The Treuman Katz Center for Pediatric Bioethics had a busy year in 2015. Two major highlights were:

**Nursing Bioethics Program in Its First Year:**
Clinical nurse specialists and bioethics fellows Kristie Klee and Leah Kroon are sharing their bioethics knowledge with nine nurse–bioethics liaisons from diverse hospital units. These liaisons are all front-line nurses who meet monthly to engage on ethical issues in their clinical units.

**Faculty Additions:**
Nanibaa’ Garrison, assistant professor, is interested in genetics and health conditions prevalent in Native American communities. Her research seeks to identify issues and barriers to Native American participation in genetics research. She was previously assistant professor at Vanderbilt University. Aaron Wightman, assistant professor, is a pediatric nephrologist with clinical research interests in decision making in infants with end-stage kidney disease and resource allocation in the care of children with chronic conditions. He was previously assistant professor at the University of Wisconsin.

The information in the 2015 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

• **Mithya Lewis-Newby** was promoted to associate professor.

• **Doug Opel** was appointed to the American Academy of Pediatrics Committee on Bioethics; he was also awarded the Faculty Teaching Award, Department of Pediatrics, University of Washington School of Medicine.

11 faculty, 4 affiliate faculty, 6 staff members and 6 fellows continue to advance our understanding of ethical issues through a diverse collection of projects and studies.

**FACULTY**

Jonna Derbenwick Clark, MD, MA  
Douglas Diekema, MD, MPH  
Nanibaa’ Garrison, PhD  
Ross Hays, MD  
Mithya Lewis-Newby, MD, MPH  
Paul Mann, MD  
Douglas Opel, MD, MPH  
Abby Rosenberg, MD, MS  
Holly Tabor, PhD  
Aaron Wightman, MD, MA  
Benjamin Wilfond, MD

**AFFILIATE FACULTY**

Denise Dudzinski, PhD, MTS  
Anna Mastroianni, JD, MPH  
Helene Starks, PhD, MPH  
David Woodrum, MD
Scholarship

- **51 presentations** including 8 at national and international meetings
- **69 publications** including 45 peer-reviewed papers and 17 commentaries, editorials and letters

Selected Publications:


- Garrison NA. *Considerations for returning research results to culturally diverse participants and families of decedents*. Journal of Law, Medicine and Ethics 2015; 43(3): 569-575.


Publications 2011 - 2015

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PRESENTATION HIGHLIGHTS

**Douglas Opel**
*Creating a Standard for an Emergency Process to Respond to Vaccine-Preventable Disease Outbreaks and Epidemics in Washington State: Ethical Considerations*


**Abby Rosenberg**
*Resilience and Positive Psychology Interventions for Adolescents and Young Adults with Cancer: Theoretical and Patient-Reported Rationale*


**Benjamin Wilfond**
*Research Ethics Consultation in the US: An Emerging Role in Academic Medical Centers*


National Leadership

Selected Highlights:

- **Jonna Clark**, Ethics Committee, United Network for Organ Sharing
- **Nanibaa’ Garrison**, Advisory Committee to the Director’s Working Group on Diversity, National Institutes of Health
- **Mithya Lewis-Newby**, Co-Chair, Conscientious Objection in Intensive Care Medicine Ad Hoc Working Group, American Thoracic Society
- **Douglas Opel**, Committee on Bioethics, American Academy of Pediatrics
- **Abby Rosenberg**, Chair, Palliative Care and Quality of Life Committee, Children’s Oncology Group
- **Aaron Wightman**, Chair, Bioethics Subcommittee, American Society of Pediatric Nephrology
Funded Research Projects

4 New Projects (9 submitted, of which 4 are pending a decision)

Selected Highlights:

• **Doug Opel**, *When Parents Refuse or Delay Childhood Vaccines: Implications for Shared Decision Making*  
  (Faculty Scholar, Greenwall Foundation)

• **Doug Opel**, *Provider-Parent Communication about Influenza Vaccine*  
  (Pediatric Pilot Award, Center for Clinical and Translational Research, Seattle Children’s Research Institute)

• **Abby Rosenberg**, *Cancer Care in the PICU: A Study of Social Work and Chaplain Roles*  
  (American Cancer Society)

• **Benjamin Wilfond**, *Assessing the Impact of Video and Comics on Knowledge and Attitudes about Randomization for Research in Medical Practices*  
  (Greenwall Foundation)

Grant Applications 2011 - 2015
Consultation

Our clinical ethics consultants completed 43 consults in 2015.

- Most common topics: treatment decisions (19), limitation of life-sustaining treatment (7), benefit/harm assessment (6), disclosure of results/information (4), informed consent/parental permission (2) and resource allocation (2)

- Most frequent requesting services: pediatric inpatient (8), medically complex child service (5), nephrology (4), psychiatry (3), adolescent medicine (2), NICU (2) and PACT team (2)

Our research ethics consultants completed 12 consults in 2015.

- Most common topics: recruitment/incentives (3), disclosure of results/information (2), research/clinical relationships (2) and benefit/harm assessment (2)

- Requesting services include: adolescent medicine, craniofacial, pediatrics, rheumatology, infectious disease, neurology, orthodontics, psychiatry and a biotech company

11th Annual Conference

In 2014, 185 clinicians and scholars from the U.S. and worldwide attended The Delicate Triangle: Responsibilities and Challenges in the Provider-Patient-Parent Relationship.

The Delicate Triangle: Responsibilities and Challenges in the Provider-Patient-Parent Relationship.
Eleventh Annual Pediatric Bioethics Conference
Bioethics Fellows

2013-present Tracy Brazg, MSW, MPH, MA, was continuing her bioethics fellowship in conjunction with completing her PhD in the University of Washington School of Social Work. Her bioethics master’s thesis was “Minimizing Disparities of Power in Clinical Ethics Consultation: A Place for Patient Advocacy.” She is interested in strengthening the scholarship and interprofessional practice connections between social work and bioethics.

“My participation in the clinical bioethics fellowship program allowed me to put my classroom learning into practice, and to develop the unique skillset required of a clinical bioethicist. Through the training and mentorship I received as a fellow, I have gained a strong understanding of how ethical principles apply in healthcare delivery, I have exercised my ability to think critically, I have become a better listener and more confident in my ability to constructively engage with teams, patients and families during times of conflict. Few social workers have the opportunity to receive this kind of formal training in bioethics. For this reason, I feel exceptionally privileged that I was afforded the chance to train amongst an impressive group of colleagues and in a dynamic and respected center for bioethics.”

2013-present Kate Gentry, MD, is an attending anesthesiologist at Seattle Children’s continuing her bioethics fellowship. Her bioethics master’s thesis was “Characterizing Informed Consent in Pediatric Anesthesiology.” She continues to pursue research related to communication quality and informed consent in the perioperative period.

“The bioethics fellowship opened my eyes to the multitude of complex ethical and communication issues that arise in the delivery of pediatric healthcare. The training has prepared me to recognize and respond to conflict, mediate discussions and seek resolutions that are amenable to all parties. The combination of clinical training and research mentorship provided by the fellowship, plus a comprehensive curriculum provided by the University of Washington Master’s program, has prepared me to forge a path as an academic anesthesiologist-ethicist. Finally, this experience has taught me that I will never be done learning. As medicine advances and societal norms shift, new questions will continue to emerge, and I look forward to grappling with those issues.”
2014-2015 Daniel Benedetti, MD, completed one year of the bioethics fellowship and conducted an empirical research project examining communication at the time of a cancer diagnosis in pediatric patients in the context of family refusal of recommended treatment. He is currently a fellow in hematology/oncology at Dana-Farber Cancer Institute.

2015-present Tyler Tate, MD, is a pediatrician who started the bioethics fellowship in 2015. He is interested in the intersection of theology and medicine and the treatment of suffering in healthcare.

Nursing Bioethics Fellows

2015-present Kristi Klee, DNP, RN (left), is a clinical nurse specialist who started the bioethics fellowship in 2015. Her research interests include communication with families of children with medically complex needs and support for clinical nurses in a complex care environment.

2015-present Leah Kroon, MN, RN (right), is a clinical nurse specialist who started the bioethics fellowship in 2015. She plans to focus on decision making around transgender care in adolescence for her master’s project.
Spotlight on Research

From Paternalism to Patient-Centered: Rethinking Shared Decision Making in Pediatrics

It used to be that doctors told patients what to do, and often administered treatments without asking the patients for their opinion, despite there being several treatment options to consider. That paternalistic model has long been replaced in medicine with an approach where the patient is viewed as a partner in the decision-making process. This middle ground is called shared decision making (SDM). The shift to SDM has many benefits. For instance, it can result in better informed, empowered and satisfied patients. To realize these benefits, though, clinicians need to know how to implement SDM. Therein lies the rub: There is no single working definition for SDM in pediatrics and no consensus about when to use it.

Recognizing a Lack of a Standardized Approach

Treuman Katz Center faculty member Doug Opel, MD, MPH, finds that he experiences this confusion firsthand in his clinical work. As a general pediatrician, he talks frequently with parents about interventions that are recommended for their children in order to prevent disease. These interventions range from immunizations to anemia screening to vitamin K prophylaxis. For some of these interventions, Opel uses SDM by partnering with parents and inviting them to participate in the decision-making process. For instance, he might say, “How do you feel about a blood test today to make sure she doesn’t have low iron?” For other interventions, he simply tells the parents what will be done, such as, “He’ll get a vitamin shot today to prevent any risk of bleeding.” Given the similarities across these interventions—all are accepted as usual care because they are low risk and have been shown to improve health—he wonders why he engages parents in such different ways, and if SDM is even appropriate to use for these interventions at all.

Exploring the Boundaries of Shared Decision Making

Answering these questions is a current focus of Opel’s research. A first step is determining what elements of a decision are needed for SDM to be appropriate. Opel explains, “One proposed requirement for using shared decision making is that the decision at hand needs to include more than one medically acceptable
option. If there is only one medically acceptable option, there really is nothing to ‘share’ and I don’t think shared decision making therefore makes much sense.” A requisite next step in this deliberation, then, becomes determining what constitutes a “medically acceptable” option, which is a weighty task in itself.

Another problem is how SDM should look when the patient is a child. If a reason to use SDM is to elicit the patient’s preferences so that their decision best matches those preferences, Opel thinks an important question to consider is whether or not SDM should look different if the person with the preferences is the parent. Opel suspects that implementing SDM in pediatrics will not be the same as in adult medicine because there are constraints on a parent’s or surrogate’s authority on behalf of a child that don’t exist for adults making medical decisions for themselves.

With support from the Greenwall Foundation, Opel seeks to answer these types of conceptual questions by exploring how SDM should look in the fields of pediatrics, public health and preventive care. He thinks that without more conceptual work to fill in current gaps in our understanding of SDM, clinicians will continue to have trouble knowing when it is appropriate to use SDM and when it is not. Opel fears that this results in him sometimes using SDM when it is not appropriate and not using it when it is. The Greenwall research project allows for dedicated time in which Opel can do this conceptual work and help delineate how SDM should be applied in different contexts.

The Greenwall Foundation’s Faculty Scholars Program in Bioethics selects up to five junior faculty members nationally for three years of funding. Innovative research projects are chosen that will address pressing ethical issues, improve patient care, inform biomedical research or enhance public policy.

“There are lots of routine, preventive care recommendations in pediatrics, and despite parallels among them—they are universally recommended, all have strong evidence base, benefits outweigh burdens, all are standard of practice—I approach them differently. Some I use shared decision making, yet for other, similar recommendations, I convey the plan in a way that limits parental input. Why do I handle interventions with similar attributes differently? If there is good reason, what are those reasons? I don’t think we’ve answered these questions, so this is an area of focus in my research.”

—Doug Opel