

Community Engagement Matters!

Presentation and Panel, May 15th, 2025

Penn Medicine & Children's Hospital of Philadelphia (CHOP) collaboration

This event aims to highlight community-based clinical research conducted by Penn and CHOP teams, and related resources. Speakers are Penn and CHOP clinical research physicians, their family partners and community advocates. Panel discussion will follow the presentations.

This event is part of [Clinical Research Week](#) 2025.

Event format:

- Virtually using Zoom Meetings.
(<https://pennmedicine.zoom.us/j/98929259125?pwd=rqyBGhyVGcLBmMNpRu7WdAuDQuXbMf.1>) Meeting ID: 989 2925 9125, Passcode: 173511
- 1:30-2:30 PM presentations by researchers (Dr Karen Glanz, Dr. Antoine Fermin)
- 2:45-3:30 PM- panel (Penn + CHOP faculty, staff, patients/families/ambassador together with moderator)

Research Investigators:

Antoine Selman: The Center for Outcomes REsearch in Surgery (CORES) seeks to generate and apply knowledge to improve the health of children with surgical conditions. CORES supports projects across the Department of Surgery at CHOP that improve patient-centered outcomes. A key component of achieving this objective is involving stakeholders, including patients and caregivers, in all phases of research from study design to disseminating results.

Áine Smalley: Áine Smalley is a Research Family Partner with CHOP and an advocate for individuals with disabilities, inspired by her 19-year-old son with Williams syndrome. Professionally, she has spent close to three decades at Medtronic, a global medical device company, where she has held leadership roles in both Research & Development and Regulatory Affairs.

Ahtish Arputhan is a Clinical Research Study Lead at the Children's Hospital of Philadelphia. He works with Dr. Andrea Kelly, a pediatric endocrinologist at CHOP, and manages her Down syndrome research studies. He has experience with research studies that involve the Down syndrome community as collaborative partners.

Dr. Caroline Watts is the Director of the Office School and Community Engagement (OSCE) at Penn GSE and works to facilitate and support partnerships with schools and communities to improve the educational outcomes and overall wellbeing of children and youth in Philadelphia. Over her career as a psychologist, program administrator, practicing child therapist, and university educator, she has focused her work on creating innovative institutional partnerships among schools, universities, and community health organizations that support equity and access to high-quality resources for urban children, youth, and families.

Dr. Erum Hartung is a pediatric nephrologist at the Children's Hospital of Philadelphia. Her research focuses on autosomal recessive polycystic kidney disease (ARPKD), a rare disease that affects kidney and liver health in children. One of her current research projects includes working with a Patient & Family

Partners panel consisting of parents of children with ARPKD and young adults with ARPKD. Our goal is to understand which patient-reported outcomes and clinical outcomes are most important to patients and families, and to understand factors that influence their decisions to take part in clinical research.

Kate Howarth is a research coordinator for the Division of Nephrology, working under Dr. Erum Hartung for the past 6 years on her various research studies. She has coordinated both in-person study visits and remote survey studies, and she has varying experience in survey tools like REDCap and Sawtooth.

Dr. Karen Glanz: is George A. Weiss University Professor, Professor of Epidemiology in the Perelman School of Medicine, Professor of Nursing in the School of Nursing, and Director of the Community Engagement and Research (CEAR) Core of the Penn/CHOP ITMAT and Co-Leader of the Cancer Control Program at the Abramson Cancer Center. Her research focuses on cancer prevention and control; obesity, nutrition, and the built environment; chronic disease prevention and control; community engagement and reducing health disparities.

Family Partners/ Community Advisory Board Members:

Alix Piccirilli is a Change Management Strategist for an International Development organization. Since her child's diagnosis of Autosomal Recessive Polycystic Kidney Disease (ARPKD) in 2017, she has become a passionate volunteer and relentless advocate for PKD families.

Aqueelah Brown is the Executive Director and Founder of Know Your Worth Girls Inc., Philadelphia-based nonprofit dedicated to empowering girls through mentorship, mental wellness, and leadership development. A survivor, author, and advocate, she has transformed her own life challenges into a powerful mission to uplift the next generation of young women. With award-winning programs and citywide recognition, Aqueelah continues to create safe spaces for girls to thrive, lead, and know their worth. Visit the non-profit- [Know Your Worth Girls Inc.](#)

Allie is 27 years old and has Down syndrome. She works, goes to college and lives independently. The Governor of Michigan appointed Allie to be on the Developmental Disability Council and is a National Down Syndrome Society Ambassador. Serving on multiple boards and committees allows Allie to be the voice of many. Allie has been participating in research with CHOP since 2023 and feels fulfillment in advancing research for the disability community.

Dawn Hayes is the parent of a 27-year-old daughter who has Down syndrome. Dawn taught special education in Michigan for 30+ years and is now retired. Serving on her local Arc Executive Board and being a NDSS Ambassador is rewarding for Dawn. Being on the Family Research Partner Team through Children's Hospital of Philadelphia is a point of pride too, for Dawn values the work done by doctors and researchers to improve the quality of life for people in the Down syndrome community and those with other disabilities as well.

Judith Peters is a founding member of the Community Advisory Board (CAB) of the University of Pennsylvania Center for AIDS Research (CFAR). She has been collaborating with communities and health departments for over 30 years assisting them in the development of health-related projects, guiding them in needs assessments, and advising communities on intervention strategies, and policy-based decisions so disenfranchised and marginalized communities are given services and opportunities to survive and thrive.

Naiymah Sanchez (she/her) is an out and proud transgender Pennsylvanian with 16 years of public service. Ms. Sanchez contributes to advancing rights, policies, and law, bringing into the rooms the experiences of Black and Brown TLGBQ+ individuals.

William Carter is the Chair of the BEAT HIV CAB, and research participant at Penn Medicine.

Organizers (Penn Medicine and Children's Hospital of Philadelphia): Office of Clinical Research (Penn), Center for Clinical Epidemiology and Biostatistics (Penn), Recruitment Enhancement Core (CHOP).

Thank you to individuals from these groups:

University of Pennsylvania- Amanda Brock, Krista Scheffey, Dr. Karen Glanz, Michelle McCarthy, Mahasweta Dutt.

Children's Hospital of Philadelphia: Rosemary Laberee, Cecily Knauer, Heather Cathrall.
