OUR MISSION
To improve the lives of children and their families by enhancing the ethical deliberations in pediatric healthcare and research.

Benjamin S. Wilfond, Director, Treuman Katz Center for Pediatric Bioethics

The Treuman Katz Center for Pediatric Bioethics had another productive year in 2017. Highlights include:

**Stephanie Kraft** was appointed acting instructor in the Division of Bioethics and joined the Center as faculty. Her research focuses on understanding patients’ perspective about the role of respect and how to convey this during research recruitment in diverse communities.

**Joon-Ho Yu** was appointed research assistant professor in the Division of Genetic Medicine and joined the Center as faculty. His research focuses on partnering with community organizations to support their engagement with genomics researchers.

With support from Seattle Children’s Guild Association, the Nursing Bioethics Liaison Program was established in 2015. The leaders of this program, **Kristi Klee**, DNP, MSN, RN, CPN, and **Leah Kroon**, MN, RN, CPHON, completed our bioethics fellowship. The Nursing Bioethics Liaison Program is now supported by the Department of Nursing and 12 bioethics liaisons have been trained who work with their respective units providing education and access to consults for challenging cases.

The Center was training six clinical fellows in 2017, the most ever. Research interests range from ethical implications of puberty suppression for transgender adolescents to the ethical appropriateness of interventions for sugar-sweetened beverages.

*The information in the 2017 Year in Review provides updated information about the efforts of our faculty, fellows and staff to improve the lives of children and their families.*
Faculty News

- **Douglas Diekema** was elected as a Hastings Center Fellow.
- **Abby Rosenberg** received the Early Career Investigator Award from American Academy of Hospice and Palliative Medicine.
Scholarship

55 presentations including 27 at national and international meetings

79 publications including 54 peer-reviewed papers/organizational statements and 15 commentaries, editorials and letters

SELECTED PUBLICATIONS:


Publications 2013 - 2017

PRESENTATION HIGHLIGHTS

Douglas Opel
Reject or Retain? A Debate on Non-medical Exemptions in Childhood Vaccine Policy

Seema Shah
Ethical Considerations for Zika Virus Human Challenge Trials

Elliott Weiss
Personalized Decision-Making in Pediatrics: Who Should Be at the Center of Medical Decisions?

National Leadership

SELECTED HIGHLIGHTS:

- Douglas Diekema, National Conference and Exhibition Planning Committee (Executive Committee Member), American Academy of Pediatrics
- Nanibaa' Garrison, Social Issues Committee, American Society of Human Genetics
- Abby Rosenberg, Bioethics Steering Committee, Children’s Oncology Group
- Aaron Wightman, Chair, Bioethics Subcommittee, American Society of Pediatric Nephrology
- Benjamin Wilfond, Standing Committee on Ethics, Canadian Institutes for Health Research
- Joon-Ho Yu, Planning Committee, Ethical, Legal and Social Implications (ELSI) Congress, National Human Genomic Research Institute
Funded Research Projects

12 new projects (21 submitted)

SELECTED HIGHLIGHTS:

• Nanibaa’ Garrison, *Perspectives and Attitudes on Genetic Research in the Navajo Nation* Center for Clinical and Translational Research Pediatric Pilot Fund

• Doug Opel, *Adolescent Immunization Learning Collaborative* Public Health Seattle & King County

• Abby Rosenberg, *Resilience Outcomes Among Adolescents and Young Adults With Advanced Cancer* American Cancer Society Research Scholar Grant

• Seema Shah, *A New Ethical and Regulatory Approach for the Use of Human Challenge Studies With Emerging Infectious Diseases* Greenwall Foundation—Making a Difference Grant

• Elliott Weiss, MD, *Parental Attitudes in Neonatal Clinical Trial Enrollment: Decision-Making Preferences and Reasoning Among Participants and Non-Participants* Center for Clinical and Translational Research Clinical Research Scholars Program

• Benjamin Wilfond, *Exome Sequencing in Diverse Populations in Colorado and Oregon* National Human Genome Research Institute

Grant Applications 2013 - 2017
Consultation

Our **clinical** ethics consultants completed **41 consults** in 2017.

- Most common topics: treatment decisions (19), limitation of life-sustaining treatment (4), resource allocation (4), benefit/harm assessment (3), disclosure of results/information to patient/family (2), informed consent/parental permission (2), religious beliefs (2)
- Requesting services include: critical care (6), neonatal intensive care (6), hematology-oncology (5), palliative care (4), hospital medicine (3), surgical service line management (2)

Our **research** ethics consultants completed **8 consults** in 2017.

- Most common topics: community considerations (2), recruitment/incentives (2)
- Requesting services include (1 each): Cystic Fibrosis Therapeutics Development Network, pediatric critical care medicine, UW Institute of Translational Health Sciences, UW Department of Global Health, UW Institute for Stem Cell and Regenerative Medicine

13th Annual Conference

**The Cutting Edge**

**Ethical Controversies in Pediatric Surgery**

13th Annual Pediatric Bioethics Conference

In 2017, **180 clinicians and scholars** from the U.S. and worldwide attended *The Cutting Edge: Ethical Controversies in Pediatric Surgery*. 

**QUESTIONS DISCUSSED AT THE CONFERENCE INCLUDED:**

- Should parents be allowed to refuse a solid organ transplant?
- Are surgical complications different from medical errors?
- Should surgeons share their success rates prior to surgery?
- Should babies with Trisomy 18 be eligible for cardiac surgery?
- Should innovative surgical techniques be subject to regulatory oversight?
Bioethics Fellows

2017 Kristi Klee, DNP, MSN, RN, CPN, is a nursing practice support leader who completed the bioethics fellowship. She is co-leading the Nursing Bioethics Liaison program, where she trains other nurses in ethical issues that commonly arise in clinical care.

2017 Leah Kroon, MN, RN, CPHON, is a clinical nurse specialist who completed the bioethics fellowship. She is co-leading the Nursing Bioethics Liaison program, where she trains other nurses in ethical issues that commonly arise in clinical care.

2017 Tyler Tate, MD, is a pediatrician who completed the bioethics fellowship and started a fellowship in Hospice & Palliative Medicine at Duke University School of Medicine.

2016–present Emily Berkman, MD, is a pediatric critical care medicine fellow in her second year of the bioethics fellowship. Her research focuses on exploring the impact of recruiting international patients on resource allocation decisions in pediatric intensive care units in this country.
2016–present Jessica Jeavons, JD, is in her second year of the bioethics fellowship. Her research focuses on the ethical appropriateness of public health interventions to reduce the use of sugar-sweetened beverages.

2016–present Jeanne Krick, MD, is a neonatology fellow in her second year of the bioethics fellowship. Her research focuses on the parental experience of uncertainty in neonatal intensive care units.
Spotlight on Research

Organ Transplants for Children With Profound Intellectual Disabilities: Examining the Ethical Considerations in Policy Decisions

Prior to the 1990s, children were denied access to solid organ transplantation due to intellectual disability. Reasons cited include reduced life expectancy, a lack of cognitive ability to understand transplantation and comply with the required post-transplant therapy, a lack of improvement in quality of life, and the scarcity of available organs.

Since 1995, the American Society of Transplant Physicians guidelines state that cognitive impairment should be considered a contraindication to transplantation only when it is so severe as to impair adherence with essential medication regimens and no caregiver is available to compensate for the individual’s limitations. Yet a 2006 survey of pediatric transplant centers reported that 56% of transplant centers would consider an IQ of less than 35 a relative contraindication to solid organ transplantation. Additionally, 38% of centers reported at least one patient who had been evaluated and was not listed for transplant but would have, but for the presence of intellectual disability.

Pediatric nephrologist and Treuman Katz Center faculty Aaron Wightman and collaborators analyzed data from the UNOS database to identify pediatric recipients of heart, liver or kidney transplant with intellectual disabilities. They found that children with intellectual disabilities comprise a significant minority of pediatric transplant recipients (up to 24% for heart, 15% for liver and 16% for kidney). These recipients had early (3-5 year) patient and allograft survival that were no different than the intellectually typical pediatric recipients. Similarly, for heart and liver transplantation there was no difference between groups in

Aaron Wightman’s research focuses on determining relevant factors to weigh for children with intellectual disabilities to guide policy decision for organ transplants.
improvement in functional status. These studies provided the first national large-scale description of children with intellectual disability who underwent solid organ transplantation.

“Solid organ allocation policies represent a clear application of rationing and require a balance of the principles of utility and justice. Our work seeks to inform and improve the development of ethical policies for organ allocation for children.”

— Aaron Wightman

Wightman and collaborators, including Treuman Katz Center faculty Douglas Diekema, have used empirical data to further explore normative arguments for and against inclusion of this population in solid organ transplant, along with other considerations such as donor source, organ scarcity, quality of life, transition to adulthood, risk to transplant centers, and the consideration of other forms of renal replacement therapies.

The team has concluded that there is no evidence to support assumptions that children with disabilities have any lower benefit than any other patient on the wait list. Fairness requires applying criteria to all in an equal manner and avoiding discriminating between individuals on morally irrelevant grounds. Policy decisions to not offer a transplant to a child with profound intellectual disabilities, then, perhaps reflect social values rather than medical factors and are in violation of guidelines intended to assure equal access to care.

**PRIMARY COLLABORATORS**
- Jodi Smith, Douglas Diekema, Miranda Bradford, Evelyn Hsu, Seattle Children’s
- Heather Bartlett, University of Wisconsin School of Medicine and Public Health
- Aviva Goldberg, University of Manitoba

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