

Network: The Cerebral Palsy Research Network (CPRN) is a group of clinician researchers and patient advocates collaborating to improve treatments and outcomes for people with cerebral palsy. The network combines the expertise of clinicians committed to treating CP with innovative data collection techniques from clinical and community settings that accelerate the planning and execution of high-quality clinical trials and quality improvement initiatives. The network enables the implementation of improved standards of care and continuous monitoring of outcomes in order to create a large-scale learning health system for cerebral palsy.

Founded: 2015 -- **Leadership Team:**

Amy Bailes, P.T., Ph.D. (Cincinnati Children’s Hospital)	Mary Gannotti, P.T., Ph.D. (University of Hartford)
Paul Gross (CPRN Chairman, University of Utah)	Susan Horn, Ph.D. (University of Utah)
Ed Hurvitz, M.D. (University of Michigan)	Jacob Kean, Ph.D. (University of Utah)
Jeffrey Leonard, M.D. (Nationwide Children’s Hospital)	Unni Narayanan, M.D. (SickKids)
Garey Noritz M.D. (Nationwide Children’s Hospital)	Michele Shusterman (CP Daily Living & CP NOW)

Sites / Site Investigators:

Al Dupont/Nemours, Wilmington DE	M. Wade Shrader, M.D., Orthopedic Surgery
Benioff Children’s Hospital, Oakland, CA	Ravinder Brar, M.D., Orthopedic Surgery
Boston Children’s Hospital, Boston, MA	Benjamin Shore, M.D., M.P.H., Orthopedic Surgery
Children’s of Alabama, Birmingham, AL	Brandon Rocque, M.D., Neurosurgery
Children’s Mercy Hospital, Kansas City, MO	Michael Partington, M.D., Neurosurgery
Colorado Children’s Hospital, Denver, CO	Susan Apkon, M.D., Physical Medicine & Rehabilitation
Gillette Children’s Specialty Hospital, St. Paul, MN	Tom Novacheck, M.D., Neurosurgery
Joe DiMaggio Children’s Hospital, Hollywood, FL	Heather Spader, M.D., Neurosurgery
Nationwide Children’s Hospital, Columbus, OH	Adam Ostendorf, M.D., Neurology
Phoenix Children’s Hospital, Phoenix, AZ	Michael Kruer, M.D., Neurology
Primary Children’s Hospital, Salt Lake City, UT	Robert Bollo, M.D., Neurosurgery
Rady Children’s Hospital, San Diego, CA	Pritha Dalal, M.D., Physical Medicine & Rehabilitation
Riley Children’s Hospital, Indianapolis, IN	Jeffrey Raskin, M.D., Neurosurgery
Texas Scottish Rite Children’s Hospital, Dallas, TX	Mauricio Delgado, M.D., Pediatric Neurology
Seattle Children’s Hospital, Seattle, WA	Kristie Bjornson, Ph.D., Physical Therapy
Texas Children’s Hospital, Houston, TX	Aloysia Schwabe, M.D., Physical Medicine & Rehabilitation
UCLA Health, Los Angeles, CA	Rachel Thompson, M.D., Orthopedic Surgery
University of Florida, Jacksonville, FL	Christine Thorogood, M.D., Pediatric Rehabilitation Medicine
University of Michigan Medical Ctr Ann Arbor, MI	Ed Hurvitz, M.D., Physical Medicine & Rehabilitation
University of North Carolina, Chapel Hill, NC	Deborah Thorpe, Ph.D., Physical Therapy
University of Texas, Houston, TX	Manish Shah, M.D., Neurosurgery
University of Virginia, Charlottesville, VA	Richard Stevenson, M.D., Developmental Pediatrics
Yale University, New Haven, CT	David Frumberg, M.D., Orthopedic Surgery

Candidate Sites / Investigators:

Akron Children’s Hospital, Akron, OH	Micah Baird, M.D., Physical Medicine & Rehabilitation
Cincinnati Children’s Hospital, Cincinnati, OH	Jilda Vargus-Adams, M.D., MSc, Rehabilitation Medicine
Columbia University, New York, NY	Jason Carmel, M.D., Ph.D., Pediatric Neurology
Johns Hopkins University, Baltimore, MD	Shenandoah Robinson, M.D., Pediatric Neurosurgery
Kennedy Krieger Institute, Baltimore, MD	Shannon Dean, M.D., Ph.D., Pediatric Neurology
Mt. Washington Pediatric Hospital, Baltimore	Stephen Nichols, M.D., Rehabilitation Services
Shirley Ryan Ability Lab, Chicago, IL	Deborah Spira-Gaebler, M.D., Physical Medicine & Rehabilitation
SickKids, Toronto, ON Canada	Unni Narayanan, M.D., MSc., Orthopedic Surgery
St. Louis Children’s Hospital, St. Louis, MO	Toni Pearson, M.D., Pediatric Neurology

Data Coordinating Center (DCC): University of Utah, Health Systems Research and Innovation Division, Department of Population Health Sciences, Jacob Kean, Ph.D. DCC Principal Investigator

Initial Research Project: Creation of a Cerebral Palsy Clinical Registry with approximately 500 data fields plus patient reported outcomes, **a Learning Health Network in which standard clinical encounters are used to collect data for original research and quality improvement.** Status: Registry up and running at Children’s of Alabama, Joe DiMaggio Children’s Hospital, Nationwide Children’s Hospital, Phoenix Children’s Hospital, Primary Children’s Hospital, Rady Children’s Hospital, Riley Children’s Hospital, Seattle Children’s Hospital, Texas Children’s Hospital, Texas Scottish Rite Hospital, University of Florida (Jacksonville), University of Virginia, UT Health (Houston).

Subsequent Research and Quality Projects:

- Setting a Patient-Centered Research Agenda for Cerebral Palsy (PCORN 4380-CPNF)
- GENOMIC INSIGHTS INTO THE NEUROBIOLOGY OF CEREBRAL PALSY (1R01NS106298-01A1)
- Enhancing a Multidisciplinary Research Network for Research & Quality in Epilepsy and Cerebral Palsy (Pediatric Epilepsy Research Foundation)
- Intrathecal Baclofen Pump Infection Quality Improvement (internal funding)
- Adult Patient Reported Outcomes Registry (internal funding)
- Healthcare Transition Quality Improvement (internal funding)
- Community Priorities in Dystonia Research (internal funding).

Publications: “Research CP: Setting a patient-centered research agenda for cerebral palsy”, *Developmental Medicine and Child Neurology*, August 21, 2018, Gross, PH, Bailes, AF, Horn, SD, Hurvitz, EA, Kean, J, Shusterman, M; “Registry-based Research in Cerebral Palsy: The Cerebral Palsy Research Network”, *Physical Medicine and Rehabilitation Clinics of North America*, November 7, 2019, Author links open overlay panel Edward A. Hurvitz MD, Paul H. Gross, Mary E. Gannotti PT, PhD, Amy F. Bailes PT, PhD, Susan D. Horn PhD

Membership Requirements: Commitment to excellence and research in CP including multi-disciplines. Submission of CPRN Registry IRB protocol. Completion of Business Associate’s Agreement. Self-funded hospital IT implementation of CPRN forms (initially Epic) or commitment of clinic research assistant support to chart abstraction of registry data into REDCap. Protected time for investigators. Approval from CPRN leadership team.

Opportunities:

- Participate in multi-center, high-quality research and national learning health network
- Improve patient care and reduce cost through quality improvement protocols;
- Leverage academic advancement opportunities;
- Collaborate in research;
- Accelerate and strengthen grant applications with preliminary.

Challenges: Epic implementation commitment from IT. Cerner in 2020. Other EMR implementations lagging. Change in practice to use EMR forms with structured data for CP clinic visits and peri-operative reporting.

Funding: Public funding for studies (Past: PCORI, Current: NIH, Pediatric Epilepsy Research Foundation), Private and Hospital Philanthropy