Our Mission

To improve the lives of children and their families by enhancing the deliberation in pediatric healthcare and research.

Our faculty advanced our understanding of ethical issues through publications in the *New England Journal of Medicine, Pediatrics, Clinical and Translational Science* and the *American Journal of Medical Genetics*. Faculty had presentations at the annual meetings of the American Academy of Pediatrics and the American Society for Bioethics and Humanities.

New research grants were awarded from the National Human Genome Research Institute and the American Society of Clinical Oncology. We provided clinical ethics consultation related to decisions about end-of-life care, disclosure of results and conflicts of interests. Our research ethics consultants provided advice to researchers in global health, neurology and orthopedics.

**The information in the 2012 Year in Review will give you a better appreciation of the efforts of our 14 faculty members, 5 staff and 3 fellows to improve the lives of children and their families.**
Faculty News

- Denise Dudzinski, Abby Rosenberg and Helene Starks were appointed as affiliate faculty members.

- Maureen Kelley, Douglas Opel and Holly Tabor were elected to the Society for Pediatric Research.

Faculty Members

- Jonna Derbenwick Clark, MD, MA
- Douglas Diekema, MD, MPH
- Denise Dudzinski, PhD, MTS
- Ross Hays, MD
- Maureen Kelley, PhD
- Mithya Lewis-Newby, MD, MPH
- Paul Mann, MD
- Anna Mastroianni, JD, MPH
- Douglas Opel, MD, MPH
- Abby Rosenberg, MD, MS
- Helene Starks, PhD, MPH
- Holly Tabor, PhD
- Benjamin Wilfond, MD
- David Woodrum, MD
Scholarship

- **14 presentations** at national and international professional meetings
- **30 publications** including 23 peer-reviewed publications and professional organizational statements

Selected Publications:

National Leadership

Selected Highlights:

- **Douglas Diekema**, Ethics Committee, American Board of Pediatrics
- **Mithya Lewis-Newby**, Ethics Committee, American Thoracic Society
- **Anna Mastroianni**, Recombinant DNA Advisory Committee, National Institutes of Health
- **Holly Tabor**, Co-Chair, Ethics and Regulatory Working Group, Centers for Mendelian Genomics, National Human Genome Research Institute
- **Benjamin Wilfond**, President, Association of Bioethics Program Directors
Funded Research Projects

6 New Projects (15 submitted):

- **Maureen Kelley**, International Research Ethics Program Development (Methodist Hospital, Houston, TX)
- **Abby Rosenberg**, Promoting Resilience in Parents of Children with Cancer (St. Baldrick’s Foundation Fellow Award)
- **Abby Rosenberg**, Understanding Resilience among Parents of Children with Cancer (Young Investigator Award: Conquer Cancer Foundation, American Society of Clinical Oncology)
- **Holly Tabor**, Innovative Approaches to Returning Results in Exome and Genome Sequencing Studies (NHGRI Supplement)
- **Benjamin Wilfond**, Research Ethics Consultation: State of the Art (VHA National Center for Ethics in Health Care)

Grants 2008 – 2012

![Bar chart showing submitted, awarded, and pending grants from 2008 to 2012]
Consultation

• **Clinical Ethics:** The bioethics consultation service at Seattle Children’s provides advice to families and providers when there are questions or disagreements about ethical aspects of care. There were **33 consults** in 2012.
  - Topics include: treatment decisions, disclosure of results, end-of-life care, conflict of interest, religious beliefs
  - Requesting service: medically complex child service, cardiology, pediatric critical care, NICU, hematology/oncology

• **Research Ethics:** Center faculty staff the research bioethics consultation service through the Institute of Translational Health Sciences (ITHS) to address novel and unsettled ethical issues for investigators and IRBs related to the design and implementation of clinical research. There were **12 consults** in 2012.
  - Topics include: informed consent/parental permission, benefit/harm assessment, disclosure of results, study withdrawal/termination
  - Requesting service: global health, neurology, orthopedics/sports medicine, psychiatry

Eighth Annual Conference

Seattle Children’s Bioethics Conference has become one of the signature events in the pediatric bioethics community, garnering strong reviews from the thousands who have attended since 2005. In 2012, **207 attended** from the U.S. and worldwide.
Bioethics Fellows

2010-2012 Jennifer Guon, JD, MA finished her bioethics fellowship and is now Director of Medical Bioethics at Kaiser Permanente in Panorama City, near Los Angeles, CA. In establishing a bioethics program at this institution, she acts as the co-chair and advisor to the Bioethics Committee and responds to both individual and organizational case consultation requests. She assures compliance with accreditation and agency standards pertaining to clinical ethics and patient rights and reviews and assists in the development of regional policies related to patient rights and bioethics.

“The experience both at Seattle Children’s in addition to the education and mentorship received through the Master’s in Bioethics at the University of Washington prepared me to handle the responsibilities establishing a new program at my hospital, and provided me with a solid foundation necessary to partake in the rigorous world of complex case consultations.”

— Jen Guon

2011-2013 Jessica Turnbull, MD, MA is a Pediatric Critical Care Specialist who was in the final year of her Bioethics Fellowship in 2012. Her Master’s degree project was “Determining Eligibility Criteria for Pediatric ECLS*: How Do Physicians Decide?” She is interested in applying qualitative research methods to study decision making for medically complex children, as well as improving palliative care delivery in the pediatric intensive care unit (PICU).

* ECLS stands for extracorporeal life support
2012-2014 Jen Kett, MD is a neonatologist who started her bioethics fellowship in 2012. Her research interests include prenatal counseling with families facing the birth of a critically ill infant and the impact of multidisciplinary fetal diagnostic and treatment centers on these families. In 2014, she will pursue additional training in palliative care through the University of Washington and Seattle Children’s Hospital.

2012-2014 Aaron Wightman, MD started his bioethics fellowship in 2012 along with the second year of his nephrology fellowship. His research interests focus on decision making for children with incurable conditions. He’s currently involved in projects examining decision making in infants with end-stage kidney disease; candidacy for solid organ transplant; and resource allocation in care for children with chronic conditions.
Spotlight on Research

The My46 Study: Studying ethical issues in the return of genetic results from sequencing

Holly Tabor, PhD, in collaboration with Mike Bamshad, MD, and the Division of Genomic Medicine, is studying how results from genetic testing should be offered and returned to research participants and patients. Newer technologies called whole genome sequencing and exome sequencing are being used in clinical and research settings to identify the genetic causes of conditions. They are different from other genetic testing approaches because they identify almost all genetic variations that could cause or contribute to health issues. This presents challenges about how to offer options for results and how to explain the meaning of results.

Dr. Tabor and colleagues have developed an innovative web-based tool called My46 (www.my46.org). My46 gives people control over what results they learn about and gives the information in a way that maximizes possible benefits and minimizes possible harms. On the My46 website people can:

- Access educational information about genetics.
- View the list of possible results that are available from sequencing.
- Select their preferences for which results they do and do not want to receive.
- Modify these preferences at any time before they view their results.
- Receive reports and summaries for the results they have chosen to receive.
- Contact a My46 genetic counselor at any point to get help with their questions or concerns.
Dr. Tabor and team are recruiting 150 people from research studies on a broad range of diseases (including brain and limb malformations, heart conditions, cystic fibrosis and autism) whose exomes have already been sequenced. The patients/families select which kinds of results they do—or do not—want to receive using My46. Half the group will receive results through My46 and half will receive results directly from a My46 genetic counselor. A range of outcomes are being assessed and compared across groups, including depression, anxiety, satisfaction, healthcare outcomes and sharing of information with healthcare providers and family members.

My46 is funded by the NIH’s National Human Genome Research Institute (NHGRI) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).

“This is one of the first studies to study the return of genetic results from sequencing, and the first to use a web-based tool to allow individuals to control their own genomic information and to make decisions about results and review result information according to their own values. My46 also allows them to share result reports with their providers and family members. We’re very excited about the results we are getting from the study and further developing this tool for use in broader research and clinical settings.”

— Holly Tabor