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 busy year in 2016. Highlights include:

Faculty Additions:
Kate Gentry, assistant professor, is a pediatric anesthesiologist whose research focuses on informed consent for anesthesia. She recently completed the bioethics fellowship at the Center. Seema Shah, associate professor, is interested in the ethical issues involved in research on emerging infectious diseases. She was previously faculty at the NIH Clinical Center Department of Bioethics. Elliott Weiss, assistant professor, is a neonatologist whose research focuses on parental decision-making preferences in the NICU. He recently completed a fellowship in neonatology and medical ethics at the Children’s Hospital of Philadelphia. Jeff Sconyers joined as affiliate faculty. He is a lecturer at the University of Washington School of Public Health.

Commitment to Community Outreach and Education:
We hosted 36 high school students from Montana as part of an Upward Bound visit to Seattle. We facilitated an interactive discussion of a hypothetical bioethics scenario to prioritize limited vaccine doses, followed by a panel presentation on careers in bioethics. Upward Bound is a federally funded program to prepare students from low-income families for college.

The information in the 2016 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, fellows and staff members continue to advance our understanding of ethical issues through a diverse collection of projects and studies.

Faculty News

- **Nanibaa’ Garrison** received a K01 award, *Genomics and Native Communities: Perspectives, Ethics and Engagement*.

- **Douglas Opel** became the director of clinical ethics at the Treuman Katz Center.

- **Abby Rosenberg** was appointed to the Bioethics Steering Committee of the Children’s Oncology Group.

- **Seema Shah** chaired an external NIH consultation on the Ethics of Zika Virus Human Challenge Trials.

- **Benjamin Wilfond** was appointed to the NIH Social and Ethical Implications of Research study section.

**FACULTY**

- Jonna Clark, MD, MA
- Douglas Diekema, MD, MPH
- Nanibaa’ Garrison, PhD
- Katherine Gentry, MD
- Ross Hays, MD
- Mithya Lewis-Newby, MD, MPH
- Douglas Opel, MD, MPH
- Abby Rosenberg, MD, MS
- Seema Shah, JD
- Elliott Weiss, MD, MSME
- Aaron Wightman, MD, MA
- Benjamin Wilfond, MD

**AFFILIATE FACULTY**

- Denise Dudzinski, PhD, MTS
- Jeff Sconyers, JD
Scholarship

- **37 presentations** including 16 at national and international meetings
- **58 publications** including 34 peer-reviewed papers/organizational statements and 16 commentaries, editorials and letters

Selected Publications:


Publications 2012 - 2016

PRESENTATION HIGHLIGHTS

Elliott Weiss
When Religion and Medicine Collide: A Structured Approach to Parental Religious Objections to Medical Care

Aaron Wightman
Critical Distance Between Steward and Advocate in Pediatric Solid Organ Transplant

Benjamin Wilfond
Research on Medical Practices (ROMP): Attitudes of IRB Professionals About Randomization and Informed Consent

National Leadership

Selected Highlights:

• Douglas Diekema, Ethics Committee/General Pediatrics Committee, American Board of Pediatrics

• Ross Hays, Nationwide Consortium for Pediatric Palliative Care Research Design and Data Collection, Pediatric Palliative Care Research Network

• Douglas Opel, Co-Chair, Bioethics Interest Group, Pediatric Academic Societies

• Abby Rosenberg, Chair, Quality of Life and Palliative Care Subcommittee, Children’s Oncology Group

• Aaron Wightman, Chair, Bioethics Subcommittee, American Society of Pediatric Nephrology

• Benjamin Wilfond, Editorial Committee, Hastings Center Report
Funded Research Projects

8 new projects

16 submitted with 1 withdrawn because investigator was awarded funding from another source

Selected Highlights:

• **Nanibaa’ Garrison**, _Genomics and Native Communities: Perspectives, Ethics and Engagement_ (K01 National Human Genome Research Institute)

• **Ross Hays**, _Pediatric Palliative Care Research Network (SHARE Project)_ (R01 National Institute of Nursing Research; PI: C. Feudtner, Children’s Hospital of Philadelphia)

• **Doug Opel**, _Use of a Novel Parent Report Measure to Improve Childhood Vaccine Uptake_ (R21 National Institute of Child Health and Human Development)

• **Abby Rosenberg**, _Promoting Resilience in Stress Management (PRISM): A Novel Supportive Intervention for Parents of Children With Cancer_ (National Palliative Care Research Center)

• **Aaron Wightman**, _Caregiver Burden in Pediatric Dialysis_ (CCTR Clinical Research Scholars Program)

• **Benjamin Wilfond**, _Beyond Consent: Patient Preferences for Governance of Use of Clinical Data and Samples_ (R01 National Library of Medicine; PI: S. Lee, Stanford University)

Grant Applications 2012 - 2016
Consultation

Our clinical ethics consultants completed 55 consults in 2016.

- Most common topics: treatment decisions (23), benefit/harm assessment (9), disclosure of results/information (5), informed consent/parental permission (4), end-of-life care (4), resource allocation (4), confidentiality/privacy (3)

- Most frequent requesting services: hospital medicine (7), NICU (5), psychiatry and behavioral medicine (5), hem-onc/BMT (4), PICU (4), CICU (3), gastroenterology (3)

Our research ethics consultants completed 7 consults in 2016.

- Most common topics: disclosure of results/information (2), research/clinical relationships (2)

- Requesting services include: neurology, rehabilitation medicine, research coordinator core, UW Department of Pathology and Biology, UW Human Subjects Division, UW Institute for Stem Cell and Regenerative Medicine

12th Annual Conference

In 2016, 179 clinicians and scholars from the U.S. and worldwide attended Autism Re-examined: Ethical Challenges in Care, Support, Research and Inclusion.

Questions discussed at the conference included:

- How have changes in the way we understand autism over time influenced ethical issues in diagnosis and treatment?

- How and why do health disparities occur in diagnosis, treatment and support, and what are the impacts? How can we reduce and ultimately eliminate disparities?

- How can we incorporate knowledge of cross-cultural differences to provide better care for children with autism and their families?

- What are the ethical challenges in the transition from adolescence to adulthood? How can they be addressed?
Bioethics Fellows

2016 Tracy Brazg, MSW, MPH, MA, completed the bioethics fellowship program concurrent with the University of Washington doctoral program in social work. She is assistant director at the UW Center for Health Sciences Interprofessional Education Research and Practice. Her research focuses on how social workers can apply their knowledge and skills in interprofessional teams to promote the goals of patient-centered care.

2016 Kate Gentry, MD, MA, also completed the bioethics fellowship program. She is an attending anesthesiologist at Seattle Children’s and a bioethics center faculty member. Her research focuses on communication quality and informed consent in the perioperative period.

2015-present Tyler Tate, MD, is a pediatrician in the second year of the bioethics fellowship. His research explores how a conceptual understanding of language can promote health and healing within the clinical encounter.

2015-present Kristi Klee, DNP, MSN, RN, CPN, is a clinical nurse specialist in her second year of the bioethics fellowship concurrent with leading the Nursing Bioethics Liaison program, where she trains other nurses in ethical issues that commonly arise in clinical care. Her research examines ethics consultations related to tracheostomies.
2015–present Leah Kroon, MN, RN, CPHON, is a clinical nurse specialist in her second year of the bioethics fellowship concurrent with leading the Nursing Bioethics Liaison program, where she trains other nurses in ethical issues that commonly arise in clinical care. Her research focuses on creating an ethical framework about puberty suppression for transgender adolescents.

2016–present Emily Berkman, MD, is a pediatric critical care medicine fellow who is concurrently in her first year of the bioethics fellowship program and master’s program.

2016–present Jessica Jeavons, JD, is in her first year of the bioethics fellowship program concurrent with the master’s program.

2016–present Jeanne Krick, MD, is a neonatology fellow who is concurrently in her first year of the bioethics fellowship program and master’s program.
Spotlight on Research

Ethics of Research on Emerging Infectious Diseases: Learning from Past Outbreaks to Prepare for Ongoing and Future Threats

Recent outbreaks of Ebola and Zika viruses have exposed the dangers posed by emerging infectious diseases and the need for epidemic preparedness for potential future threats. Treuman Katz Center faculty member and lawyer-bioethicist Seema Shah studies the ethics of research on emerging infectious diseases, and has worked on issues related to the recent Ebola and Zika virus epidemics.

Lessons Learned from Ebola Outbreaks

In the Ebola epidemic, questions arose about whether or not unproven interventions should be used outside of research, given the relatively high mortality for people infected with Ebola virus disease and the limited treatment and prevention options. Some high-profile cases of treatment with experimental interventions led to claims of injustice. This experience made clear that there are many reasons for engaging communities, including developing trust, fostering transparency, allowing the community to evaluate the benefits of research, enabling the community to protect themselves from potential harms, and obtaining buy-in and support for ongoing research in the locations from which participants are drawn.

Organizations such as the World Health Organization (WHO) and the National Institutes of Health (NIH) recognize an urgent need for research to develop effective interventions for emerging infectious diseases. There are several ethical issues that arise, however, including:

• How should we protect and respect participants given the limited time and capacity to conduct and review research?

• How should we engage communities?

• When can novel and controversial research designs be used ethically?

• When should experimental medications be made available to individuals who are not enrolled in the research?

Shah believes that although patients may have good reason to try unproven interventions when there are few alternatives, there are many reasons not to offer these interventions, including limited time, resources and concerns about doing more harm than good.

NIH Ethics Consultation on Zika Virus Research

Shah serves as chair of a group of experts from various disciplines and federal agencies that has provided recommendations on the ethics of human challenge trials on Zika virus. In these trials, researchers...
deliberately expose healthy volunteers to infectious diseases. There is a long history of successful challenge trials, which can be powerful tools to efficiently study new vaccines and treatments. In a famous example from 1796, Edward Jenner’s research ultimately led to the smallpox vaccine. Although researchers have proposed conducting Zika human challenge trials, these types of trials are ethically complex and understudied. Systematic ethical analysis of challenge trials is a relatively recent endeavor and has been limited in scope and application.

The committee’s report, *Ethical Considerations for Zika Virus Human Challenge Trials*, stated that while Zika human challenge trials could be ethically justified, their final recommendation was that it would be premature to proceed with these at present, given the many unknowns about the Zika virus.

*The panel weighed the public health urgency against the risk to human research subjects (and those to whom they might pass the virus), and considered the risk too great. They understood the need for a vaccine, the importance of the research. They provided a path forward. But they also told the researchers: Not quite, not yet.*

— Paul McLean, bioethicist, Boston Children’s Hospital, in a March 2017 commentary about the panel’s report

**Future Research on the Ethics of Challenge Trials**

The committee encountered some questions that they did not have time to fully explore. For instance, are volunteers vulnerable, or do they understand the risks and have good reasons to participate? Shah plans to build on the committee’s ethical analysis by empirically studying the motivations of volunteers. Additionally, she will work with stakeholders, researchers and ethicists in collaboration with the WHO, NIH and PATH to develop a comprehensive framework to determine when and how human challenge trials in emerging infectious diseases are ethically acceptable. This framework will address unresolved questions from her work on the Zika report, such as:

- Is it better to conduct a Zika virus challenge trial in a region that doesn’t face the threat of a Zika epidemic and the risks involved, or one that does?
- If there is a risk that a disease studied in a challenge trial might spread to some members of the community, what level of risk is acceptable, and how can that risk be ethically justified?

This framework may also be developed into guidelines for the WHO. Further down the line, Shah plans to empirically evaluate whether the framework is useful for review committees and acceptable to communities, or if the framework needs further refinement and adaptation. This work is supported by funding from the Greenwall Foundation.

Shah’s work has the potential to advance key issues in research ethics, develop ethical preparedness for future outbreaks of emerging infectious diseases, and strike the delicate balance necessary between protecting and respecting human subjects and communities, and also conducting valuable research.