



Seattle Children's®
HOSPITAL • RESEARCH • FOUNDATION

UW Medicine
UNIVERSITY OF WASHINGTON
MEDICAL CENTER

Annual Report

Fiscal Year 2022



Bioethics and Palliative Care Program

Bioethics and Palliative Care Clinical Services
Division of Bioethics and Palliative Care
Treuman Katz Center for Pediatric Bioethics

Report Overview

- **Letter from Program**
- **Program Overview**
 - Program & Center Mission and Vision
 - Organizational Chart
 - Program Councils and Committees
 - Program Highlights
 - Equity, Diversity, Inclusion, & Anti-Racism
- **Bioethics and Palliative Care Clinical Services**
 - Clinical Bioethics Consultation Service
 - Organizational Ethics Consultation Service
 - Palliative Care Clinical Service
 - Quality Programs
- **Division of Bioethics and Palliative Care**
 - Education
 - Fellowship Training Programs
- **Treuman Katz Center for Pediatric Bioethics**
 - Letter from Center Leadership
 - Center Vision
 - Center Scholarship
 - New and Continuing Awards
 - Center Highlights
- **Program Member Highlights**
- **Looking Forward and Appreciations**
- **Appendix: Complete list of Publications**

LETTER FROM PROGRAM LEADERSHIP



The past year in our nation and the world has been marked by persistent challenges: the global pandemic, political violence, attacks against historically marginalized groups, climate crises, and others. We each have had to face these challenges in different proportions and in different forms. And we each have had to cope with them in our own ways. And yet, despite these challenges, our team members have continued to do incredible work.

Our mission as a Bioethics and Palliative Care Program is to ensure that each child, family, and community benefits from excellent, equitable healthcare and research centered on their needs and values. We worked to advance this mission in 2022 in several ways. For instance, we were able to grow our interdisciplinary clinical palliative care team, adding team members and trainees in order to help us increase palliative care access and serve more patients and families now and in the future. We also worked hard to continue to provide excellent clinical ethics support and to sustain our close partnership with the Center for Diversity and Health Equity at Seattle Children's Hospital. We also managed to greatly expand our organizational ethics program, increasing access to this important resource. We undertook successful recruitments and grew our Division faculty. We added new trainees in both palliative care and bioethics. Our interdisciplinary team members taught locally, regionally, nationally, and internationally.

The Treuman Katz Center continued to make significant advances in bioethics and palliative care scholarship. We added 5 new members to augment our research operations and our research portfolio to include health equity and neuroethics. The Center hosted its 17th annual bioethics conference on "Breakthroughs in Pediatrics: Past Lessons, Present Controversies, Future Challenges." And Center members secured nearly \$1.6 million in grant funding in FY22, a >10% increase over FY21.

We continue to be so grateful to be a part of such a remarkable program. We are so proud of the way that, despite the various challenges we each face, our program members continue to devote their talent, time, and energy to benefit our patients, their families, and the community at-large. This incredible work keeps us optimistic about the future.

Doug Opel, Arika Patneaude,
Colleen Lee and Jen Kett
Bioethics & Palliative Care Leaders



Program Overview

Program Mission and Vision

PROGRAM MISSION: Ensure each child, family and community benefits from excellent, equitable healthcare and research centered on their needs and values.

VISION: Use our interprofessional expertise in bioethics and palliative care to address complex challenges in pediatric healthcare and advance the well-being of children, families, and communities.

Seattle Children's Valued-Based behaviors

COMPASSION



EXCELLENCE



INTEGRITY



COLLABORATION



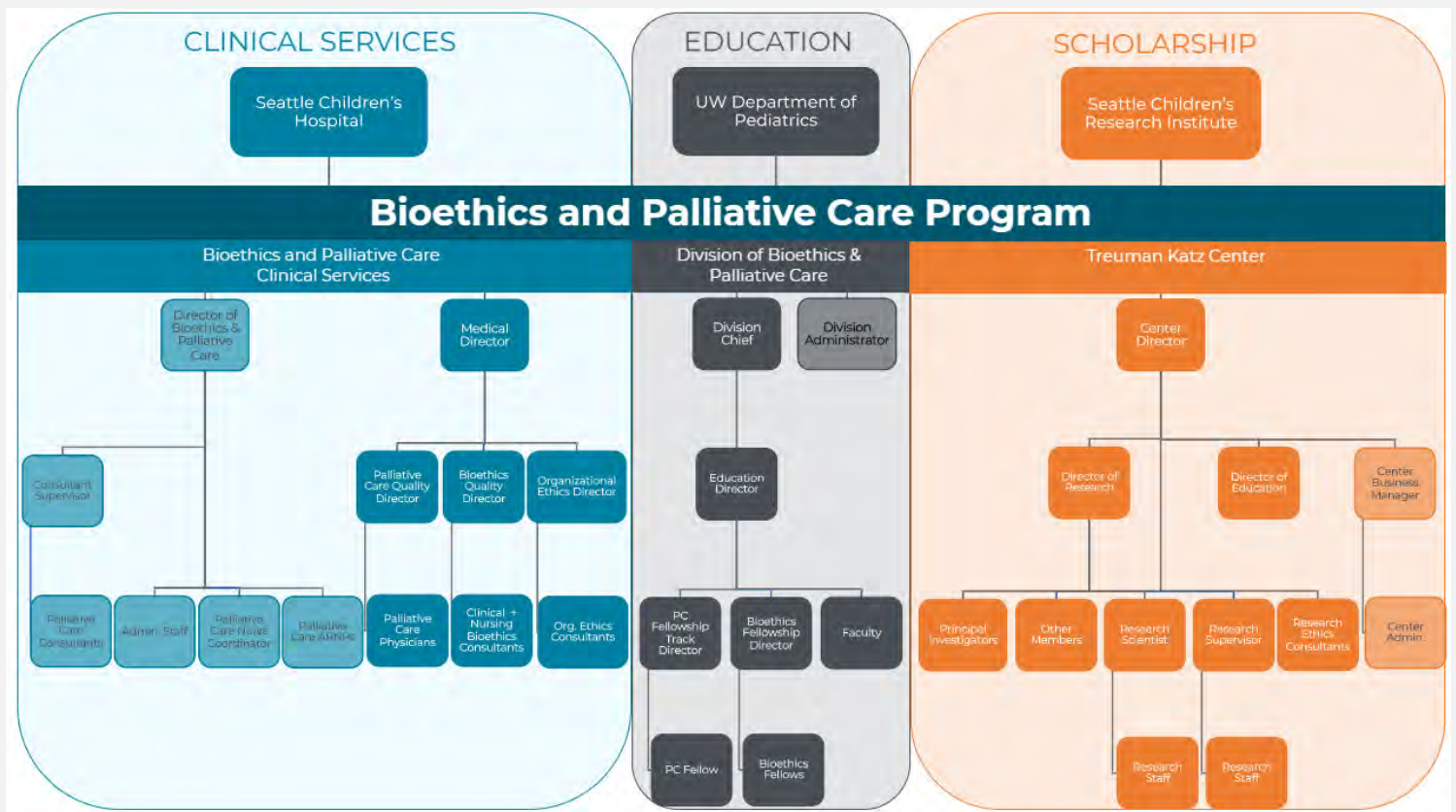
EQUITY



INNOVATION



Organizational Chart



Program Councils and Committees



Advisory Council –

FY 22 Council Members – **Dina Frank, Treuman Katz, Cilla Joondeph, Barbara Mann, Kathy Randall, Jeff Sconyers, Peggy Walton, Simon Pritikin, Monica Long.**

The Advisory Council is comprised of current and past members of Seattle Children's Hospital Board of Trustees, Executive Leadership, Foundation Leadership, and Research Advisory Committees. The Council provides input to program leaders regarding community engagement, philanthropy, and strategic initiatives.



Steering Committee –

FY 22 Committee Members - **Arika Patneaude, Doug Opel, Dawn Marie Pares, Devan Duenas, Anne Anderson, Amy Trowbridge, Doug Diekema, Elliott Weiss, Kate MacDuffie, Jori Bogetz, Paula McPoland, Aaron Wightman, Leah Kroon, Stephanie Kraft, Jennifer Kett.**

The Program Steering Committee is comprised of a broad group of team members from varied disciplines who provide visioning, advice, and guidance to program leaders regarding the overall direction of the program and the implementation of new ideas.

Equity Council -

FY22 Equity Council Members – **Amanda Mercer, Hannah Lewis, Arika Patneaude, Emily Berkman, Holly Vo, Dawn Marie Pares, Elizabeth Julian and Jennifer Kett.**

The Bioethics and Palliative Care Equity Council has had a busy year. We said goodbye to Amanda Mercer and Hannah Lewis as they left the program to pursue educational endeavors. We sponsored a film discussion in program seminar on the important film *'Crip Camp: A Disability Revolution'*. Equity Council members Dawn Marie Pares & Holly Vo prepared and led an excellent and engaging discussion! We started weekly equity emails, 'Days of Note', as a resource for program members on upcoming equity events including holidays across cultures, healthcare focused awareness events, information, and activities on equity focused days/months.

As we look ahead to FY23, we are beginning work on equity principles for the program and continued sponsorship of quarterly equity focused program seminars.

Program Highlights

NWPPCC (Northwest Pediatric Palliative Care Coalition)

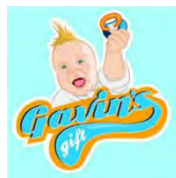
Seattle Children's Palliative Care and the Division Bioethics and Palliative Care at University of Washington in collaboration with Doernbecher Children's Hospital at OHSU, the Washington State Hospice and Palliative Care Organization and the Oregon Hospice and Palliative Care Association, launched the Northwest Pediatric Palliative Care Coalition (NWPPCC) for the states of Alaska, Idaho, Montana, Oregon, and Washington, in the fall of 2021. Our VISION is that all children and families in the Pacific Northwest region facing serious illness will have access to comprehensive palliative care support through the duration of serious illness both in the hospital and at home in the community with the goal to prevent, anticipate and mitigate suffering. Our MISSION is to empower our interprofessional workforce to advocate for every child and family to have access to the support necessary to live as well as possible with the goal to prevent, anticipate and mitigate suffering. Our MISSION is to empower our interprofessional workforce to advocate for every child and family to have access to the support necessary to live as well as possible with serious illness. With approximately 140 members, we hold twice annual virtual meetings and send out monthly newsletters that highlight different participating programs and resources throughout our region. Visit our website to learn more: seattlechildrens.org/clinics/palliative-care-consultation/nwppcc

If you have any questions or would like to contact us, please email the coalition at NWPPCC@seattlechildrens.org. All are welcome!



Guild and Endowment Support to Families

Palliative Care is generously supported by two Seattle Children's Guilds - Susannah White's Three Feet of Sunshine and Gavin's Gift Guilds. With their support, we are able to provide 'Quality of Life' (QOL) items to patients and families who are cared for by the Palliative Care Team.



The Palliative Care Cost Center provides funeral assistance to families who have been supported by the team and whose child has passed. With support from Barbara and Eric Mann, we are able to double the support provided in the month of December.



- Patients and Families Served through Quality-of-life fund: 431



- Total amount spent supporting Patient and families through the quality-of-life fund: \$14,474.70



- Number of families assisted with funeral cost: 48



- Total amount Contributed towards funeral costs: \$10,432.10

Ethics Committee



Mithya Lewis Newby, MD, MPH
Chair



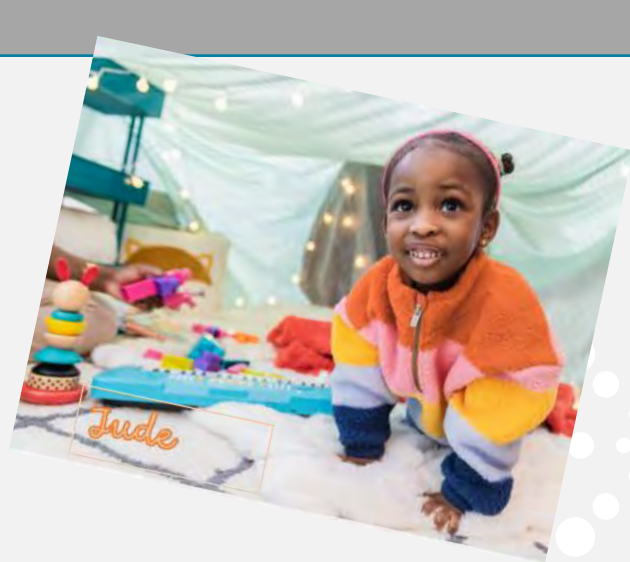
Leah Kroon, MA, MN, RN, CPHON
Vice Chair



Maya Scott, MSW, LICSW
Vice Chair

Throughout Fiscal Year 2022, the Ethics Committee Leadership Team and Steering Committee continued work to update the functions, processes, and documents of the committee to meet the evolving needs of the Seattle Children's community. Work included revisions to the membership structure, enhanced membership expectations, development and implementation of an equitable workforce member recruitment process, significant revisions of the committee charter, rewriting the membership manual, and development of a new member onboarding process. Future work in the coming year includes recruitment of new family representatives, and establishment of a shared committee educational resource space.

We're so close!!!



Equity, Diversity, Inclusion, & Anti-Racism



The Bioethics and Palliative Care Program is strongly committed to addressing racism and anti-Blackness and creating a just and equitable society for all. Some of our EDI and anti-racism efforts include:

Partnership with Seattle Children's Hospital Center for Diversity and Health Equity (CDHE)



Seattle Children's[®]
HOSPITAL • RESEARCH • FOUNDATION

Center for Diversity
and Health Equity



In FY22 The Bioethics Consultation Service completed 22 ethics consultations in which equity was at the forefront of the request, either implicitly or explicitly. In partnership with our colleagues from CDHE as subject matter experts, each of these consults was completed within the paradigm that equity cannot be separate from ethics.

Bias Reduction in Internal Medicine Initiative (BRIM)



The Division of Bioethics and Palliative Care was one of the divisions chosen to pilot the BRIM-Pediatrics Initiative. Division faculty member, Roberto Montenegro, MD, PhD, is a Principal Investigator for BRIM-Pediatrics.

"Cultural stereotypes can Influence our judgments, decision-making, and behaviors In unwanted and unintended ways. The BRIM Initiative offers the opportunity to help 'break the bias habit' and align our judgments and behaviors with our explicit commitments to be fair and objective." (medicine.uw.edu/diversity/BRIM)

In FY22, 31 participants of faculty and staff participated from 2 divisions in the Department of Pediatrics. In FY23, BRIM will continue to add more divisions to the project. Some notable quotes of participants Included:

"The knowledge presented is essential groundwork to establish for everyone, and I really appreciate that it is a separate discussion and workshop on its own."

"Helped me connect more dots and deepen my consideration of both interpersonal and institutional actions possible."

"(The) content is excellent and the discussions it fosters among division colleagues is what we need."

Race-Based Caucusing

As part of our program's commitment to becoming anti-racist, we provide monthly race-based caucusing as a modality for team members to share resources, ideas, and community towards building an anti-racist team and contributing towards a more equitable society.

Work in People of Color Caucus	Work in White Caucus
<p>Creates a brave space to talk about and address experiences of racism.</p> <ul style="list-style-type: none">► Offers a retreat from continuous scrutiny and an antidote to white-dominated spaces► Creates an alternative power base/ "counterspace" for BIPOC within white spaces► Builds relationships and support through courageous and difficult conversations	<p>Creates accountable space to work through barriers that prevent white people from allying together toward anti-racist goals.</p> <ul style="list-style-type: none">► Builds relationships and deepens understanding of power/privilege► Builds collective tools for race equity► Offers space to discuss emotions, questions, and learning edges without causing harm to people of color

Black, Indigenous, People of Color Caucus - (BIPOC)

The Black, Indigenous, People of Color (BIPOC) caucus group met intermittently in FY22. The group brings together the 12 BIPOC team members of the program of diverse cultural backgrounds. The intention of the caucus is to create a space in which members can build community, get support, and provide "gut checks" on our lived experiences as members of racial and ethnic communities that have been excluded, marginalized or invisible within academia and healthcare. Our FY23 goal is to get together in person and share community and food from across our varied cultural traditions!

White Ally Anti-Racist Caucus – (WAAR)

Ellie Oslin became the primary facilitator of the WAAR Caucus after Amanda and Hannah departed from SCH in July. Our WAAR Caucus Committee consists of Ellie, Stephanie Kraft and Dawn Marie Pares, which meets monthly to brainstorm discussion ideas, regulatory needs, and accountability across caucus members. Recently, the WAAR Caucus members collectively decided to move to a guided discussion model. Now each caucus session is led by a different member who signs up for date to lead, prepares a topic and sends out materials prior to meetings. We have decided to alternate between the first Wednesday and Thursday of the month in order to enhance the ability of participants to attend caucus at least once every other month.

Bioethics & Palliative Care Clinical Services

Clinical Bioethics Consultation Service

Bioethics consultation provides a forum for discussion and analysis of areas of ethical uncertainty or disagreement in the care of children.

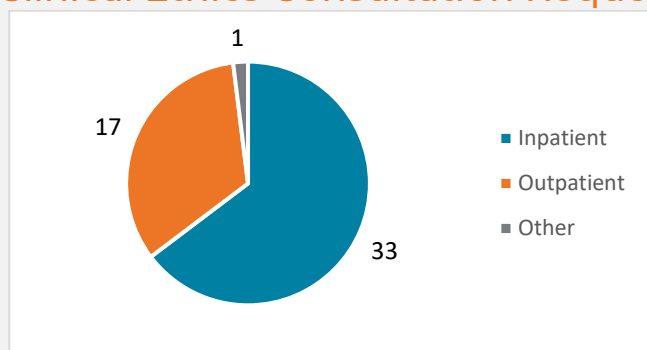
Bioethics consultants offer advice and recommendations to families, clinical teams, and hospital leadership facing challenging decisions.

Core Consultation Team Members FY22

Kate Gentry, MD, MA
Jennifer Kett, MD, MA
Brennan Kim, MD**
Dan Kim, MD**
Brittany Lee, MD, MA
Allyson Lyle, MD, MA**
Doug Opel, MD, MPH

Katie Stephenson, MD**
Holly Vo, MD, MPH, MSc, MA
Aaron Wightman, MD, MA
Kirsten Wilhelm, MD**
Benjamin Wilfond, MD
**Bioethics Fellows

Clinical Ethics Consultation Requests by Setting



Highlights:

51 Ethics Consultation requests
In FY22, down by 11% from FY21

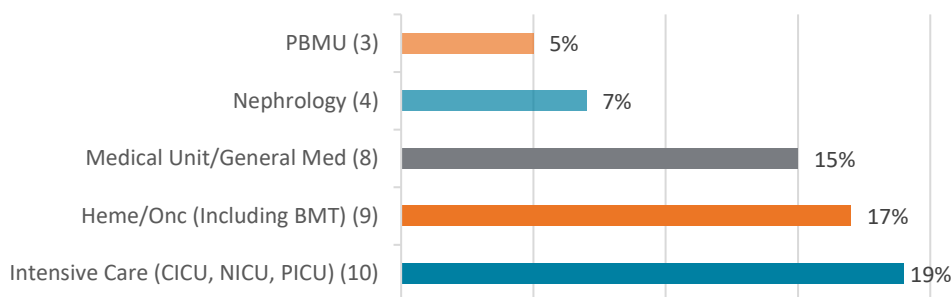
41% (n=21) of Clinical Ethics consultations were completed in partnership with CDHE as there was a health equity component

Clinical Ethics Consultation Requests by Service

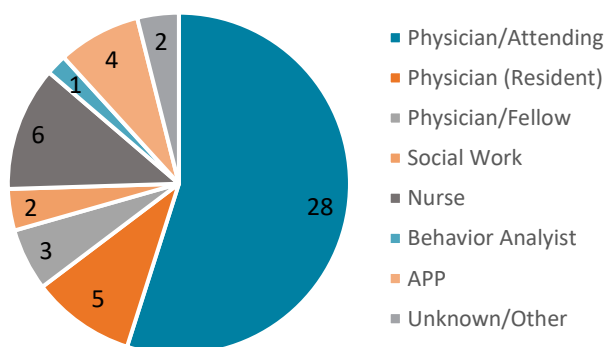
Referring Services:

Out of the 51 consultation requests 63% of them came from these top 5 referring services.

Top 5 Referring services



Clinical Ethics Consultation Requests by Role



Consult Request by Role:

Physician/Attending role makes up 55% of the total requests for a Clinical Ethics Consultation.

Organizational Ethics Consultation Service



FY22 Annual Report Organizational Ethics Service (OES)

Organizational Ethics Consultations provide support to the institution by helping program and institutional leaders identify, analyze, and assist with ethical challenges that may impact *groups* of patients, staff members, or communities.

FY22 brought growth and formalization of the Organizational Ethics Consult Service. **Dr. Denise Dudzinski**, Professor in Bioethics & Humanities joined Bioethics and Palliative Care as the Director of Organizational Ethics. In collaboration with our interprofessional team, Dr. Dudzinski formalized intake and quality assurance procedures, building upon the firm foundation of the service.

Ethics is a dimension of most organizational decisions, including the impact of health care financing, engagement with diverse communities, and efforts to improve population health. The Organizational Ethics Service provides recommendations to institutional invested parties and hospital leadership regarding ethical issues that arise at the organizational level.

In FY22, there were 10 new Organizational Ethics consult requests. Organizational Ethics consults are often longitudinal and require meetings, research and analysis over weeks and months. Consultants often help to revise hospital policies and procedures at the invitation of content experts.



Denise Dudzinski, PhD, MTS, HEC-C
Director Organizational Ethics



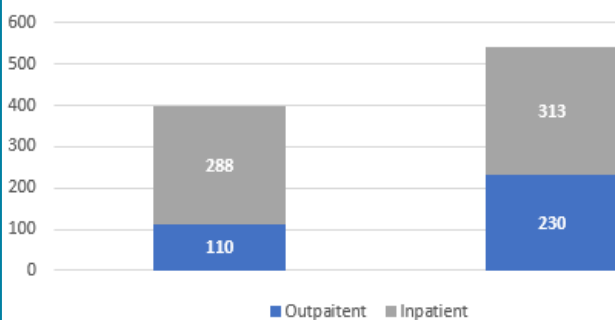
Palliative Care Clinical Service

"Palliative Care Clinical Service Team"

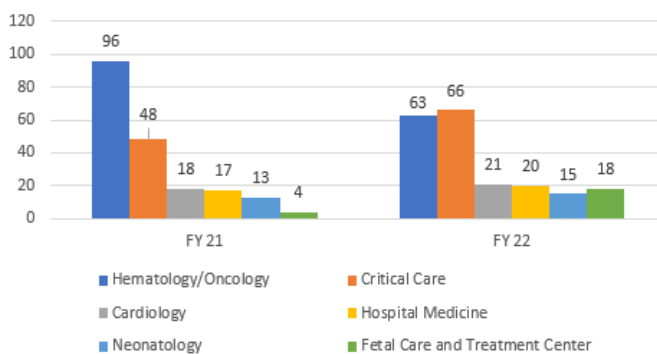


The Palliative Care Clinical Service Team includes doctors, nurse practitioners, nurse care coordinators, and palliative care consultants with backgrounds in social work, chaplaincy, or nursing. The team specializes in palliative care for children, teens, young adults, and their families. Their services are available through referrals. In FY22, the team's outpatient services increased by 110% and inpatient services increased by 9% from FY21. The top 6 divisions who submitted referral services in FY22 were Critical Care, Hematology/Oncology, Cardiology, Hospital Medicine, Neonatology and Fetal Care and Treatment Center.

Total Referrals received



Top 6 Referring Services



Inpatient Referrals FY22



Outpatient Referrals FY22



Telemedicine

As part of the Ambulatory Program, Palliative Care provides telehealth services. In FY22, of the 230 ambulatory visits, 213 (93%) of those visits were telemedicine.

Completed Telehealth Appointments

- 7 Providers
- 213 Appointments
- 31 Appointments per provider
- 92 minutes avg. provider time per appointment

Quality Programs



Ethics FY22 Quality Data

In FY22 the Ethics Quality Committee completed the quality charter for the clinical ethics service. With a focus on equity, we identified three QA/PI metrics for every case discussed at the twice monthly Ethics QA (quality assurance) meetings.

These questions are:

1. Did the clinical ethics team speak with the bedside nurse during the course of the consult?
2. Did the clinical ethics team speak with the family during the course of the consult?
3. Was there a focus on equity during the course of the consult?



Ethics QA Committee Members

Aaron Wightman, MD, MA
Arika Patneaude, MSW, LICSW, APHSW-C
Jennifer Kett, MD, MA

Palliative Care FY22 Quality Data:

The Palliative Care Quality Committee's focus for FY22 was on hand hygiene, equity, competency of team members and ambulatory goals. 90% of clinical team members completed the Grow@SC hand hygiene course in order to do our part in decreasing CLABSI across the organization. We integrated equity into the IDT (interdisciplinary team) meeting, specifically focusing on equity as each patient was discussed. We implemented our team competencies with 85% of team members completing a self- assessment and finally we met our ambulatory goal of patients/families being contacted within 5 business days of a referral being received by our team.



Palliative Care QA Team Members

Arika Patneaude, MSW, LICSW, APHSW-C
Jori Bogetz, MD
Jennifer Kett, MD, MA
Kimberly Liekweg, MD
Melanie Neff, MSW, LICSW
April Endsley, MA

Division of Bioethics & Palliative Care

Education

Mann Family Pediatric Palliative Care Grand Rounds



“Centering the Good”

Blyth Lord

Founder and Executive Director,
Courageous Parents Network
Board Member, National
Tay-Sachs and Allied Diseases
Association

Co-chair, Parent Working Group,
American Academy of Pediatrics Section
on Hospice and Palliative Medicine

Barbara and Eric Mann have generously supported the Pediatric Palliative Care Service since 2007. Their sponsorship allows for specialized education and training for highly skilled clinicians in order to enhance the care of patients and families at Seattle Children's Hospital. As a tribute to their generosity, we have established an annual Pediatric Palliative Care Grand Rounds in their honor.

Fellowship Training Programs



The Bioethics and Palliative Care Program has two fellowship tracks, one in ethics and one in palliative care.

In FY22, through the steadfast leadership of Palliative Care Fellowship Director Paula McPoland, the Palliative Care Fellowship received a temporary complement increase to add a second pediatric fellow. We have applied to make the increase permanent. The palliative care fellowship is ACGME accredited and operates through the University of Washington.

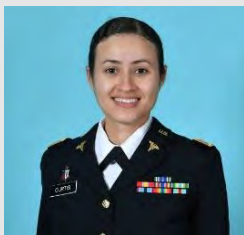
In FY22 through the exceptional leadership of co-Directors Doug Diekema and Aaron Wightman, the ethics fellowship welcomed three first year subspecialty ethics fellows. The Ethics fellowship is non-ACGME accredited. Because the bioethics fellowship is a University of Washington fellowship, we follow ACGME guidelines.

Palliative Care Director



Paula McPoland, MD

Palliative Care Fellows:



CPT (P) Yasmin Curtis, MD

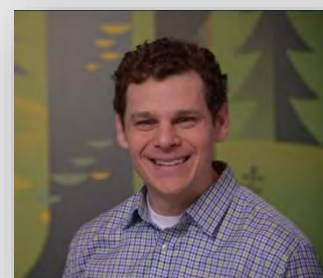


Hannah Deming, MD

Bioethics Co-Directors



Douglas Diekema, MD, MPH

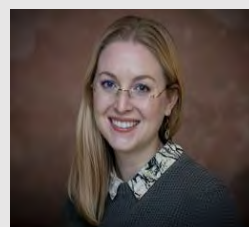


Aaron Wightman, MD, MA

Bioethics Senior Fellows:



Allison Lyle, MD, MA



Kirsten Wilhelm, MD

Bioethics First Year Fellows:



Brennan Kim, MD



Daniel Kim, MD



Kathryn Stephenson, MD



► Our Mission

To conduct innovative interdisciplinary scholarship that promotes the dignity, rights, and welfare of patients and research participants and advances high-quality, equitable research and healthcare for children, families, and communities.

► Letter from Leadership

FY22 has been a year of hopefulness and transformation. Hopefulness as we slowly emerge from the COVID-19 pandemic and regain some normalcy in our routines, and transformation as work begins to chart the path forward at Seattle Children's Research Institute (SCRI) after SCRI received Huron Consulting Group's key findings and recommendations. There is a renewed sense of optimism for FY23.

There have been several changes at the Center in FY22 worth celebrating. Foremost, we welcomed Drs. Kate MacDuffie and Holly Vo into their new roles as Principal Investigators and added 4 new staff members to our team: Debbie Poon as Senior Administrative Assistant, Colleen Lee as Center Manager, Ellie Oslin as Clinical Research Coordinator II, and Abril Beretta as Clinical Research Coordinator I. All six have already contributed enormously, bringing unique skillsets and perspectives to their work at the Center. We also have developed a new intramural Visiting Scholar program to facilitate collaborative work between Treuman Katz Center members and scholars from other institutions. And we survived yet another move as our 6th floor space in the Jack MacDonald Building was re-designed!

Amidst these changes, we have remained focused on advancing palliative care and bioethics scholarship. From our existing programs—Research Ethics Consultation, Annual Conference, and Grand Rounds—to new grants and research findings, our Center continues to be a national leader in pediatric bioethics and palliative care. We have flourished in FY22. I truly am excited for all that awaits us in FY23.

Doug Opel, MD, MPH
Center Director
Treuman Katz Center



► Scholarship

Principal Investigators (PIs) at the Treuman Katz Center often apply for funding for their scholarship through internal and external funding sources. Here is a synopsis of the funded awards where Treuman Katz Center members were PIs or site PIs in Fiscal Year 2022 (FY22 - October 1, 2021 through September 30, 2022).

New vs. Continuing Funding Awards



\$638,618 from **10**
New Awards



\$1,039,202 from **12**
Continuing Awards

22 awards totaling
Grand Total **\$1,677,820**

Funding by Sponsor Type

\$1,346,926
from
Federal
Agencies



\$220,265
from Local
and State
Agencies



\$82,966 from
Non-Profit
Organizations



\$27,663
from
Seattle
Children's



Extramural vs Intramural Funding



\$1,650,157 from **19**
Extramural Awards



\$27,663 from **3**
intramural Awards



New Awards

Treuman Katz Center members were PI or site PI on 10 new awards starting during the Fiscal Year 2022 timeframe (FY22 - October 1, 2021 through September 30, 2022) from extramural and Intramural funding sources.





Continuing Awards

Treuman Katz Center members continued 12 awards as PI or site PI entering their 2nd year or beyond during the Fiscal Year 2022 (FY22 - October 1, 2021 through September 30, 2022) timeframe from internal and external funding sources

Jori Bogetz, *Quality of End-of-Life Care for Children with Cancer: Can we Measure It?* Funded by American Cancer Society

Stephanie Kraft, *Respect for Persons in the Genomics Research Enrollment Process: Incorporating Diverse Experiences and Attitudes*, Award# 5K01HG01361-04, Funded by National Human Genome Research Institute (NHGRI)

Elliott Weiss, *Improving Diversity in Neonatal Clinical Trial Enrollment*, Award# 1K23HD103872-01, Funded by National Institute of Child Health & Human Development (NICHD)

Benjamin Wilfond, *Exome Sequencing in Diverse Populations in Colorado & Oregon*, Award# U01HG007292, Funded by National Human Genome Research Institute (NHGRI)

Benjamin Wilfond, *The Dog Aging Project: Genetic and Environmental Determinants of Healthy Aging in Companion Dogs*, Award #5U19AG057377-04, Funded by National Institute on Aging (NIA)

Benjamin Wilfond, *Health Care Systems Research Collaboratory – Coordinating Center*, Award #5U24AT009676-05, Funded by National Center for Complementary & Integrative Health (NCCIH)

Roberto Montenegro, *Bias Reduction in Curricular Content: Using Artificial Intelligence to Assess Bias in Medical Education*, Funded by National Board of Medical Examiners

Doug Opel, *Evaluation of the Presumptively Initiating Vaccines and Optimizing Talk with Motivational Interviewing (PIVOT with MI) Intervention*, Award # R01 HD093628-01A1, Funded by National Institute of Child Health & Human Development (NICHD)

Doug Opel, *Validation of a Framework for Shared Decision-Making in Pediatrics*, Award # R03 HS26994-01A1, Funded by Agency for Healthcare Research and Quality (AHRQ)

Doug Opel, *WA- Child Health Improvement Partnership*, Funded by WA Department of Health

Doug Opel, *King County Child Health Improvement Partnership*, Funded by Washington Chapter of the American Academy of Pediatrics (WCAAP)

Doug Opel, *Kitsap WA-CHIP Learning Collaborative*, Funded by Washington Chapter of the American Academy of Pediatrics (WCAAP)



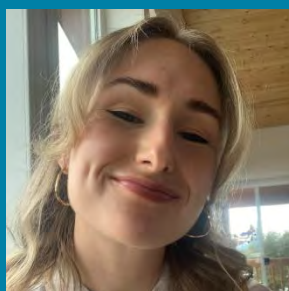
► Center Highlights

Treuman Katz Center sponsors several internal programs and activities to support its faculty and staff. Here are some highlights from FY22.

Treuman Katz Incubator Program



The Treuman Katz Incubator Program is designed to promote promising new research and stimulate preliminary data that ultimately leads to successful external funding for research conducted at the Treuman Katz Center. In FY22, Dr. Amy Trowbridge (pictured above) received an Incubator award for her proposal, *Mock No Code – A Simulation-Based Goals of Care Curriculum for Pediatric Residents*.



In FY22, we also launched the Treuman Katz Research Staff Funding Program to promote Treuman Katz Center research staff career development and support scholarship that advances the Center's mission. This year, Amanda Mercer (pictured above) received an award for their proposal, *Interpersonal Influences on Treatment Decisions for Nausea and Vomiting During Pregnancy*, mentored by Dr. Kate MacDuffie.

Visiting Scholars Program



The Treuman Katz Visiting Scholars Program was developed in 2022 to facilitate collaborative work between Treuman Katz Center principal investigators, staff and scholars from other institutions. This program was developed because on campus visits from outside scholars are an impactful way to facilitate productive collaborations, generate new research questions, and gain new insights on the existing work of the Center. The program also aims to enable Center members and the broader SCRI, SCH, and UW community to hear about the outside scholar's work while also conducting meetings to make progress on collaborative ideas and/or learn new methods. Visits prioritize the visiting scholar's time with fellows/trainees and advancing DEI in the Center. Currently the program can support up to 2 visiting scholars per year and the inaugural visiting scholar visit took place in Fall 2022.

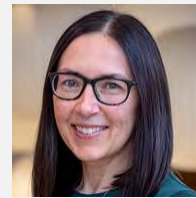
Research Bioethics Consultation Service

The Research Bioethics Consultation Service offers support and education to investigators by providing a forum for in-depth conversation and analysis of ethical issues in clinical and translational research. Our consultants offer advice to researchers, research staff, personnel involved in the protection of human subjects, and research participants who have questions about any aspect of a research study. We assist when there are ethical issues that arise related to the development, implementation, or analysis of clinical and translational research.

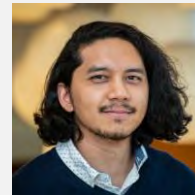
Primary Topics FY22:

- Recruitment/Incentives
- Informed Consent/Parental Permission
- Legal/Regulatory
- Benefit/Harm Assessment
- Disclosure of Results
- Other

Meet the Team:

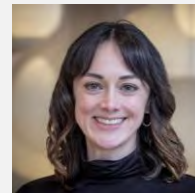


Director – Katie Porter, JD, MPH



Coordinator – Devan Duenas, MA

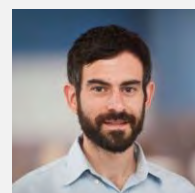
Consultants –



Stephanie Kraft, JD



Kate MacDuffie, PhD, MA



Elliott Weiss, MD, MSME



Ben Wilfond, MD



The dream of imminent breakthroughs in the diagnosis and treatment of pediatric disease is an integral part of the pediatric practice and a source of hope for patients, families, clinicians, researchers, and the public.

The history of innovation in pediatrics offers examples of amazing successes. Breakthroughs offer new ways of understanding and treating disease, and advance hope of dramatic improvement, treatments, or cure where none existed before. This history is also riddled with failures and mistaken assumptions about the promise of breakthroughs. Breakthroughs can also raise significant ethical questions, including questions about access and allocation, risk, choice, and personhood. While promoted as solutions, breakthroughs may also lead to initially unappreciated harms, and unmask disparities, inequities, and bias within pediatrics.

This year's conference will include discussions of lessons that can be learned from past breakthroughs along with a careful examination of the ethical challenges that arise or are likely to arise from current and future breakthroughs.

The 17th Annual Pediatric Bioethics Conference wrestled with questions such as:

- What is the relationship between innovation and research?
- When does a breakthrough become standard care?
- What is the meaning of hope in the face of unproven therapies?
- Are moral enhancements medical treatments?
- What is the role of health care providers as gatekeepers of breakthrough medical technology?
- What ethical questions do artificial intelligence and machine learning raise for pediatrics?
- What limits should be placed on medical innovation?

July 15-16, 2022

Bell Harbor International Conference Center, Seattle, WA

DAY 1: FRIDAY, JULY 15, 2022

8:00	Sign-in and Continental Breakfast	1:00	Big Data, Artificial Intelligence, Machine Learning: Revisiting Our Assumptions About Science and Ethics <i>Stephen Rosenfeld MD MBA</i>
8:30	Welcome and Introduction <i>Douglas Opel MD MPH</i>	1:30	Breakthroughs in Pediatric Transplantation: From the Masden Twins to Baby Fae and Zion Harvey <i>Lainie Friedman Ross MD PhD</i>
8:40	Introduction to the Conference <i>Aaron Wightman MD MA</i>	2:05	Modeling Neurodevelopment with Human Brain Organoids: Clinical Potential and Ethical Challenges <i>Kate MacDuffie PhD MA</i>
8:45	Breakthroughs in Pediatrics: Determining Ethical Permissibility <i>Mark Mercurio MD MA</i>	2:35	How would Moral Bioenhancement Impact Children of Color? <i>Timothy Brown PhD</i>
9:20	Therapeutic Misadventures in the Newborn <i>Norman Fost MD MPH</i>	3:05	Break
10:05	Break	3:20	A Conversation About Breakthroughs in Pediatric Bioethics Moderator: <i>Douglas Diekema MD MPH</i> <i>All speakers from 1st day</i>
10:20	From Smallpox to COVID-19: Breakthroughs in Vaccination and Public Health Policy <i>Douglas Diekema MD MPH</i>	4:00	Questions from the Audience
10:50	Ethical Issues in Access to and Use of Unproven Interventions in Pediatrics <i>Allison Bateman-House MPH PhD</i>	4:30	Adjourn
11:25	Ethical Challenges in Expanding Access Internationally to Breakthrough Clinical Trials <i>Emily Berkman MD MA</i>		
12:00	Lunch (provided)		

DAY 2: SATURDAY, JULY 16, 2022

7:45	Sign-in and Continental Breakfast	10:05	Break
8:15	Welcome and Introduction <i>Douglas Diekema MD MPH</i>	10:20	Breakout Sessions: ABSTRACTS
8:20	Breakthroughs in Pediatric Bioethics <i>Aaron Wightman MD MA</i>	11:20	Break
8:55	Why Not My Child? <i>Maya Scott MSW</i>	11:35	Breakthroughs and Hoping for a Miracle <i>Patrick Smith PhD</i>
9:30	Breakthroughs in Pediatric Surgery: The Ethics of Surgical Innovation <i>Ryan Antiel MD MSME</i>	12:30	Concluding Comments and Adjourn



Conference Attendance:

120 attendees from 11 states (WA, OR, ID, IL, PA, TX, AR, MN, FL, CA, & MD) & **Canada.**

2022 PLANNING COMMITTEE

Douglas Diekema MD MPH (Co-Chair)

Aaron Wightman MD MA (Co-Chair)

Emily Berkman MD MA

Denise Dudzinski PhD MTS HEC-C

Devan Duenas MA

Jennifer Kett MD MA

Leah Kroon RN MN MA CPHN

Colleen Lee BA

Mithya Lewis-Newby MD MPH

Kate MacDuffie PhD MA

Douglas Opel MD MPH

Debbie Poon BA

Emily Rice MBA

Maya Scott MSW LICSW

Margarett Shnorhavorian MD MPH

➤ 15th Annual Treuman Katz Lectureship, October 17, 2021



60 Attendees

Brief Outline of Talk:

As a scholar whose research has long focused on understanding the mechanisms leading to inequity in the medical profession, **Dr. Reshma Jagsi** will begin by providing an overview of the patterns of women's participation in the profession of medicine. She will then describe studies led by her team and others that have investigated the drivers of women's persistent under-representation among the leaders of the medical profession, even in an era when half of all medical students are female. These include myriad complex challenges, including gendered expectations, unconscious bias, and overt discrimination and harassment. She will conclude by discussing innovative interventions that have been implemented to begin the process of cultural transformation in medicine.



Reshma Jagsi, MD, D.Phil

Dr. Reshma Jagsi is a Newman Family Professor and Deputy Chair in the Department of Radiation Oncology and Director of the Center for Bioethics and Social Sciences in Medicine at the University of Michigan.

➤ Sconyers/Godfrey Bioethics Grand Rounds, February 10, 2022



121 Attendees

Brief Outline of Talk:

In her case commentary **Dr. Wilson** highlighted her scholarship applying some of the theoretical tools provided by intersectionality's intellectual approach (how race, gender, and other social identities converge in order to create unique forms of oppression) to the clinical environment. Such an approach offers the opportunity for additional ethical insights and guidance.



Yolonda Wilson PhD

Yolonda Yvette Wilson is Associate Professor of Health Care Ethics at Saint Louis University, with additional appointments in the Departments of Philosophy and African American Studies.

Program Member Highlights

The Bioethics and Palliative Care Program is comprised of 53 members. Each member highlighted a personal accomplishment achieved during Fiscal Year 2022 (FY22 - October 1, 2021 through September 30, 2022).

Division listed is part of Department of Pediatrics*

Anne Anderson, BSN, RN, CHPPN

Nurse Coordinator
Palliative Care Clinical Service

*Courageous Parents Network, 2022 Margaret S. Lindsay
Courageous Provider Award.*



Abril Beretta, BS

Clinical Research Coordinator I
Treuman Katz Center

Joined Treuman Katz Center In 2022.



Emily Berkman, MD, MA

Assistant Professor, Division of Bioethics & Palliative Care*
Assistant Professor, Division of Critical Care Medicine*
Principal Investigator, Treuman Katz Center

*Gave Grand Rounds on Ethics of Obesity In Pediatric Transplant In
September 2022.*





Jori Bogetz, MD

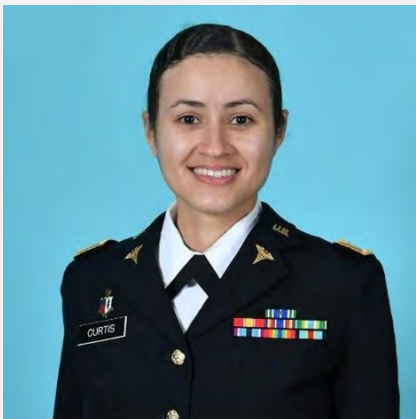
Assistant Professor, Division of Bioethics & Palliative Care*
Principal Investigator, Treuman Katz Center
Director of Pediatric Quality Improvement, UW Cambia Palliative
Care Center of Excellence

*Elected as member at large In the Roundtable on Quality Care for
People with Serious Illness at the National Academies Sciences
Engineering Medicine (NASEM).*

Jonna Clark, MD, MA

Associate Professor, Division of Critical Care Medicine*
Associate Professor, Division of Bioethics & Palliative Care*
Principal Investigator, Treuman Katz Center

*Published two chapters on End of Life Decision-Making and Do Not
Resuscitate Orders in the textbook: Professional, Ethical, Legal and
Educational Lessons in Medicine: A Problem Based Learning
Approach.*



CPT (P) Yasmin Curtis, MD

Fellow, Palliative Care

Started Palliative Care fellowship in 2022.

Hannah Deming, MD

Fellow, Palliative Care

Started Palliative Care fellowship in 2022.





Douglas Diekema, MD, MPH

Co-Director of Ethics Fellowship, Division of Bioethics & Palliative Care
Co-Director of Education, Treuman Katz Center
Professor, Division of Bioethics & Palliative Care*
Professor, Division of Emergency Medicine Professor*
Principal Investigator, Treuman Katz Center

Appointed Medical Editor, American Board of Pediatrics, Pediatric Emergency Medicine Sub-board

Denise Dudzinski, PhD, MTS, HEC-C

Director, Organizational Ethics, Seattle Children's
Professor, Division of Bioethics & Palliative Care*
Professor, Department of Bioethics and Humanities
Principal Investigator, Treuman Katz Center
Chief, UW Medicine Ethics Consultation Service
Faculty, Center for Surgical Ethics, Department of Surgery, UW School of Medicine

Serves on the American Society for Bioethics (ASBH) Task Force to Update the Core Competencies in Healthcare Ethics Consultation, Third Edition.



Devan Duenas, MA

Clinical Research Coordinator II
Treuman Katz Center for Pediatric Bioethics

Published as 1st author and co-authored five other research publications.

Nic Dundas, MPH

Clinical Research Coordinator II
Treuman Katz Center

Speaker at Seattle Children's Science Insights Day Lightning Talk.





April Endsley, CMA

Senior Administrative Assistant
Bioethics & Palliative Care Program

Designed the logo and successfully completed the website build for the NWPPCC.

Katherine Gentry, MD, MA

Associate Professor, Department of Anesthesiology & Pain Medicine
Associate Professor, Division of Bioethics & Palliative Care*
Principal Investigator, Treuman Katz Center
Medical Director, Pre-Anesthesia Surgical Services (PASS) Clinic

Designated as the Education Lead within the Department of Anesthesiology's Equity, Diversity, and Inclusion council. Developing and implementing brand-new EDI curriculum for the University of Washington Anesthesiology residency program. Selected to be an EDI peer trainer for the University of Washington School of Medicine.



Ross Hays, MD,

Professor Emeritus, Division of Bioethics & Palliative Care*
Attending Physician, Palliative Care

Elizabeth Julian, MSW, LICSW

Inpatient Supervisor
Palliative Care Clinical Service

Successfully completed the Palliative Care Graduate Certificate program.





Jennifer Kett, MD, MA

Interim Chief, Division of Bioethics & Palliative Care*
Associate Professor, Division of Bioethics & Palliative Care*
Principal Investigator, Treuman Katz Center

Successfully took medical and parental leave in order to manage a complicated pregnancy and premature delivery.

Brennan Kim, MD

Fellow, Bioethics
Fellow, Neonatal Perinatal Medicine

Started bioethics fellowship in 2022.



Dan Kim, MD

Fellow, Bioethics
Fellow, Pediatric Critical Care

Started bioethics fellowship in 2022.

Kristi Klee, DNP, MA, RN, CPHQ

Director, Clinical Nursing Quality & Safety
Center Member, Treuman Katz Center
Co-Leader, Nursing Bioethics Liaison Program

*Awarded the March of Dimes, Washington Heroes in Action,
Distinguished Nurse of the Year.*





Stephanie Kraft, JD

Assistant Professor, Division of Bioethics & Palliative Care*
Director of Research, Treuman Katz Center
Principal Investigator, Treuman Katz Center

Awarded an NIH grant to examine community perspectives about artificial intelligence-enabled mobile health tools and develop a resource to guide ethical and equitable development of such tools.

Leah Kroon, MA, MN, RN, CPHON

Vice Chair, Hospital Ethics Committee
Nursing Practice Specialist, Cancer and Blood Disorder, Infusion Services
Center Member, Treuman Katz Center
Co-Leader, Nursing Bioethics Liaison Program

Nominee for David Fisher Patient Safety Award.



Brittany Lee, MD, MA

Attending Physician, Cancer and Blood Disorders Center
Clinician Researcher, Division of Hematology/Oncology*
Attending Consultant, Bioethics Consult Service

Graduated from Pediatric Hematology/Oncology and Clinical Bioethics Fellowships at Seattle Children's Hospital and earned a Master of Arts in Bioethics and Humanities at University of Washington.

Colleen Lee, BA

Center Business Manager
Treuman Katz Center

Started as the Manager of the Treuman Katz Center in July 2022. Served a 2nd term as the Principal Chair of the Asian Inclusion Network at Seattle Children's.





Mithya Lewis-Newby, MD, MPH

Chair, Hospital Ethics Committee
Associate Professor, Division of Bioethics & Palliative Care*
Associate Professor, Division of Critical Care Medicine*
Principal Investigator, Treuman Katz Center

Elected as a member of the Society of Critical Care Medicine Ethics Committee.

Kimi Liekweg, MD

Clinical Assistant Professor, Division of Bioethics & Palliative Care*

Appointed Medical Director of the Carousel Program through Providence Hospice and Home Care of Snohomish County.



Allison Lyle, MD, MA

Fellow, Bioethics
Fellow, Neonatal-Perinatal Medicine

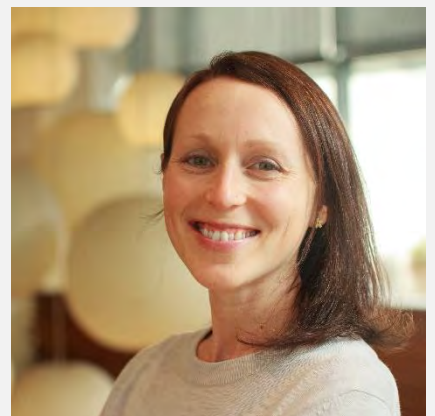
Currently, Allison serves as the AAP Section on Pediatric Trainees Liaison to the Section on Bioethics and is an Editor for the AAP Pediatric Resident Ethics Curriculum. She is also Co-Director of the AAP Trainee and Early Career Neonatologist (TECaN) Ethics special interest group.



Kate MacDuffie, PhD, MA

Assistant Professor, Division of Bioethics and Palliative Care*
Principal Investigator, Treuman Katz Center

Joined the faculty as Assistant Professor in September 2022.





Annie McDermott, RN, MN, ARNP

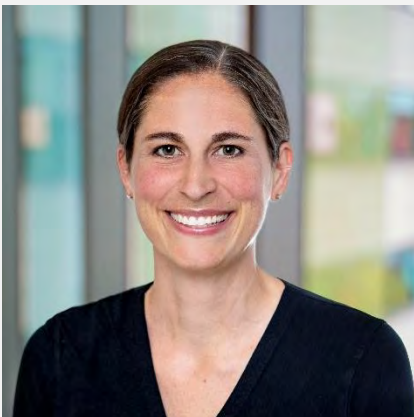
Nurse Practitioner
Palliative Care Clinical Service

Started the Graduate Certificate Program in Palliative Care at the University of Washington.

Macallagh McEvoy, RN, MN, ARNP

Nurse Practitioner
Palliative Care Clinical Service

Presented at the Montreal International Congress in Palliative Care, Oct 2022



Paula McPoland, MD

Fellowship Track Director, Pediatrics Hospice & Palliative Care Medicine

Assistant Professor, Division of Bioethics & Palliative Care*

Assistant Professor, Department of Anesthesia & Pain Medicine

Associate Director, Hospice and Palliative Medicine Fellowship

Continued to grow and expand the Hospice and Palliative Medicine Fellowship.

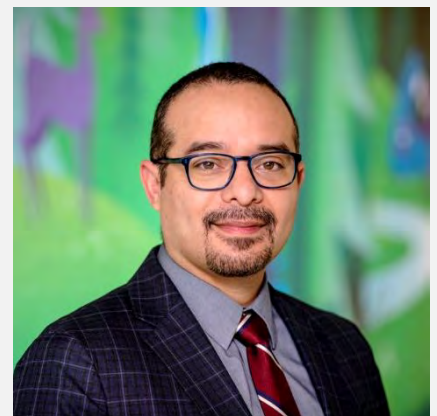
Roberto Montenegro, MD, PhD

Assistant Professor, Department of Psychiatry & Behavioral Medicine

Assistant Professor, Division of Bioethics & Palliative Care*

Principal Investigator, Treuman Katz Center

Successfully completed first year of research with the National Board of Medical Examiners and AuCode Computer Sciences to utilize Natural Language Processing (NLP) computer science strategies to examine how racial bias is propagated through medical text (exams, lecture materials, etc.) in medical training.





Prisca Nakuya, MSW, LICSW

Palliative Care Consultant
Palliative Care Clinical Service

Completed the Social Work Licensing exam and is now a licensed clinical independent social worker.

Melanie Neff, MSW, LICSW

Palliative Care Consultant
Palliative Care Clinical Service

Completed UW Palliative Care Training Center Certificate program.



Douglas Opel, MD, MPH

Interim Center Director, Treuman Katz Center
Professor, Division of Bioethics & Palliative Care*
Principal Investigator, Treuman Katz Center

Completed service on the Vaccine Confidence Subcommittee of the National Vaccine Advisory Committee at the US Department of Health and Human Services, which culminated in a report to the US Assistant Secretary of Health.

Ellie Oslin, BA

Clinical Research Coordinator II
Treuman Katz Center

Promoted to a Clinical Research Coordinator II after six months at Seattle Children's.





Dawn Marie Pares, BA

Program Coordinator II
Bioethics & Palliative Care Program

Became part of the White Ally Anti-Racist Caucus Leadership Committee.

Arika Patneaude, MSW, LICSW, APHSW-C

Administrator, Division of Bioethics & Palliative Care*
Director, Bioethics & Palliative Care
Center Member, Treuman Katz Center

Completed the Advanced Training in Healthcare Ethics (ATHE) certificate program through UW School of Medicine Department of Bioethics & Humanities.



Debbie Poon, BA

Senior Administrative Assistant
Treuman Katz Center

Coordinated the first in person grand rounds and conference for the Treuman Katz Center after the pandemic restrictions were lifted.

Katie Porter, JD, MPH

Clinical Research Scientist, Treuman Katz Center
Director, Research Bioethics Consultation Service

Became course instructor for Research Ethics and Regulation, a required course in the Bioethics Master's Program through the University of Washington Department of Bioethics and Humanities.





Eileen Rhee, MD, MS

Associate Professor, Division of Bioethics & Palliative Care
 Associate Professor, Division of Pediatric Critical Care Medicine
 Associate Program Director for PCCM Fellowship

Promoted to Associate Professor in Academic Clinician track; selected for the Physician Leadership Development Program at SCH; co-launched 2 different communication workshops – one at SCH for PCCM APPs with Jonna Clark and Alisa Van Cleave and one for a national bootcamp program for PCCM fellows.

Jeff Sconyers, JD

Teaching Professor Emeritus, Department of Health Systems and Population Health
 Adjunct Professor, Division of Pediatrics
 Center Member, Treuman Katz Center

Appointed to 3-year term on the King County Board of Health as a community stakeholder.



Sharee Smith, BS

Program Coordinator III
 Bioethics & Palliative Care Program

Invited to support the BRIM pilot project with Roberto Montenegro and Ellie Oslin which ended with great success and outcomes for greater opportunities for faculty.

Heather Spielvogle, PhD

Research Manager
 Treuman Katz Center

Presented at the Pediatrics Academic Society Annual Conference.





Kathryn Stephenson, MD

Fellow, Bioethics
Fellow, Gastroenterology

Started bioethics fellowship in 2022.

Amy Trowbridge, MD

Director of Education, Division of Bioethics & Palliative Care
Assistant Professor, Division of Bioethics & Palliative Care*
Principal Investigator, Treuman Katz Center

Co- launched the Network of Pediatric Palliative Care Educators (NPPCE). NPPCE's mission is access to and quality of interprofessional pediatric palliative care education through a community for collaboration and dissemination of educational best practices, research, and resources. So far, NPPCE has over 450 members!



Alisa Van Cleave, MD

Clinical Associate Professor, Division of Bioethics & Palliative Care*
Clinical Associate Professor, Division of Critical Care Medicine*

Along with BE/PC colleagues Dr. Jonna Clark and Dr. Eileen Rhee, implemented a 2-day simulation-based Difficult Communication Workshop (based on Vital Talk curriculum) for our Pediatric Critical Care APP group, which will recur on an annual basis.

Holly Hoa Vo, MD, MPH, MSc, MA

Assistant Professor, Division of Bioethics & Palliative Care *
Assistant Professor, Division of Pediatric Pulmonary & Sleep Medicine*
Principal Investigator, Treuman Katz Center

Awardee of Seattle Children's Center for Clinical and Translational Research Pediatric Pilot Funds Program.





Elliott Weiss, MD, MSME

Associate Professor, Division of Neonatology
Principal Investigator, Treuman Katz Center

Promoted to Associate Professor of Pediatrics.

Aaron Wightman

Quality Director, Bioethics
Associate Fellowship Director, Bioethics
Co-Director of Education, Treuman Katz Center
Associate Professor, Division of Bioethics & Palliative Care*
Associate Professor, Division of Nephrology*
Adjunct Associate Professor, Department of Bioethics and Humanities
Principal Investigator, Treuman Katz Center

Co-organized the summer bioethics conference.



Benjamin Wilfond, MD

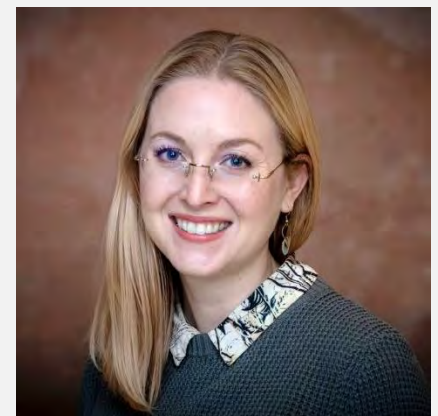
Professor, Division of Bioethics & Palliative Care*
Professor, Division of Pulmonary & Sleep Medicine*
Principal Investigator, Treuman Katz Center

Received an honorary degree and was the commencement speaker at Muhlenberg College on May 22, 2022. He graduated from Muhlenberg in 1981.

Kirsten Wilhelm, MD

Fellow, Bioethics
Senior Resident, Pediatric Neurology

Became a senior bioethics fellow.





Joon-Ho Yu, PhD, MPH

Research Assistant Professor, Division of Genetic Medicine
Research Assistant Professor, Division of Bioethics & Palliative Care*
Center Member, Treuman Katz Center for Pediatric Bioethics
Associate Director, Institute for Public Health Genetics

Became Associate Director of the Institute for Public Health Genetics and Adjunct Assistant Research Professor in the Department of Epidemiology, University of Washington School of Public Health.

Haley Zetterberg, RN, BSN

Palliative Care Consultant
Palliative Care Clinical Service

Joined the Palliative Care Team in 2022.



Looking Forward

As we look forward, we remain focused on delivering world-class clinical care, education/training, and scholarship in Pediatric Bioethics and Pediatric Palliative Care. We plan to continue to do so with an intense focus on health equity, and to continue to be leaders in our fields in this regard. Our strength is our people—and we have an incredible team. We look forward to another year of growing together, helping team members to achieve their goals, and advancing our mission and the missions of the organizations that we serve.

Appreciations

We are appreciative of the ongoing support we have received from **Seattle Children's Hospital, The University of Washington Department of Pediatrics, The Seattle Children's Research Institute, and The Bioethics and Palliative Care Advisory Council.** We greatly appreciate our collaboration with the **Department of Bioethics and Humanities.** We are also deeply grateful for the philanthropic support we have received, particularly from **Treuman Katz, Debra Godfrey, Jeff Sconyers, Barbara, and Eric Mann,** as well as two Seattle Children's Hospital Guilds: **Susannah White's Three Feet of Sunshine** and **Gavin's Gift.** We are thankful to **Simon Pritikin** and **Monica Long** from the Seattle Children's Foundation for their continued partnership and support.

This annual report was made possible through the expertise, hard work, creativity, and diligence of our incredible Administrative Staff. Our most sincere thanks to April Endsley and Debbie Poon for their amazing work on this project. We are also grateful to Colleen Lee for her contributions as Center Business Manager. We deeply appreciate Arika Patneaude, Director of Bioethics and Palliative Care, for shepherding this project from idea to final concept.



Appendix: Complete List of Publications

Current Program Members' Publications FY 22

Anne Anderson, RN, BSN

- 1: Bogetz JF, **Anderson A**, Holland M, Macauley R. Pediatric Hospice and Palliative Care Services and Needs Across the Northwest United States. *J Pain Symptom Manage*. 2022 Jul;64(1):e7-e14. doi: 10.1016/j.jpainsymman.2022.02.015. Epub 2022 Feb 19. PMID: 35192876.

Emily Berkman, MD, MA

- 1: Thompson AD, **Berkman ER**, Simmons S, Porter KM, Kroon L, Goldman R, Ramasamy RS. Ethical Considerations in Balancing Use of Seclusion and Restraint With Risk of COVID-19 Exposure: Recommendations for Youth Inpatient Psychiatry Units. *J Am Acad Child Adolesc Psychiatry*. 2022 Apr 29; S0890-8567(22)00246-5. doi: 10.1016/j.jaac.2022.04.016. Online ahead of print. PMID: 35513190
- 2: **Berkman E**, Brown E, Scott M, Adiele A. Racism in child welfare: Ethical considerations of harm. *Bioethics*. 2022 Mar;36(3):298-304. doi: 10.1111/bioe.12993. Epub 2022 Jan 19. PMID: 35045196.
- 3: **Berkman ER**, Richardson KL, Clark JD, Dick AAS, Lewis-Newby M, Diekema DS, Wightman AG. An ethical analysis of obesity as a contraindication of pediatric kidney transplant candidacy. *Pediatr Nephrol*. 2022 Apr 29. doi: 10.1007/s00467-022-05572-8. Epub ahead of print. PMID: 35488137.
- 4: Clark JD, Baden HP, **Berkman ER**, Bourget E, Brogan TV, Di Gennaro JL, Doorenbos AZ, McMullan DM, Roberts JS, Turnbull JM, Wilfond BS, Lewis-Newby M; Seattle Ethics in ECLS (SEE) Consortium. Ethical Considerations in Ever-Expanding Utilization of ECLS: A Research Agenda. *Front Pediatr*. 2022 May 19;10:896232. doi: 10.3389/fped.2022.896232. PMID: 35664885; PMCID: PMC9160718.
- 5: **Berkman E**, Clark J, Diekema D, Jecker NS. A world away and here at home: a prioritisation framework for US international patient programmes. *J Med Ethics*. 2022 Aug;48(8):557-565. doi: 10.1136/medethics-2020-106772. Epub 2021 Mar 22. PMID: 33753472.
- 6: Chiotos K, Blumenthal J, Boguniewicz J, Palazzi DL, Stalets EL, Rubens JH, Tamma PD, Cabler SS, Newland J, Crandall H, **Berkman E**, Kavanagh RP, Stinson HR, Gerber JS. Antibiotic indications and appropriateness in the pediatric intensive care unit: a ten-center point prevalence study. *Clin Infect Dis*. 2022 Sep 1;ciac698. doi: 10.1093/cid/ciac698. Epub ahead of print. PMID: 36048543.
- 7: Lewis-Newby M, **Berkman E**, Diekema D, Clark J. Heroics at the End of Life in Pediatric Cardiac Intensive Care: The Role of the Intensivist in Supporting Ethical Decisions around Innovative Surgical Interventions. *Ethics in Biology, Engineering and Medicine: An International Journal* 2021. DOI: 10.1615/EthicsBiologyEngMed.2021041108.

- 8: Lewis-Newby M, **Berkman E**, Diekema DS. Ethics in Pediatric Intensive Care. In Fuhrman & Zimmerman's Pediatric Critical Care, 6th Edition. Editors: Zimmerman JJ, Rotta AT. Philadelphia, PA: Elsevier, 2021:144-153.

Jori Bogetz, MD

- 1: **Bogetz JF**, Boss RD, Lemmon ME. Communicating With Families of Children With Severe Neurological Impairment. *J Pain Symptom Manage*. 2022 Feb;63(2): e264-e266. doi: 10.1016/j.jpainsymman.2021.10.012. Epub 2021 Nov 10. PMID: 34767920; PMCID: PMC9624372.
- 2: Morris EL, Hauer J, **Bogetz JF**. Asset-Based Health Care for Children With Severe Neurologic Impairment. *Pediatrics*. 2022 Sep 1;150(3): e2021055654. doi: 10.1542/peds.2021 055654. PMID: 35922560.
- 3: **Bogetz JF**, Trowbridge A, Lewis H, Jonas D, Hauer J, Rosenberg AR. Forming Clinician Parent Therapeutic Alliance for Children With Severe Neurologic Impairment. *Hosp Pediatr*. 2022 Mar 1;12(3):282-292. doi: 10.1542/hpeds.2021-006316. PMID: 35141756.
- 4: Jonas D, Scanlon C, **Bogetz JF**. Parental Decision-Making for Children With Medical Complexity: An Integrated Literature Review. *J Pain Symptom Manage*. 2022 Jan;63(1): e111 e123. doi: 10.1016/j.jpainsymman.2021.07.029. Epub 2021 Aug 29. PMID: 34363953.
- 5: **Bogetz JF**, Trowbridge A, Lewis H, Shipman KJ, Jonas D, Hauer J, Rosenberg AR. Parents Are the Experts: A Qualitative Study of the Experiences of Parents of Children With Severe Neurological Impairment During Decision-Making. *J Pain Symptom Manage*. 2021 Dec;62(6):1117-1125. doi: 10.1016/j.jpainsymman.2021.06.011. Epub 2021 Jun 17. PMID: 34147578; PMCID: PMC8648906.
- 6: **Bogetz JF**, Trowbridge A, Jonas D, Root MC, Mullin J, Hauer J. The Impact of Caring for Children With Severe Neurological Impairment on Clinicians. *Clin Pediatr (Phila)*. 2022 Oct;61(10):707-716. doi: 10.1177/00099228221099135. Epub 2022 May 24. PMID: 35610773.
- 7: **Bogetz J**, Trowbridge A, Kingsley J, Taylor M, Wiener L, Rosenberg AR, Barton KS. Stuck Moments and Silver-Linings: The Spectrum of Adaptation Among Non-Bereaved and Bereaved Parents of Adolescents and Young Adults With Advanced Cancer. *J Pain Symptom Manage*. 2021 Oct;62(4):709-719. doi: 10.1016/j.jpainsymman.2021.03.015. Epub 2021 Mar 26. PMID: 33775813; PMCID: PMC8464607.
- 8: **Bogetz JF**, Revette A, Partin L, DeCoursey DD. Relationships and Resources Supporting Children With Serious Illness and Their Parents. *Hosp Pediatr*. 2022 Sep 1;12(9):832-842. doi: 10.1542/hpeds.2022-006596. PMID: 35945359.
- 9: **Bogetz JF**, Munjapara V, Henderson CM, Raisanen JC, Jabre NA, Shipman KJ, Wilfond BS, Boss RD. Home mechanical ventilation for children with severe neurological impairment: Parents' perspectives on clinician counselling. *Dev Med Child Neurol*. 2022 Jul;64(7):840-846. doi: 10.1111/dmcn.15151. Epub 2022 Jan 26. PMID: 35080259.
- 10: **Bogetz JF**, Johnston E, Ananth P, Patneaude A; Cambia Advisory Workgroup, Thienprayoon R, Rosenberg AR. Survey of Pediatric Palliative Care Quality

Improvement Training, Activities, and Barriers. *J Pain Symptom Manage*. 2022 Sep;64(3):e123-e131. doi: 10.1016/j.jpainsymman.2022.04.182. Epub 2022 May 14. PMID: 35577143.

- 11: **Bogetz JF**, Anderson A, Holland M, Macauley R. Pediatric Hospice and Palliative Care Services and Needs Across the Northwest United States. *J Pain Symptom Manage*. 2022 Jul;64(1):e7-e14. doi: 10.1016/j.jpainsymman.2022.02.015. Epub 2022 Feb 19. PMID: 35192876.
- 12: Kingsley J, Taylor M, **Bogetz JF**, Trowbridge A, Rosenberg AR, Barton KS. Grief Trajectories of Bereaved Parents of Adolescents and Young Adults With Advanced Cancer: A Qualitative Analysis Using Phenomenology. *Omega (Westport)*. 2022 May 15:30228221101705. doi: 10.1177/0030228221101705. Epub ahead of print. PMID: 35575201.
- 13: **Bogetz JF**, Revette A, DeCoursey D. Bereaved Parent Perspectives on the Benefits and Burdens of Technology Assistance among Children with Complex Chronic Conditions. *J Palliat Med*. 2022 Feb;25(2):250-258. doi: 10.1089/jpm.2021.0221. Epub 2021 Oct 7. PMID: 34618616; PMCID: PMC8861906.
- 14: **Bogetz JF**, Lewis H, Trowbridge A, Jonas D, Hauer J, Wilfond BS. From Monochromatic to Technicolor: Parent Perspectives on Challenges and Approaches to Seeing Children with Severe Neurological Impairment Holistically. *J Palliat Med*. 2022 Mar;25(3):437-444. doi: 10.1089/jpm.2021.0344. Epub 2021 Sep 22. PMID: 34551279
- 15: Lewis H, Trowbridge A, Jonas D, Rosenberg AR, **Bogetz JF**. A Qualitative Study of Clinicians and Parents of Children with Severe Neurological Impairment on Tools to Support Family Centered Care. *J Palliat Med*. 2022 Sep;25(9):1338-1344. doi: 10.1089/jpm.2021.0579. Epub 2022 May 20. PMID: 35593900; PMCID: PMC9639233.
- 16: **Bogetz JF**, Revette A, DeCoursey D. Bereaved Parent Perspectives on the Benefits and Burdens of Technology Assistance among Children with Complex Chronic Conditions. *J Palliat Med*. 2022 Feb;25(2):250-258. doi: 10.1089/jpm.2021.0221. Epub 2021 Oct 7. PMID: 34618616; PMCID: PMC8861906.

Jonna Clark, MD, MA

- 1: Killien EY, Loftis LL, **Clark JD**, Muszynski JA, Rissmiller BJ, Singleton MN, White BR, Zimmerman JJ, Maddux AB, Pinto NP, Fink EL, Watson RS, Smith M, Ringwood M, Graham RJ; POST-PICU and PICU-COS Investigators of the Pediatric Acute Lung Injury and Sepsis Investigators and the Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Networks. Health-related quality of life outcome measures for children surviving critical care: a scoping review. *Qual Life Res*. 2021 Dec;30(12):3383-3394. doi: 10.1007/s11136-021-02928-9. Epub 2021 Jun 29. PMID: 34185224; PMCID: PMC9116894.
- 2: Sawyer KE, Kraft SA, Wightman AG, **Clark JD**. Pediatric Death by Neurologic Criteria: The Ever-Changing Landscape and the Expanding Role of Palliative Care Professionals. *J Pain Symptom Manage*. 2021 Nov;62(5):1079-1085. doi: 10.1016/j.jpainsymman.2021.04.026. Epub 2021 May 11. PMID: 33984463.

- 3: **Clark JD**, Baden HP, Berkman ER, Bourget E, Brogan TV, Di Gennaro JL, Doorenbos AZ, McMullan DM, Roberts JS, Turnbull JM, Wilfond BS, Lewis-Newby M; Seattle Ethics in ECLS (SEE) Consortium. Ethical Considerations in Ever- Expanding Utilization of ECLS: A Research Agenda. *Front Pediatr*. 2022 May 19;10:896232. doi: 10.3389/fped.2022.896232. PMID: 35664885; PMCID: PMC9160718.
- 4: Berkman ER, Richardson KL, **Clark JD**, Dick AAS, Lewis-Newby M, Diekema DS, Wightman AG. An ethical analysis of obesity as a contraindication of pediatric kidney transplant candidacy. *Pediatr Nephrol*. 2022 Apr 29. doi: 10.1007/s00467-022-05572-8. Epub ahead of print. PMID: 35488137.
- 5: Pinto NP, Maddux AB, Dervan LA, Woodruff AG, Jarvis JM, Nett S, Killien EY, Graham RJ, Choong K, Luckett PM, Heneghan JA, Biagas K, Carlton EF, Hartman ME, Yagiela L, Michelson KN, Manning JC, Long DA, Lee JH, Slomine BS, Beers SR, Hall T, Morrow BM, Meert K, Arias Lopez MDP, Knoester H, Houtrow A, Olson L, Steele L, Schlapbach LJ, Burd RS, Grosskreuz R, Butt W, Fink EL, Watson RS; POST-PICU Investigators of the Pediatric Acute Lung Injury and Sepsis Investigators (PALISI) Network and the Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN). A Core Outcome Measurement Set for Pediatric Critical Care. *Pediatr Crit Care Med*. 2022 Nov 1;23(11):893-907. doi: 10.1097/PCC.0000000000003055. Epub 2022 Aug 29. PMID: 36040097; PMCID: PMC9633391.
- 6: Berkman E, **Clark J**, Diekema D, Jecker NS. A world away and here at home: a prioritization framework for US international patient programmes. *J Med Ethics*. 2022 Aug;48(8):557-565. doi: 10.1136/medethics-2020-106772. Epub 2021 Mar 22. PMID: 33753472.
- 7: von Saint Andre-von Arnim AO, Kumar RK, **Clark JD**, Wilfond BS, Nguyen QP, Mutonga DM, Zimmerman JJ, Oron AP, Walson JL. Family-Assisted Severity of Illness Monitoring for Hospitalized Children in Low-Resource Settings-A Two-Arm Interventional Feasibility Study. *Front Pediatr*. 2022 May 23;10:804346. doi: 10.3389/fped.2022.804346. PMID: 35676898; PMCID: PMC9169086.
- 8: Lewis-Newby M, Berkman E, Diekema D, **Clark J**. Heroics at the End of Life in Pediatric Cardiac Intensive Care: The Role of the Intensivist in Supporting Ethical Decisions around Innovative Surgical Interventions. *Ethics in Biology, Engineering and Medicine: An International Journal* 2021. DOI: 10.1615/EthicsBiologyEngMed.2021041108.
- 9: Eaton SM, **Clark JD**, Cummings CL, Kon AK, Morrison W, Feudtner C, Streuli JC. Title: Pediatric shared decision making for simple and complex decisions: Delphi panel recommendations. *Pediatrics* 2022, 150(5), e2022057978. PMID: 36217896.

Douglas Diekema, MD, MPH

- 1: **Diekema DS**. Rhetoric, Persuasion, Compulsion, and the Stubborn Problem of Vaccine Hesitancy. *Perspect Biol Med*. 2022;65(1):106-123. doi:10.1353/pbm.2022.0006. PMID: 35307704. Project MUSE – Rhetoric, Persuasion, Compulsion, and the Stubborn Problem of Vaccine Hesitancy (jhu.edu)

- 2: Sun BZ, Wightman A, **Diekema DS**. Caregiver COVID-19 vaccination for solid organ transplant candidates. *Am J Transplant*. 2022 Sep;22(9):2135-2138. doi: 10.1111/ajt.17078. Epub 2022 May 7. PMID: 35485987; PMCID: PMC9111252.
- 3: **Diekema DS**; COMMITTEE ON BIOETHICS. Technical Report: Health Care Clinicians and Product Promotion by Industry. *Pediatrics*. 2022 Apr 1;149(4):e2022056549. doi: 10.1542/peds.2022-056549. PMID: 35977093.
- 4: **Diekema DS**. Policy Statement: Health Care Clinicians and Product Promotion by Industry. *Pediatrics*. 2022 Apr 1;149(4):e2022056548. doi: 10.1542/peds.2022-056548. PMID: 35977092.
- 5: Wightman A, Goldberg A, **Diekema D**. Considering a COVID-19 vaccine mandate for pediatric kidney transplant candidates. *Pediatr Nephrol*. 2022 Nov;37(11):2559-2569. doi: 10.1007/s00467-022-05511-7. Epub 2022 Mar 25. PMID: 35333972; PMCID: PMC8949834.
- 6: Berkman ER, Richardson KL, Clark JD, Dick AAS, Lewis-Newby M, **Diekema DS**, Wightman AG. An ethical analysis of obesity as a contraindication of pediatric kidney transplant candidacy. *Pediatr Nephrol*. 2022 Apr 29. doi: 10.1007/s00467-022-05572-8. Epub ahead of print. PMID: 35488137.
- 7: Berkman E, Clark J, **Diekema D**, Jecker NS. A world away and here at home: a prioritization framework for US international patient programmes. *J Med Ethics*. 2022 Aug;48(8):557-565. doi: 10.1136/medethics-2020-106772. Epub 2021 Mar 22. PMID: 33753472.
- 8: Butler CR, Webster LB, Sakata VL, Tonelli MR, **Diekema DS**, Gray MM. Functionality of Scarce Healthcare Resource Triage Teams During the COVID-19 Pandemic: A Multi Institutional Simulation Study. *Crit Care Explor*. 2022 Jan 21;4(1):e0627. doi: 10.1097/CCE.0000000000000627. PMID: 35083438; PMCID: PMC8785932.
- 9: Butler CR, Webster LB, **Diekema DS**. Staffing crisis capacity: a different approach to healthcare resource allocation for a different type of scarce resource. *J Med Ethics*. 2022 Jul 1;medethics-2022-108262. doi: 10.1136/jme-2022-108262.
- 10: Gray MM, Butler CR, Webster LB, Tonelli MR, Sakata VL, **Diekema DS**. Patient Information Items Needed to Guide the Allocation of Scarce Life-Sustaining Resources: A Delphi Study of Multidisciplinary Experts. *Disaster Med Public Health Prep*. 2022 Feb 10;1-7. doi: 10.1017/dmp.2021.351. Epub ahead of print. PMID: 35139979.
- 11: Butler CR, Webster LB, **Diekema DS**, Gray MM, Sakata VL, Tonelli MR, Vranas KC. Perspectives of Triage Team Members Participating in Statewide Triage Simulations for Scarce Resource Allocation During the COVID-19 Pandemic in Washington State. *JAMA Netw Open*. 2022 Apr 1;5(4):e227639. doi: 10.1001/jamanetworkopen.2022.7639. PMID: 35435971; PMCID: PMC9016492.
- 12: Lewis-Newby M, Berkman E, **Diekema D**, Clark J. Heroics at the End of Life in Pediatric Cardiac Intensive Care: The Role of the Intensivist in Supporting Ethical Decisions around Innovative Surgical Interventions. *Ethics in Biology, Engineering and Medicine: An International Journal* 2021. DOI: 10.1615/EthicsBiologyEngMed.2021041108.

- 13: Opel DJ, Ross LF, **Diekema DS**. Vaccine Mandates for Kids: The Question isn't Whether, But When. Hastings Center Bioethics Forum 2021. Vaccine Mandates for Kids: It's Not Whether, But When - The Hastings Center
- 14: Trail Mix. Camera Bag: Don't Miss the Shot! Washington Trails 2022;57(2):42-43. Don't Miss the Shot: Tips for Capturing Spontaneous Outdoor Photos — Washington Trails Association (wta.org)
- 15: Lewis-Newby M, Berkman E, **Diekema DS**. Ethics in Pediatric Intensive Care. In Fuhrman & Zimmerman's Pediatric Critical Care, 6th Edition. Editors: Zimmerman JJ, Rotta AT. Philadelphia, PA: Elsevier, 2021:144-153.
- 16: **Diekema DS**, Hester DM. Ethical Issues in Pediatrics (Chapter 19). In Guidance for Healthcare Ethics Committees, 2nd Edition. Eds DM Hester and T Schonfeld. New York: Cambridge University Press, 2022. Pp 165-174.

Denise Dudzinski, PhD, MTS, HEC-C

- 1: **Dudzinski DM**. Moral Outrage Toward Willfully Unvaccinated COVID-19 Patients. J Gen Intern Med. 2022 Jun;37(8):2070-2071. doi: 10.1007/s11606-022-07496-3. Epub 2022 Apr 1. PMID: 35364754; PMCID: PMC8974797.
- 2: Campelia GD, Kirkpatrick JN, Treece PD, Shirley JL, **Dudzinski DM**. Discharging to the Street: When Patients Refuse Medically Safer Options. J Clin Ethics. 2022 Summer;33(2):92-100. PMID: 35731813.
- 3: Campelia, GD, **Dudzinski DM**. Forthcoming 2022. "Mission, Vision, Goals and consultation process", In Hester, M & T McGuire (Eds) Guidance for Healthcare Ethics Committees, Second Edition. Cambridge University Press.
- 4: Parsi, K & **Dudzinski DM**. 2022. The Need for Praxis in Combating the Race Idea: Reflection, Action, and Theory. *American Journal of Bioethics*, 22(3):4-5.

Devan Duenas, MA

- 1: Wilfond BS, **Duenas DM**, Johnson LM. Supporting Community-Academic Research Partnerships: Reflections from the Ground. Am J Bioeth. 2021 Oct;21(10):44-45. Doi: 10.1080/15265161.2021.1965255. PMID: 34554061; PMCID: PMC8591989
- 2: Johnson LM, **Duenas DM**, Wilfond BS. When Professional Meets Personal: How Should Research Staff Advertise on Social Media for Research Opportunities? Am J Bioeth. 2021 Oct;21(10):38-39. Doi: 10.1080/15265161.2021.1965251. PMID: 34554059; PMCID: PMC8591987
- 3: Lindberg NM, Mittendorf KF, **Duenas DM**, Anderson K, Koomas A, Kraft SA, Okuyama S, Shipman KJ, Vandermeer ML, Goddard KA, Wilfond BS, McMullen C. Engaging Patient Advisory Committees to Inform a Genomic Cancer Risk Study: Lessons for Future Efforts. Perm J. 2022 Jun 29;26(2):28-39. Doi: 10.7812/TPP/21.091. Epub 2022 Jun 17. PMID: 35933674; PMCID: PMC9662241
- 4: Wilfond BS, **Duenas DM**, Johnson LM. Enrolling Adolescents with Rare Disease for Early Phase Clinical Trials While Under the Care of Child Protection Services: Balancing Protection and Access. AM J Bioeth. 2022 Apr;22(4):81-82. Doi: 10.1080/15265161.2022.2044552. PMID: 35420512; PMCID: PMC9534357

- 5: Mittendorf KF, Lewis HS, **Duenas DM**, Eubanks DJ, Filmore MJ, Godddard KAB, Joseph G, Kauffman TL, Kraft SA, Lindberg NM, Reyes AA, Shuster E, Syngal S, Ukaegbu C, Zepp JM, Wilfond BS, Porter KM. Literacy-adapted, electronic family history assessment for genetics referral in primary care: patient user insights from qualitative interview. *Hered cancer Clin Pract*. 2022 Jun 10;20(1):22. Doi: 10.1186/s13053-022-00231-3. PMID: 35689290; PMCID: PMC9188215
- 6: Mittendorf KF, Kauffman TL, Amendola LM, Anderson KP, Biesecker BB, Dorschner MO, **Duenas DM**, Eubanks DJ, Feigelson HS, Gilmore MJ, Hunter JE, Joseph G, Kraft SA, Lee SSJ, Leo MC, Liles EG, Lindberg NM, Muessig KR, Okuyama S, Porter KM, Riddle LS, Rolf BA, Rope AF, Zepp JM, Jarvik GP, Wilfond BS, Goddard KABI; CHARM study team. Corrigendum to “Cancer Health Assessments Reach Many (CHARM): A clinical trial assessing a multimodal cancer genetics services delivery program and its impact on diverse populations” [*Contemporary clinical Trials* 106 (2021)106432]. *Contemp Clin Trials*. 2022 Mar; 114:106682. Doi: 10.106/j.cct.2022.106682. Epub 2022 Feb 3. Erratum for: *Comtemp Clin Trials*. 2021 Jul; 106:106432. PMID: 35123916
- 7: **Duenas DM**, Shipman KJ, Porter KM, Shuster E, Guerra C, Reyes A, Kauffman TL, Hunter JE, Goddard KAB, Wilfond BS, Kraft SA. Motivations and concerns of patients considering participation in an implementation study of a hereditary cancer risk assessment program in diverse primary care settings. *Genet Med*. 2022 Mar;24(3):610-621. Doi: 10.1016/j.gim.2021.11.017. Epub 2021 Nov 23. PMID: 34906471; PMCID: PMC8939763
- 8: Joseph G, Leo MC, Riddle L, Guerra C, Amendola LM, Gilmore MJ, Rolf BA, Dorschner MO, Zepp J, Biesecker BB, Caruncho M, Hunter JE, Keast E, Lewis HS, **Duenas D**, Kauffman T, Bulkley JE, Anderson KP, Jarvik GP, Goddard KAB, Wilfond BS; CHARM Study Team. An accessible, relational, inclusive, and actionable (ARIA) model of genetic counseling compared with usual care: Results of a randomized controlled trial. *Genet Med*. 2022 Nov;24(11):2228-2239. Doi: 10.1016/j.gim.2022.07.025. Epub 2022 Sep 2. PMID: 36053287
- 9: Amendola LM, Shuster E, Leo MC, Dorschner MO, Rolf BA, Shirts BH, Gilmore MJ, Okuyama S, Zepp JM, Kauffman TL, Mittendorf KF, Bellcross C, Jenkins CL, Joseph G, Riddle L, Syngal S, Ukaebu C, Goddard KAB, Wilfond BS, Jarvik GP; CHARM Study. Laboratory-related outcomes from integrating an accessible delivery model for hereditary cancer risk assessment and genetic testing in populations with barriers to access. *Genet Med*. 2022 Jun;24(6):1196-1205. Doi: 10.1016/j.gim.2022.02.006. Epub 2022 Mar 16. PMID: 35305866

Nicolas Dundas, MPH

- 1: Claw KG, **Dundas N**, Parrish MS, Begay RL, Teller TL, Garrison NA, Sage F. Perspectives on Genetic Research: Results From a Survey of Navajo Community Members. *Front Genet*. 2021 Dec 2; 12:734529. doi: 10.3389/fgene.2021.734529. PMID: 34925442; PMCID: PMC8675633.
- 2: Opel DJ, Furniss A, Zhou C, Rice JD, Spielvogel H, Spina C, Perreira C, Giang J, **Dundas N**, Dempsey A, Pahud B, Robinson J, O’Leary S. Parent Attitudes Towards Childhood Vaccines After the Onset of SARS-CoV-2 in the United States. *Acad*

Pediatr. 2022 Nov-Dec;22(8):1407-1413. doi: 10.1016/j.acap.2022.06.014. Epub 2022 Jul 1. PMID: 35787455; PMCID: PMC9249407.

Jennifer Kett, MD, MA

- 1: Olszewski AE, Adiele A, Patneaude A, Zerr DM, **Kett JC**. The Health Equity Impact Assessment: A Case Study in COVID-19 Visitor Policy. Hosp Pediatr. 2021 Nov 4;hpeds.2021-006128. Doi: 10.1542/hpeds.2021-006128. Epub ahead of print. PMID: 34737217
- 2: Trowbridge A, Wightman A, **Kett J**. Promise me she'll survive: Navigating emotion and uncertainty in paediatric chronic disease with low-mortality rates. Acta Paediatr. 2022 Mar;111(3):464-466. Doi: 10.1111/apa.16179. Epub 2021 Dec 3. PMID: 34751969

Kristi Klee, DNP, MA, RN, CPHQ

- 1: **Klee K**, Wilfond B, Thomas K, Ridling D. Conflicts between parents and clinicians: Tracheotomy decisions and clinical bioethics consultation. Nurs Ethics. 2022 May;29(3):685-695. doi: 10.1177/09697330211023986. Epub 2022 Jan 31. PMID: 3594605

Stephanie Kraft, JD

- 1: Mittendorf KF, Knerr S, Kauffman TL, Lindberg NM, Anderson KP, Feigelson HS, Gilmore MJ, Hunter JE, Joseph G, **Kraft SA**, Zepp JM, Syngal S, Wilfond BS, Goddard KAB. Systemic Barriers to Risk-Reducing Interventions for Hereditary Cancer Syndromes: Implications for Health Care Inequities. JCO Precis Oncol. 2021 Nov 3;5:PO.21.00233. doi: 10.1200/PO.21.00233. PMID: 34778694; PMCID: PMC8585306.
- 2: Sawyer KE, **Kraft SA**, Wightman AG, Clark JD. Pediatric Death by Neurologic Criteria: The Ever-Changing Landscape and the Expanding Role of Palliative Care Professionals. J Pain Symptom Manage. 2021 Nov;62(5):1079-1085. doi: 10.1016/j.jpainsymman.2021.04.026. Epub 2021 May 11. PMID: 33984463.
- 3: Morain SR, **Kraft SA**, Wilfond BS, McGuire A, Dickert NW, Garland A, Sugarman J. Toward Meeting the Obligation of Respect for Persons in Pragmatic Clinical Trials. Hastings Cent Rep. 2022 May;52(3):9-17. doi: 10.1002/hast.1391. PMID: 35763201; PMCID: PMC9704739.
- 4: Smith HS, Morain SR, Robinson JO, Canfield I, Malek J, Rubanovich CK, Bloss CS, Ackerman SL, Biesecker B, Brothers KB, Goytia CN, Horowitz CR, Knight SJ, Koenig B, **Kraft SA**, Outram S, Rini C, Shipman KJ, Waltz M, Wilfond B, McGuire AL. Perceived Utility of Genomic Sequencing: Qualitative Analysis and Synthesis of a Conceptual Model to Inform Patient Centered Instrument Development. Patient. 2022 May;15(3):317-328. doi: 10.1007/s40271-021-00558-4. Epub 2021 Oct 18. PMID: 34658003; PMCID: PMC9013723.
- 5: Lindberg NM, Mittendorf KF, Duenas DM, Anderson K, Koomas A, **Kraft SA**, Okuyama S, Shipman KJ, Vandermeer ML, Goddard KA, Wilfond BS, McMullen C.

Engaging Patient Advisory Committees to Inform a Genomic Cancer Risk Study: Lessons for Future Efforts. Perm J. 2022 Jun 29;26(2):28-39. doi: 10.7812/TPP/21.091. Epub 2022 Jun 17. PMID: 35933674; PMCID: PMC9662241.

- 6: Mittendorf KF, Lewis HS, Duenas DM, Eubanks DJ, Gilmore MJ, Goddard KAB, Joseph G, Kauffman TL, **Kraft SA**, Lindberg NM, Reyes AA, Shuster E, Syngal S, Ukaegbu C, Zepp JM, Wilfond BS, Porter KM. Literacy-adapted, electronic family history assessment for genetics referral in primary care: patient user insights from qualitative interviews. Hered Cancer Clin Pract. 2022 Jun 10;20(1):22. doi: 10.1186/s13053-022-00231-3. PMID: 35689290; PMCID: PMC9188215.
- 7: Mittendorf KF, Kauffman TL, Amendola LM, Anderson KP, Biesecker BB, Dorschner MO, Duenas DM, Eubanks DJ, Feigelson HS, Gilmore MJ, Hunter JE, Joseph G, **Kraft SA**, Lee SSJ, Leo MC, Liles EG, Lindberg NM, Muessig KR, Okuyama S, Porter KM, Riddle LS, Rolf BA, Rope AF, Zepp JM, Jarvik GP, Wilfond BS, Goddard KAB; CHARM study team. Corrigendum to "Cancer Health Assessments Reaching Many (CHARM): A clinical trial assessing a multimodal cancer genetics services delivery program and its impact on diverse populations" [Contemporary Clinical Trials 106 (2021) 106432]. Contemp Clin Trials. 2022 Mar;114:106682. doi: 10.1016/j.cct.2022.106682. Epub 2022 Feb 3. Erratum for: Contemp Clin Trials. 2021 Jul;106:106432. PMID: 35123916.
- 8: Duenas DM, Shipman KJ, Porter KM, Shuster E, Guerra C, Reyes A, Kauffman TL, Hunter JE, Goddard KAB, Wilfond BS, **Kraft SA**. Motivations and concerns of patients considering participation in an implementation study of a hereditary cancer risk assessment program in diverse primary care settings. Genet Med. 2022 Mar;24(3):610-621. doi: 10.1016/j.gim.2021.11.017. Epub 2021 Nov 23. PMID: 34906471; PMCID: PMC8939763.
- 9: Roman C, Nowakowski A, Lazzara J, Aliaj E, Porter K, **Kraft SA**, Shah S, Borowitz D, Wilfond BS, Lessons learned about publication of results of community surveys when regulatory oversight has not occurred, SSM - Qualitative Research in Health, Volume 2, 2022, 100091, ISSN 2667-3215,

Leah Kroon, MA, MN, RN, CPHON

- 1: Thompson AD, Berkman ER, Simmons S, Porter KM, **Kroon L**, Goldman R, Ramasamy RS. Ethical Considerations in Balancing Use of Seclusion and Restraint With Risk of COVID-19 Exposure: Recommendations for Youth Inpatient Psychiatry Units. J Am Acad Child Adolesc Psychiatry. 2022 Apr 29; S0890-8567(22)00246-5. doi: 10.1016/j.jaac.2022.04.016. Online ahead of print. PMID: 35513190

Brittany Lee, MD, MA

- 1: **Lee BM**, Jecker NS, Marron JM, Rosenberg AR. Striving for equity: Patient prioritization during a critical cancer drug shortage. Pediatr Blood Cancer. 2021 Nov;68(11):e29280. doi: 10.1002/pbc.29280. Epub 2021 Aug 6. PMID: 34357696. Striving for equity: Patient prioritization during a critical cancer drug shortage – Lee – 2021 – Pediatric Blood & Cancer – Wiley Online Library
- 2: Koff A, Burns R, Auerbach M, Lee B, Pearce J, Ciener D, Augenstein J, Yeung C, Thomas A. Pediatric Emergency Medicine Didactics and Simulation (PEMDAS)

Telesimulation Series: Hyperleukocytosis. MedEdPORTAL. 2021 Dec 13;17:11205. doi: 10.15766/mep_2374-8265.11205. PMID: 34963902; PMCID: PMC8666409. Pediatric Emergency Medicine Didactics and Simulation (PEMDAS) Telesimulation Series: Hyperleukocytosis – PMC (nih.gov)

- 3: Hunter JD, Robertson EG, Hetherington K, Ziegler DS, Marshall GM, Kirk J, Marron JM, Denburg AE, Barlow-Stewart K, Warby M, Tucker KM, **Lee BM**, O'Brien TA, Wakefield CE. What's in a Name? Parents' and Healthcare Professionals' Preferred Terminology for Pathogenic Variants in Childhood Cancer Predisposition Genes. J Pers Med. 2022 Aug 18;12(8):1327. doi: 10.3390/jpm12081327. PMID: 36013276; PMCID: PMC9410181. What's in a Name? Parents' and Healthcare Professionals' Preferred Terminology for Pathogenic Variants in Childhood Cancer Predisposition Genes – PMC (nih.gov)
- 4: **Lee BM**, Bonkowski E, Marron JM, Barton KS, Rosenberg AR. Communication with caregivers about tumor genomic sequencing in childhood cancers. Journal of Clinical Oncology. 2022; 40 (28_suppl), 245-245. Communication with caregivers about tumor genomic sequencing in childhood cancers. | Journal of Clinical Oncology (ascopubs.org)

Hannah Lewis, BA

- 1: Bogetz JF, Trowbridge A, **Lewis H**, Jonas D, Hauer J, Rosenberg AR. Forming Clinician-Parent Therapeutic Alliance for Children With Severe Neurologic Impairment. Hosp Pediatr. 2022 Mar 1;12(3):282-292. doi: 10.1542/hpeds.2021-006316. PMID: 35141756. Forming Clinician-Parent Therapeutic Alliance for Children With Severe Neurologic Impairment | Hospital Pediatrics | American Academy of Pediatrics (aap.org)
- 2: Bogetz JF, Trowbridge A, **Lewis H**, Shipman KJ, Jonas D, Hauer J, Rosenberg AR. Parents Are the Experts: A Qualitative Study of the Experiences of Parents of Children With Severe Neurological Impairment During Decision-Making. J Pain Symptom Manage. 2021 Dec;62(6):1117-1125. doi: 10.1016/j.jpainsymman.2021.06.011. Epub 2021 Jun 17. PMID: 34147578; PMCID: PMC8648906. Parents Are the Experts: A Qualitative Study of the Experiences of Parents of Children with Severe Neurological Impairment During Decision-Making – PMC (nih.gov)
- 3: Bogetz JF, **Lewis H**, Trowbridge A, Jonas D, Hauer J, Wilfond BS. From Monochromatic to Technicolor: Parent Perspectives on Challenges and Approaches to Seeing Children with Severe Neurological Impairment Holistically. J Palliat Med. 2022 Mar;25(3):437-444. doi: 10.1089/jpm.2021.0344. Epub 2021 Sep 22. PMID: 34551279. From Monochromatic to Technicolor: Parent Perspectives on Challenges and Approaches to Seeing Children with Severe Neurological Impairment Holistically | Journal of Palliative Medicine (liebertpub.com)
- 4: **Lewis H**, Trowbridge A, Jonas D, Rosenberg AR, Bogetz JF. A Qualitative Study of Clinicians and Parents of Children with Severe Neurological Impairment on Tools to Support Family-Centered Care. J Palliat Med. 2022 Sep;25(9):1338-1344. Doi: 10.1089/jpm.2021.0579. Epub 2022 May 20. PMID: 35593900; PMCID: PMC9639233. https://www.liebertpub.com/doi/10.1089/jpm.2021.0579?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%20pubmed
- 5: Mittendorf KF, **Lewis HS**, Duenas DM, Eubanks DJ, Gilmore MJ, Goddard KAB,

Joseph G, Kauffman TL, Kraft SA, Lindberg NM, Reyes AA, Shuster E, Syngal S, Ukaegbu C, Zepp JM, Wilfond BS, Porter KM. Literacy-adapted, electronic family history assessment for genetics referral in primary care: patient user insights from qualitative interviews. *Hered Cancer Clin Pract.* 2022 Jun 10;20(1):22. doi: 10.1186/s13053-022-00231-3. PMID: 35689290; PMCID: PMC9188215. Literacy-adapted, electronic family history assessment for genetics referral in primary care: patient user insights from qualitative interviews | Hereditary Cancer in Clinical Practice | Full Text (biomedcentral.com)

- 6: Joseph G, Leo MC, Riddle L, Guerra C, Amendola LM, Gilmore MJ, Rolf BA, Dorschner MO, Zepp J, Biesecker BB, Caruncho M, Hunter JE, Keast E, **Lewis HS**, Duenas D, Kauffman T, Bulkley JE, Anderson KP, Jarvik GP, Goddard KAB, Wilfond BS; CHARM Study Team. An accessible, relational, inclusive, and actionable (ARIA) model of genetic counseling compared with usual care: Results of a randomized controlled trial. *Genet Med.* 2022 Nov;24(11):2228-2239. doi: 10.1016/j.gim.2022.07.025. Epub 2022 Sep 2. PMID: 36053287. [No free PDF. Can ask Library to purchase]
- 7: Amendola LM, Shuster E, Leo MC, Dorschner MO, Rolf BA, Shirts BH, Gilmore MJ, Okuyama S, Zepp JM, Kauffman TL, Mittendorf KF, Bellcross C, Jenkins CL, Joseph G, Riddle L, Syngal S, Ukaegbu C, Goddard KAB, Wilfond BS, Jarvik GP; CHARM Study. Laboratory-related outcomes from integrating an accessible delivery model for hereditary cancer risk assessment and genetic testing in populations with barriers to access. *Genet Med.* 2022 Jun;24(6):1196-1205. doi: 10.1016/j.gim.2022.02.006. Epub 2022 Mar 16. PMID: 35305866. Laboratory-related outcomes from integrating an accessible delivery model for hereditary cancer risk assessment and genetic testing in populations with barriers to access – ScienceDirect

Mithya Lewis-Newby, MD, MPH

- 1: Clark JD, Baden HP, Berkman ER, Bourget E, Brogan TV, Di Gennaro JL, Doorenbos AZ, McMullan DM, Roberts JS, Turnbull JM, Wilfond BS, **Lewis-Newby M**; Seattle Ethics in ECLS (SEE) Consortium. Ethical Considerations in Ever- Expanding Utilization of ECLS: A Research Agenda. *Front Pediatr.* 2022 May 19;10:896232. doi: 10.3389/fped.2022.896232. PMID: 35664885; PMCID: PMC9160718.
- 2: Berkman ER, Richardson KL, Clark JD, Dick AAS, **Lewis-Newby M**, Diekema DS, Wightman AG. An ethical analysis of obesity as a contraindication of pediatric kidney transplant candidacy. *Pediatr Nephrol.* 2022 Apr 29. doi: 10.1007/s00467-022-05572-8. Epub ahead of print. PMID: 35488137.
- 3: **Lewis-Newby M**, Berkman E, Diekema D, Clark J. Heroics at the End of Life in Pediatric Cardiac Intensive Care: The Role of the Intensivist in Supporting Ethical Decisions around Innovative Surgical Interventions. *Ethics in Biology, Engineering and Medicine: An International Journal* 2021. DOI: 10.1615/EthicsBiologyEngMed.2021041108.
- 4: **Lewis-Newby M**, Berkman E, Diekema DS. Ethics in Pediatric Intensive Care. In *Fuhrman & Zimmerman's Pediatric Critical Care*, 6th Edition. Editors: Zimmerman JJ, Rotta AT. Philadelphia, PA: Elsevier, 2021:144-153. [Chapter]

Kate MacDuffie, PhD, MA

- 1: **MacDuffie KE**, Hyun I, Krogen MM, Dempsey JC, Murry CE, Copp AJ, Glass IA, Doherty D. Rescuing human fetal tissue research in the United States: A call for additional regulatory reform. *Stem Cell Reports*. 2021 Dec 14;16(12):2839-2843. Doi: 10.1016/j.stemcr. 2021.10.016. Epub 2021 Nov 24. PMID: 34822773; PMCID: PMC8693650
- 2: **MacDuffie KE**. What Brain Organoid Research Can Gain From Engaging Biospecimen Donors. *AJOB Neurosci*, 2022 Apr-Jun;13(2):95-97. Doi: 10.1080/21507740.2022.2048734. PMID: 35324405; PMCID: PMC9707507
- 3: **MacDuffie KE**, Patneaud A, Bell S, Adiele A, Makhija N, Wilfond B, Opel D. Addressing racism in the healthcare encounter: The role of clinical ethics consultants. *Bioethics*. 2022 Mar;36(3):313-317. Doi:10.1111/bioe.13008. Epub 2022 Feb 7. PMID: 35132655
- 4: **MacDuffie KE**, Ransom S, Klein E. Neuroethics Inside and Out: A Comparative Survey of Neural Device Industry Representatives and the General Public on Ethical Issues and Principles in Neurotechnology. *AJOB Neurosci*, 2022 Jan-Mar;13(1):44-54. doi: 10.1080/21507740.2021.1896596. Epub 2021 Mar 31. PMID: 33787456

Macallagh McEvoy, RN, MN, ARNP

- 1: **McEvoy MJ**, Scott MJ, Sawyer KE. Requests for Accommodation in Brain Death Cases: Emerging Role for Pediatric Palliative Care. *J Pain Symptom Manage*. 2021 Dec;62(6):1319-1324. doi: 10.1016/j.jpainsymman.2021.04.020. Epub 2021 Apr 29. PMID: 33933614. Requests for Accommodation in Brain Death Cases: Emerging Role for Pediatric Palliative Care – ScienceDirect

Douglas Opel, MD, MPH

- 1: Omer SB, Benjamin RM, Brewer NT, Bутtenheim AM, Callaghan T, Caplan A, Carpiano RM, Clinton C, DiResta R, Elharake JA, Flowers LC, Galvani AP, Lakshmanan R, Maldonado YA, McFadden SM, Mello MM, **Opel DJ**, Reiss DR, Salmon DA, Schwartz JL, Sharfstein JM, Hotez PJ. Promoting COVID-19 vaccine acceptance: recommendations from the Lancet Commission on Vaccine Refusal, Acceptance, and Demand in the USA. *Lancet*. 2021 Dec 11;398(10317):2186-2192. doi: 10.1016/S0140-6736(21)02507-1. Epub 2021 Nov 15. PMID: 34793741; PMCID: PMC8592561.
- 2: Brewer NT, Bутtenheim AM, Clinton CV, Mello MM, Benjamin RM, Callaghan T, Caplan A, Carpiano RM, DiResta R, Elharake JA, Flowers LC, Galvani AP, Hotez PJ, Lakshmanan R, Maldonado YA, Omer SB, Salmon DA, Schwartz JL, Sharfstein JM, **Opel DJ**. Incentives for COVID-19 vaccination. *Lancet Reg Health Am*. 2022 Apr;8:100205. doi: 10.1016/j.lana.2022.100205. Epub 2022 Feb 24. PMID: 35229080; PMCID: PMC8866051.

- 3: Bryan MA, Hofstetter AM, **Opel DJ**, Simon TD. Vaccine Administration in Children's Hospitals. *Pediatrics*. 2022 Feb 1;149(2):e2021053925. doi: 10.1542/peds.2021-053925. PMID: 35001100; PMCID: PMC9677936.
- 4: Bryan MA, Hofstetter AM, Ramos D, Ramirez M, **Opel DJ**. Facilitators and Barriers to Providing Vaccinations During Hospital Visits. *Hosp Pediatr*. 2021 Oct;11(10):1137-1152. doi: 10.1542/hpeds.2020-004655. PMID: 34556537.
- 5: Kroshus E, Bowen D, **Opel D**, Chrisman SPD, Rivara FP. Understanding Decision Making by Families About Youth Football Participation Postconcussion. *Health Promot Pract*. 2021 Nov;22(6):829-839. doi: 10.1177/1524839920945255. Epub 2020 Jul 30. PMID: 32729330.
- 6: Beck J, O'Hara KL, Falco CN, Bassett HK, Randall CL, Cruz S, Senturia K, Hanson JL, Wignall J, **Opel DJ**. How Attendings Can Help Residents Navigate Moral Distress: A Qualitative Study. *Acad Pediatr*. 2021 Nov-Dec;21(8):1458-1466. doi: 10.1016/j.acap.2021.06.006. Epub 2021 Jun 17. PMID: 34146721.
- 7: **Opel DJ**, Reich JA, Peek ME. Amplifying Appeals to the Common Good in COVID-19 Vaccine Messaging. *JAMA Health Forum*. 2022 May 6;3(5):e220991. doi: 10.1001/jamahealthforum.2022.0991. PMID: 36219029.
- 8: Mello MM, **Opel DJ**, Benjamin RM, Callaghan T, DiResta R, Elharake JA, Flowers LC, Galvani AP, Salmon DA, Schwartz JL, Brewer NT, Buttenheim AM, Carpiano RM, Clinton C, Hotez PJ, Lakshmanan R, Maldonado YA, Omer SB, Sharfstein JM, Caplan A. Effectiveness of vaccination mandates in improving uptake of COVID-19 vaccines in the USA. *Lancet*. 2022 Aug 13;400(10351):535-538. doi: 10.1016/S0140-6736(22)00875-3. Epub 2022 Jul 8. PMID: 35817078; PMCID: PMC9270060.
- 9: MacDuffie KE, Patneaude A, Bell S, Adiele A, Makhija N, Wilfond B, **Opel D**. Addressing racism in the healthcare encounter: The role of clinical ethics consultants. *Bioethics*. 2022 Mar;36(3):313-317. doi: 10.1111/bioe.13008. Epub 2022 Feb 7. PMID: 35132655.
- 10: Zaveri PP, Clark S, Kan K, Lee BR, Naik V, **Opel DJ**, Popovsky E, Ren D, Simpson J, Watts J, White ML, Myers AL. Rapid Development and Testing of a COVID-19 Vaccine Curriculum for Pediatricians. *Acad Pediatr*. 2022 Sep 16:S1876-2859(22)00430-2. doi: 10.1016/j.acap.2022.09.010. Epub ahead of print. PMID: 36122826; PMCID: PMC9479378.
- 11: **Opel DJ**, Furniss A, Zhou C, Rice JD, Spielvogle H, Spina C, Perreira C, Giang J, Dundas N, Dempsey A, Pahud B, Robinson J, O'Leary S. Parent Attitudes Towards Childhood Vaccines After the Onset of SARS-CoV-2 in the United States. *Acad Pediatr*. 2022 Nov-Dec;22(8):1407-1413. doi: 10.1016/j.acap.2022.06.014. Epub 2022 Jul 1. PMID: 35787455; PMCID: PMC9249407.
- 12: Ross LF, **Opel DJ**. The case against COVID-19 vaccine mandates in pediatric solid organ transplantation. *Pediatr Transplant*. 2022 Nov;26(7):e14243. doi: 10.1111/petr.14243. Epub 2022 Feb 12. PMID: 35150196; PMCID: PMC9115529.
- 13: **Opel DJ**, Ross LF, Diekema DS. Vaccine Mandates for Kids: The Question isn't Whether, But When. *Hastings Center Bioethics Forum* 2021. Vaccine Mandates for Kids: It's Not Whether, But When - The Hastings Center

- 14: **Opel, D**, Larson, H. (2021). Vaccine Confidence and the Importance of an Interdisciplinary Approach. *Journal of Law, Medicine & Ethics*, 49(4), 596-598. doi:10.1017/jme.2021.82

Arika Patneaude, MSW, LICSW, APHSW-C

- 1: Olszewski AE, Adiele A, **Patneaude A**, Zerr DM, Kett JC. The Health Equity Impact Assessment: A Case Study in COVID-19 Visitor Policy. *Hosp Pediatr*. 2021 Nov 4;hpeds.2021-006128. doi: 10.1542/hpeds.2021-006128. Epub ahead of print. PMID: 34737217.
- 2: MacDuffie KE, **Patneaude A**, Bell S, Adiele A, Makhija N, Wilfond B, Opel D. Addressing racism in the healthcare encounter: The role of clinical ethics consultants. *Bioethics*. 2022 Mar;36(3):313-317. doi: 10.1111/bioe.13008. Epub 2022 Feb 7. PMID: 35132655.
- 3: Bogetz JF, Johnston E, Ananth P, **Patneaude A**; Cambia Advisory Workgroup, Thienprayoon R, Rosenberg AR. Survey of Pediatric Palliative Care Quality Improvement Training, Activities, and Barriers. *J Pain Symptom Manage*. 2022 Sep;64(3):e123-e131. doi: 10.1016/j.jpainsymman.2022.04.182. Epub 2022 May 14. PMID: 35577143.
- 4: Jonas D, **Patneaude A**, Purol N, Scanlon C, Remke S. Defining Core Competencies and a Call to Action: Dissecting and Embracing the Crucial and Multifaceted Social Work Role in Pediatric Palliative Care. *J Pain Symptom Manage*. 2022 Jun;63(6):e739-e748. doi: 10.1016/j.jpainsymman.2022.02.341. Epub 2022 Feb 27. PMID: 35235858.

Kathryn Porter, JD, MPH

- 1: Thompson AD, Berkman ER, Simmons SW, **Porter KM**, Kroon L, Goldman R, Ramasamy RS. Ethical Considerations in Balancing Use of Seclusion and Restraint With Risk of COVID-19 Exposure: Recommendations for Youth Inpatient Psychiatry Units. *J Am Acad Child Adolesc Psychiatry*. 2022 Nov;61(11):1319-1321. doi: 10.1016/j.jaac.2022.04.016. Epub 2022 May 2. PMID: 35513190; PMCID: PMC9057649.
- 2: Mittendorf KF, Lewis HS, Duenas DM, Eubanks DJ, Gilmore MJ, Goddard KAB, Joseph G, Kauffman TL, Kraft SA, Lindberg NM, Reyes AA, Shuster E, Syngal S, Ukaegbu C, Zepp JM, Wilfond BS, **Porter KM**. Literacy-adapted, electronic family history assessment for genetics referral in primary care: patient user insights from qualitative interviews. *Hered Cancer Clin Pract*. 2022 Jun 10;20(1):22. doi: 10.1186/s13053-022-00231-3. PMID: 35689290; PMCID: PMC9188215.
- 3: Taylor HA, **Porter KM**, Paquette ET, McCormick JB, Tumilty E, Arnold JF, Spector-Bagdady K, Danis M, Brandt D, Shah J, Wilfond BS, Lee LM. Creating a Research Ethics Consultation Service: Issues to Consider. *Ethics Hum Res*. 2021 Sep;43(5):18-25. doi: 10.1002/eahr.500101. PMID: 34496156; PMCID: PMC9254506.
- 4: Duenas DM, Shipman KJ, **Porter KM**, Shuster E, Guerra C, Reyes A, Kauffman TL, Hunter JE, Goddard KAB, Wilfond BS, Kraft SA. Motivations and concerns of patients considering participation in an implementation study of a hereditary cancer risk assessment program in diverse primary care settings. *Genet Med*. 2022

Mar;24(3):610-621. doi: 10.1016/j.gim.2021.11.017. Epub 2021 Nov 23. PMID: 34906471; PMCID: PMC8939763.

- 5: Liles EG, Leo MC, Freed AS, **Porter KM**, Zepp JM, Kauffman TL, Keast E, McMullen CK, Groß I, Biesecker BB, Muessig KR, Eubanks DJ, Amendola LM, Dorschner MO, Rolf BA, Jarvik GP, Goddard KAB, Wilfond BS. ORCA, a values-based decision aid for selecting additional findings from genomic sequencing in adults: Efficacy results from a randomized trial. *Genet Med*. 2022 Aug;24(8):1664-1674. doi: 10.1016/j.gim.2022.04.008. Epub 2022 May 6. PMID: 35522237; PMCID: PMC9586129.
- 6: Roman C, Nowakowski A, Lazzara J, Aliaj E, **Porter K**, Kraft SA, Shah S, Borowitz D, Wilfond BS. Lessons learned about publication of results of community surveys when regulatory oversight has not occurred, *SSM - Qualitative Research in Health*, Volume 2, 2022, 100091, ISSN 2667-3215,

Eileen Rhee, MD, MS

- 1: Quintana Grijalba C, **Rhee E**, Zimmerman JJ. The ICU Liberation ABCDEF Bundle: Utilization Among Critically Ill Little Adults. *Crit Care Med*. 2022 Jan 1;50(1):163-165. doi: 10.1097/CCM.0000000000005214. PMID: 34914649. The ICU Liberation ABCDEF Bundle: Utilization Among Critical... : Critical Care Medicine (lww.com)

Heather Spielvogle, PhD

- 1: Opel DJ, Furniss A, Zhou C, Rice JD, **Spielvogle H**, Spina C, Perreira C, Giang J, Dundas N, Dempsey A, Pahud B, Robinson J, O'Leary S. Parent Attitudes Toward Childhood Vaccines After the Onset of SARS-CoV-2 in the United States. *Acad Pediatr*. 2022 Nov-Dec;22(8):1407-1413. Doi: 10.1016/j.acap.2022.06.014. Epub 2022 Jul 1. PMID: 35787455; PMCID: PMC92494070

Amy Trowbridge, MD

- 1: Bogetz JF, **Trowbridge A**, Lewis H, Jonas D, Hauer J, Rosenberg AR. Forming Clinician-Parent Therapeutic Alliance for Children With Severe Neurologic Impairment. *Hosp Pediatr*. 2022 Mar 1;12(3):282-292. doi: 10.1542/hpeds.2021-006316. PMID: 35141756.
- 2: Bogetz JF, **Trowbridge A**, Lewis H, Shipman KJ, Jonas D, Hauer J, Rosenberg AR. Parents Are the Experts: A Qualitative Study of the Experiences of Parents of Children With Severe Neurological Impairment During Decision-Making. *J Pain Symptom Manage*. 2021 Dec;62(6):1117-1125. doi: 10.1016/j.jpainsymman.2021.06.011. Epub 2021 Jun 17. PMID: 34147578; PMCID: PMC8648906.
- 3: Bogetz JF, **Trowbridge A**, Jonas D, Root MC, Mullin J, Hauer J. The Impact of Caring for Children With Severe Neurological Impairment on Clinicians. *Clin Pediatr (Phila)*. 2022 Oct;61(10):707-716. doi: 10.1177/00099228221099135. Epub 2022 May 24. PMID: 35610773.
- 4: Bogetz J, **Trowbridge A**, Kingsley J, Taylor M, Wiener L, Rosenberg AR, Barton KS. Stuck Moments and Silver-Linings: The Spectrum of Adaptation Among Non-Bereaved and Bereaved Parents of Adolescents and Young Adults With Advanced

Cancer. *J Pain Symptom Manage*. 2021 Oct;62(4):709-719. doi: 10.1016/j.jpainsymman.2021.03.015. Epub 2021 Mar 26. PMID: 33775813; PMCID: PMC8464607.

- 5: **Trowbridge A**, Wightman A, Kett J. Promise me she'll survive: Navigating emotion and uncertainty in paediatric chronic disease with low-mortality rates. *Acta Paediatr*. 2022 Mar;111(3):464-466. doi: 10.1111/apa.16179. Epub 2021 Dec 3. PMID: 34751969.
- 6: Kingsley J, Taylor M, Bogetz JF, **Trowbridge A**, Rosenberg AR, Barton KS. Grief Trajectories of Bereaved Parents of Adolescents and Young Adults With Advanced Cancer: A Qualitative Analysis Using Phenomenology. *Omega (Westport)*. 2022 May 15:302228221101705. doi: 10.1177/00302228221101705. Epub ahead of print. PMID: 35575201.
- 7: Bogetz JF, Lewis H, **Trowbridge A**, Jonas D, Hauer J, Wilfond BS. From Monochromatic to Technicolor: Parent Perspectives on Challenges and Approaches to Seeing Children with Severe Neurological Impairment Holistically. *J Palliat Med*. 2022 Mar;25(3):437-444. doi: 10.1089/jpm.2021.0344. Epub 2021 Sep 22. PMID: 34551279.
- 8: Lewis H, **Trowbridge A**, Jonas D, Rosenberg AR, Bogetz JF. A Qualitative Study of Clinicians and Parents of Children with Severe Neurological Impairment on Tools to Support Family-Centered Care. *J Palliat Med*. 2022 Sep;25(9):1338-1344. doi: 10.1089/jpm.2021.0579. Epub 2022 May 20. PMID: 35593900; PMCID: PMC9639233.

Elliott Weiss, MD, MSME

- 1: **Weiss EM**, Guttman KF, Olszewski AE, Magnus BE, Li S, Kim SYH, Shah AR, Juul SE, Wu YW, Ahmad KA, Bendel-Stenzel E, Isaza NA, Lampland AL, Mathur AM, Rao R, Riley D, Russell DG, Salih ZNI, Torr CB, Weitkamp JH, Anani UE, Chang T, Dudley J, Flibotte J, Havrilla EM, O'Kane AC, Perez K, Stanley BJ, Shah SK, Wilfond BS. Parental Enrollment Decision-Making for a Neonatal Clinical Trial. *J Pediatr*. 2021 Dec;239:143-149.e3. doi: 10.1016/j.jpeds.2021.08.014. Epub 2021 Aug 14. PMID: 34400207; PMCID: PMC8610170.
- 2: **Weiss EM**, Kukora S, Barrington KJ. Use of composite NICU research outcomes for goals of care counselling creates ethical challenges. *Acta Paediatr*. 2021 Dec;110(12):3251-3254. doi: 10.1111/apa.16018. Epub 2021 Jul 14. PMID: 34214207.
- 3: Boss RD, Henderson CM, **Weiss EM**, Falck A, Madrigal V, Shapiro MC, Williams EP, Donohue PK; Pediatric Chronic Critical Illness Collaborative. The Changing Landscape in Pediatric Hospitals: A Multicenter Study of How Pediatric Chronic Critical Illness Impacts NICU Throughput. *Am J Perinatol*. 2022 Apr;39(6):646-651. doi: 10.1055/s-0040-1718572. Epub 2020 Oct 19. PMID:33075841.

Aaron Wightman, MD, MA

- 1: Sun BZ, **Wightman A**, Diekema DS. Caregiver COVID-19 vaccination for solid organ transplant candidates. *Am J Transplant*. 2022 Sep;22(9):2135-2138. doi: 10.1111/ajt.17078. Epub 2022 May 7. PMID: 35485987; PMCID: PMC9111252.

- 2: **Wightman A**, Goldberg A, Diekema D. Considering a COVID-19 vaccine mandate for pediatric kidney transplant candidates. *Pediatr Nephrol*. 2022 Nov;37(11):2559-2569. doi: 10.1007/s00467-022-05511-7. Epub 2022 Mar 25. PMID: 35333972; PMCID: PMC8949834.
- 3: Butler CR, **Wightman AG**. Scarce Health Care Resources and Equity during COVID-19: Lessons from the History of Kidney Failure Treatment. *Kidney360*. 2021 Oct 23;2(12):2024-2026. doi: 10.34067/KID.0005292021. PMID: 35419528; PMCID:PMC8986052.
- 4: Bauer A, Blanchette E, Taylor Zimmerman C, **Wightman A**. Caregiver burden in pediatric dialysis: application of the Paediatric Renal Caregiver Burden Scale. *Pediatr Nephrol*. 2021 Dec;36(12):3945-3951. doi: 10.1007/s00467-021-05149-x. Epub 2021 Jun 14. PMID: 34128095.
- 5: Sawyer KE, Kraft SA, **Wightman AG**, Clark JD. Pediatric Death by Neurologic Criteria: The Ever-Changing Landscape and the Expanding Role of Palliative Care Professionals. *J Pain Symptom Manage*. 2021 Nov;62(5):1079-1085. doi: 10.1016/j.jpainsymman.2021.04.026. Epub 2021 May 11. PMID: 33984463.
- 6: Berkman ER, Richardson KL, Clark JD, Dick AAS, Lewis-Newby M, Diekema DS, **Wightman AG**. An ethical analysis of obesity as a contraindication of pediatric kidney transplant candidacy. *Pediatr Nephrol*. 2022 Apr 29. doi: 10.1007/s00467-022-05572-8. Epub ahead of print. PMID: 35488137.
- 7: Pais P, **Wightman A**. Addressing the Ethical Challenges of Providing Kidney Failure Care for Children: A Global Stance. *Front Pediatr*. 2022 Mar 11;10:842783. doi: 10.3389/fped.2022.842783. PMID: 35359883; PMCID: PMC8963107.
- 8: Stahl JL, **Wightman AG**, Flythe JE, Weiss NS, Hingorani SR, Stoep AV. Psychiatric Diagnoses in Children With CKD Compared to the General Population. *Kidney Med*. 2022 Mar 18;4(6):100451. doi: 10.1016/j.xkme.2022.100451. PMID: 35620082; PMCID: PMC9127686.
- 9: Trowbridge A, **Wightman A**, Kett J. Promise me she'll survive: Navigating emotion and uncertainty in paediatric chronic disease with low-mortality rates. *Acta Paediatr*. 2022 Mar;111(3):464-466. doi: 10.1111/apa.16179. Epub 2021 Dec 3. PMID: 34751969.
- 10: House TR, Rosenberg AR, Zimmerman CT, Barton KS, **Wightman A**. Caregiver perspectives of dialysis initiation for children with kidney disease: a qualitative study. *Pediatr Nephrol*. 2022 Oct;37(10):2457-2469. doi: 10.1007/s00467-022-05472-x. Epub 2022 Feb 18. PMID: 35181825.
- 11: Kulkarni S, Flescher A, Ahmad M, Bayliss G, Bearl D, Biondi L, Davis E, George R, Gordon E, Lyons T, **Wightman A**, Ladin K. Ethical analysis examining the prioritisation of living donor transplantation in times of healthcare rationing. *J Med Ethics*. 2022 Jan 4;medethics-2021-107574. doi: 10.1136/medethics-2021-107574. Epub ahead of print. PMID: 34983855.
- 12: House TR, **Wightman A**, Rosenberg AR, Sayre G, Abdel-Kader K, Wong SPY. Challenges to Shared Decision Making About Treatment of Advanced CKD: A Qualitative Study of Patients and Clinicians. *Am J Kidney Dis*. 2022 May;79(5):657-

666.e1. doi: 10.1053/j.ajkd.2021.08.021. Epub 2021 Oct 19. PMID: 34673161; PMCID: PMC9016096.

Benjamin Wilfond, MD

- 1: Smith HS, Brothers KB, Knight SJ, Ackerman SL, Rini C, Veenstra DL, McGuire AL, **Wilfond BS**, Malek J. Conceptualization of utility in translational clinical genomics research. *Am J Hum Genet.* 2021 Nov 4;108(11):2027-2036. doi: 10.1016/j.ajhg.2021.08.013. Epub 2021 Oct 22. PMID: 34687653; PMCID: PMC8595895.
- 2: **Wilfond BS**, Duenas DM, Johnson LM. Supporting Community-Academic Research Partnerships: Reflections from the Ground. *Am J Bioeth.* 2021 Oct;21(10):44-45. doi: 10.1080/15265161.2021.1965255. PMID: 34554061; PMCID: PMC8591989.
- 3: Mittendorf KF, Knerr S, Kauffman TL, Lindberg NM, Anderson KP, Feigelson HS, Gilmore MJ, Hunter JE, Joseph G, Kraft SA, Zepp JM, Syngal S, **Wilfond BS**, Goddard KAB. Systemic Barriers to Risk-Reducing Interventions for Hereditary Cancer Syndromes: Implications for Health Care Inequities. *JCO Precis Oncol.* 2021 Nov 3;5:PO.21.00233. doi: 10.1200/PO.21.00233. PMID: 34778694; PMCID: PMC8585306.
- 4: Henderson CM, Raisanen JC, Shipman KJ, Jabre NA, **Wilfond BS**, Boss RD. Life with pediatric home ventilation: Expectations versus experience. *Pediatr Pulmonol.* 2021 Oct;56(10):3366-3373. doi: 10.1002/ppul.25577. Epub 2021 Jul 26. PMID: 34310864.
- 5: Weiss EM, Guttman KF, Olszewski AE, Magnus BE, Li S, Kim SYH, Shah AR, Juul SE, Wu YW, Ahmad KA, Bendel-Stenzel E, Isaza NA, Lampland AL, Mathur AM, Rao R, Riley D, Russell DG, Salih ZNI, Torr CB, Weitkamp JH, Anani UE, Chang T, Dudley J, Flibotte J, Havrilla EM, O'Kane AC, Perez K, Stanley BJ, Shah SK, **Wilfond BS**. Parental Enrollment Decision-Making for a Neonatal Clinical Trial. *J Pediatr.* 2021 Dec;239:143-149.e3. doi: 10.1016/j.jpeds.2021.08.014. Epub 2021 Aug 14. PMID: 34400207; PMCID: PMC8610170.
- 6: Johnson LM, Duenas DM, **Wilfond BS**. When Professional Meets Personal: How Should Research Staff Advertise on Social Media for Research Opportunities? *Am J Bioeth.* 2021 Oct;21(10):38-39. doi: 10.1080/15265161.2021.1965251. PMID: 34554059; PMCID: PMC8591987.
- 7: **Wilfond BS**. I know things now: The challenges for genetic counseling of adolescents with a family history of hereditary breast cancer. *J Pediatr.* 2022 Aug 17:S0022-3476(22)00728-4. doi: 10.1016/j.jpeds.2022.08.019. Epub ahead of print. PMID: 35985537.
- 8: Jabre NA, Raisanen JC, Shipman KJ, Henderson CM, Boss RD, **Wilfond BS**. Parent perspectives on facilitating decision-making around pediatric home ventilation. *Pediatr Pulmonol.* 2022 Feb;57(2):567-575. doi: 10.1002/ppul.25749. Epub 2021 Nov 10. PMID: 34738745.
- 9: Clark JD, Baden HP, Berkman ER, Bourget E, Brogan TV, Di Gennaro JL, Doorenbos AZ, McMullan DM, Roberts JS, Turnbull JM, **Wilfond BS**, Lewis-Newby M; Seattle Ethics in ECLS (SEE) Consortium. Ethical Considerations in Ever- Expanding

Utilization of ECLS: A Research Agenda. *Front Pediatr*. 2022 May 19;10:896232. doi: 10.3389/fped.2022.896232. PMID: 35664885; PMCID: PMC9160718.

- 10: Morain SR, Kraft SA, **Wilfond BS**, McGuire A, Dickert NW, Garland A, Sugarman J. Toward Meeting the Obligation of Respect for Persons in Pragmatic Clinical Trials. *Hastings Cent Rep*. 2022 May;52(3):9-17. doi: 10.1002/hast.1391. PMID: 35763201; PMCID: PMC9704739.
- 11: Riddle L, Karliner LS, Livaudais-Toman J, Guerra C, Roat CE, Rope AF, Wade A, Caruncho M, Zepp JM, Giang J, **Wilfond BS**, Joseph G. Development and evaluation of an exome sequencing training course for medical interpreters. *Per Med*. 2022 Mar;19(2):125-138. doi: 10.2217/pme-2021-0091. Epub 2022 Feb 16. PMID: 35171038.
- 12: MacDuffie KE, Patneaude A, Bell S, Adiele A, Makhija N, **Wilfond B**, Opel D. Addressing racism in the healthcare encounter: The role of clinical ethics consultants. *Bioethics*. 2022 Mar;36(3):313-317. doi: 10.1111/bioe.13008. Epub 2022 Feb 7. PMID: 35132655.
- 13: Smith HS, Morain SR, Robinson JO, Canfield I, Malek J, Rubanovich CK, Bloss CS, Ackerman SL, Biesecker B, Brothers KB, Goytia CN, Horowitz CR, Knight SJ, Koenig B, Kraft SA, Outram S, Rini C, Shipman KJ, Waltz M, **Wilfond B**, McGuire AL. Perceived Utility of Genomic Sequencing: Qualitative Analysis and Synthesis of a Conceptual Model to Inform Patient-Centered Instrument Development. *Patient*. 2022 May;15(3):317-328. doi: 10.1007/s40271-021-00558-4. Epub 2021 Oct 18. PMID: 34658003; PMCID: PMC9013723.
- 14: Bogetz JF, Munjapara V, Henderson CM, Raisanen JC, Jabre NA, Shipman KJ, **Wilfond BS**, Boss RD. Home mechanical ventilation for children with severe neurological impairment: Parents' perspectives on clinician counselling. *Dev Med Child Neurol*. 2022 Jul;64(7):840-846. doi: 10.1111/dmcn.15151. Epub 2022 Jan 26. PMID: 35080259.
- 15: Klee K, **Wilfond B**, Thomas K, Ridling D. Conflicts between parents and clinicians: Tracheotomy decisions and clinical bioethics consultation. *Nurs Ethics*. 2022 May;29(3):685-695. doi: 10.1177/09697330211023986. Epub 2022 Jan 31. PMID: 35094605.
- 16: Spector-Bagdady K, Lynch HF, Bierer BE, Gelinas L, Hull SC, Magnus D, Meyer MN, Sharp RR, Sugarman J, **Wilfond BS**, Yearby R, Mohapatra S. Allocation of Opportunities to Participate in Clinical Trials during the Covid-19 Pandemic and Other Public Health Emergencies. *Hastings Cent Rep*. 2022 Jan;52(1):51-58. doi: 10.1002/hast.1297. Epub 2021 Dec 15. PMID: 34908169; PMCID: PMC9414770.
- 17: Lindberg NM, Mittendorf KF, Duenas DM, Anderson K, Koomas A, Kraft SA, Okuyama S, Shipman KJ, Vandermeer ML, Goddard KA, **Wilfond BS**, McMullen C. Engaging Patient Advisory Committees to Inform a Genomic Cancer Risk Study: Lessons for Future Efforts. *Perm J*. 2022 Jun 29;26(2):28-39. doi: 10.7812/TPP/21.091. Epub 2022 Jun 17. PMID: 35933674; PMCID: PMC9662241.
- 18: Rolf BA, Schneider JL, Amendola LM, Davis JV, Mittendorf KF, Schmidt MA, Jarvik GP, **Wilfond BS**, Goddard KAB, Ezzell Hunter J. Barriers to family history

knowledge and family communication among LGBTQ+ individuals in the context of hereditary cancer risk assessment. *J Genet Couns*. 2022 Feb;31(1):230-241. doi: 10.1002/jgc4.1476. Epub 2021 Jul 23. PMID: 34302314; PMCID: PMC8783924.

- 19: von Saint Andre-von Arnim AO, Kumar RK, Clark JD, **Wilfond BS**, Nguyen QP, Mutonga DM, Zimmerman JJ, Oron AP, Walson JL. Family-Assisted Severity of Illness Monitoring for Hospitalized Children in Low-Resource Settings-A Two-Arm Interventional Feasibility Study. *Front Pediatr*. 2022 May 23;10:804346. doi: 10.3389/fped.2022.804346. PMID: 35676898; PMCID: PMC9169086.
- 20: Federico CA, Heagerty PJ, Lantos J, O'Rourke P, Rahimzadeh V, Sugarman J, Weinfurt K, Wendler D, **Wilfond BS**, Magnus D. Ethical and epistemic issues in the design and conduct of pragmatic stepped-wedge cluster randomized clinical trials. *Contemp Clin Trials*. 2022 Apr;115:106703. doi: 10.1016/j.cct.2022.106703. Epub 2022 Feb 15. PMID: 35176501; PMCID: PMC9272561.
- 21: Amendola LM, Shuster E, Leo MC, Dorschner MO, Rolf BA, Shirts BH, Gilmore MJ, Okuyama S, Zepp JM, Kauffman TL, Mittendorf KF, Bellcross C, Jenkins CL, Joseph G, Riddle L, Syngal S, Ukaegbu C, Goddard KAB, **Wilfond BS**, Jarvik GP; CHARM Study. Laboratory-related outcomes from integrating an accessible delivery model for hereditary cancer risk assessment and genetic testing in populations with barriers to access. *Genet Med*. 2022 Jun;24(6):1196-1205. doi: 10.1016/j.gim.2022.02.006. Epub 2022 Mar 16. PMID: 35305866.
- 22: Crain PR, Zepp JM, Gille S, Jenkins L, Kauffman TL, Shuster E, Goddard KAB, **Wilfond BS**, Hunter JE. Identifying patients with Lynch syndrome using a universal tumor screening program in an integrated healthcare system. *Hered Cancer Clin Pract*. 2022 Apr 18;20(1):17. doi: 10.1186/s13053-022-00217-1. PMID: 35436948; PMCID: PMC9014602.
- 23: Bogetz JF, Lewis H, Trowbridge A, Jonas D, Hauer J, **Wilfond BS**. From Monochromatic to Technicolor: Parent Perspectives on Challenges and Approaches to Seeing Children with Severe Neurological Impairment Holistically. *J Palliat Med*. 2022 Mar;25(3):437-444. doi: 10.1089/jpm.2021.0344. Epub 2021 Sep 22. PMID: 34551279.
- 24: Ali J, Morain SR, O'Rourke PP, **Wilfond B**, O'Brien EC, Zigler CK, Staman KL, Weinfurt KP, Sugarman J. Responding to signals of mental and behavioral health risk in pragmatic clinical trials: Ethical obligations in a healthcare ecosystem. *Contemp Clin Trials*. 2022 Feb;113:106651. doi: 10.1016/j.cct.2021.106651. Epub 2022 Jan 5. PMID: 34998990; PMCID: PMC8844235.
- 25: Mittendorf KF, Lewis HS, Duenas DM, Eubanks DJ, Gilmore MJ, Goddard KAB, Joseph G, Kauffman TL, Kraft SA, Lindberg NM, Reyes AA, Shuster E, Syngal S, Ukaegbu C, Zepp JM, **Wilfond BS**, Porter KM. Literacy-adapted, electronic family history assessment for genetics referral in primary care: patient user insights from qualitative interviews. *Hered Cancer Clin Pract*. 2022 Jun 10;20(1):22. doi: 10.1186/s13053-022-00231-3. PMID: 35689290; PMCID: PMC9188215.
- 26: Mittendorf KF, Kauffman TL, Amendola LM, Anderson KP, Biesecker BB, Dorschner MO, Duenas DM, Eubanks DJ, Feigelson HS, Gilmore MJ, Hunter JE, Joseph G, Kraft SA, Lee SSJ, Leo MC, Liles EG, Lindberg NM, Muessig KR, Okuyama S, Porter

- KM, Riddle LS, Rolf BA, Rope AF, Zepp JM, Jarvik GP, **Wilfond BS**, Goddard KAB; CHARM study team. Corrigendum to "Cancer Health Assessments Reaching Many (CHARM): A clinical trial assessing a multimodal cancer genetics services delivery program and its impact on diverse populations" [Contemporary Clinical Trials 106 (2021) 106432]. *Contemp Clin Trials*. 2022 Mar;114:106682. doi: 10.1016/j.cct.2022.106682. Epub 2022 Feb 3. Erratum for: *Contemp Clin Trials*. 2021 Jul;106:106432. PMID: 35123916.
- 27: Mittendorf KF, Ukaegbu C, Gilmore MJ, Lindberg NM, Kauffman TL, Eubanks DJ, Shuster E, Allen J, McMullen C, Feigelson HS, Anderson KP, Leo MC, Hunter JE, Sasaki SO, Zepp JM, Syngal S, **Wilfond BS**, Goddard KAB. Adaptation and early implementation of the PREdiction model for gene mutations (PREMM5™) for lynch syndrome risk assessment in a diverse population. *Fam Cancer*. 2022 Apr;21(2):167-180. doi: 10.1007/s10689-021-00243-3. Epub 2021 Mar 23. PMID: 33754278; PMCID: PMC8458476.
- 28: Duenas DM, Shipman KJ, Porter KM, Shuster E, Guerra C, Reyes A, Kauffman TL, Hunter JE, Goddard KAB, **Wilfond BS**, Kraft SA. Motivations and concerns of patients considering participation in an implementation study of a hereditary cancer risk assessment program in diverse primary care settings. *Genet Med*. 2022 Mar;24(3):610-621. doi: 10.1016/j.gim.2021.11.017. Epub 2021 Nov 23. PMID: 34906471; PMCID: PMC8939763.
- 29: Liles EG, Leo MC, Freed AS, Porter KM, Zepp JM, Kauffman TL, Keast E, McMullen CK, Gruß I, Biesecker BB, Muessig KR, Eubanks DJ, Amendola LM, Dorschner MO, Rolf BA, Jarvik GP, Goddard KAB, **Wilfond BS**. ORCA, a values-based decision aid for selecting additional findings from genomic sequencing in adults: Efficacy results from a randomized trial. *Genet Med*. 2022 Aug;24(8):1664-1674. doi: 10.1016/j.gim.2022.04.008. Epub 2022 May 6. PMID: 35522237; PMCID: PMC9586129.
- 30: Joseph G, Leo MC, Riddle L, Guerra C, Amendola LM, Gilmore MJ, Rolf BA, Dorschner MO, Zepp J, Biesecker BB, Caruncho M, Hunter JE, Keast E, Lewis HS, Duenas D, Kauffman T, Bulkley JE, Anderson KP, Jarvik GP, Goddard KAB, **Wilfond BS**; CHARM Study Team. An accessible, relational, inclusive, and actionable (ARIA) model of genetic counseling compared with usual care: Results of a randomized controlled trial. *Genet Med*. 2022 Nov;24(11):2228-2239. doi: 10.1016/j.gim.2022.07.025. Epub 2022 Sep 2. PMID: 36053287.
- 31: **Wilfond BS**, Duenas DM, Johnson LM. Enrolling Adolescents with Rare Disease for Early Phase Clinical Trials While Under the Care of Child Protection Services: Balancing Protection and Access. *Am J Bioeth*. 2022 Apr;22(4):81-82. doi: 10.1080/15265161.2022.2044552. PMID: 35420512; PMCID: PMC9534357.
- 32: An Open Science Study of Ageing in Companion Dogs. Creevy KE, Akey JM, Kaeberlein M, Promislow DEL, Dog Aging Project Consortium.; *Nature*. 2022 Feb;602(7895):51-57.
- 33: Christina Roman, Alexandra C.H. Nowakowski, Julie Lazzara, Enid Aliaj, Kathryn M. Porter, Stephanie A. Kraft, Seema K. Shah, Drucy Borowitz, **Benjamin S. Wilfond**, Lessons learned about publication of results of community surveys when regulatory oversight has not occurred, *SSM - Qualitative Research in Health*, Volume 2, 2022, 100091, ISSN 2667-3215, <https://doi.org/10.1016/j.ssmqr.2022.100091>.

Joon-Ho Yu, PhD, MPH

- 1: Wagner JK, **Yu JH**, Chong JX, Royal CD, Bamshad MJ. Centering Equity in Human Genetics and Genomics Advances. HGG Adv. 2021 Aug 19;2(4):100048. doi: 10.1016/j.xhgg.2021.100048. PMID: 35047840; PMCID: PMC8756494.
- 2: Lemke AA, Esplin ED, Goldenberg AJ, Gonzaga-Jauregui C, Hanchard NA, Harris-Wai J, Ideozu JE, Isasi R, Landstrom AP, Prince AER, Turbitt E, Sabatello M, Schrier Vergano SA, Taylor MRG, **Yu JH**, Brothers KB, Garrison NA. Addressing underrepresentation in genomics research through community engagement. Am J Hum Genet. 2022 Sep 1;109(9):1563-1571. doi: 10.1016/j.ajhg.2022.08.005. PMID: 36055208; PMCID: PMC9502069.
- 3: **Yu JH**. Solidarity in the Absence of Sovereignty: Expanding Group Protections in New Research Contexts. Am J Bioeth. 2021 Oct;21(10):22-24. doi: 10.1080/15265161.2021.1965259. PMID: 34554076.
- 4: **Yu JH**. Leveraging Academic Institutional Structures to Support Asian American Community Organizations' Engagement in Research: The Korean Community Service Center. Am J Bioeth. 2021 Oct;21(10):49-51. doi: 10.1080/15265161.2021.1965253. PMID: 34554067.
- 5: Lemke AA, Choi SH, Dang V, Dang TQ, **Yu JH**. Assessing Vietnamese American patient perspectives on population genetic testing in primary care: A community-engaged approach. HGG Adv. 2022 Aug 6;3(4):100134. doi:10.1016/j.xhgg.2022.100134. PMID: 36039118; PMCID: PMC9418978.