands their perspective. The data gathered will be used to develop strategies and create a relationship-building communication tool to be used by both clinicians and parents of children when they are facing challenging decisions. Bogetz’s work will help us learn how enhancing communication improves care for children with severe neurological impairments, their families and other children with complex chronic conditions.

Clinician ability to connect and communicate with families is important, as many of these children don’t have the ability to speak due to their illness. Bogetz has been able to get to know the children by seeing them through their parents’ eyes. She envisions a future in which hospital systems are designed to elicit parents’ voices, values and priorities and to provide a picture of who the child is beyond the hospital bed. Despite their limitations, these children have very meaningful lives and caring for them and their families can be a joyful and meaningful experience for clinicians.

PRIMARY COLLABORATORS
• Abby Rosenberg, Benjamin Wilfond, Seattle Children’s
• Julie Hauer, Boston Children’s Hospital

FUNDING
• Clinical Research Scholars Program, Center for Clinical and Translational Research, Seattle Children’s