



Curriculum Vitae

Cerebral Palsy Research Network

CP Research Network Leadership

Paul Gross, BA

President, CEO, and Co-Founder

Co-Founder of and advisor to the Hydrocephalus Clinical Research Network, Co-Founder of the Adult Hydrocephalus Clinical Research Network, Co-Founder, Hydrocephalus Association Network for Discovery Science

Kristie Bjornson, PT, MS, PhD

Scientific Research Director

Pediatric Physical Therapist, Professor of Developmental Medicine- Pediatrics at the University of Washington and Seattle Children's Hospital Research Institute.

Michele Shusterman, BA

Director of Education and Wellness, Co-Founder

Founder of CPDailyLiving.com, Recipient of the "Making a Difference" award by the American Academy for Cerebral Palsy and Developmental Medicine.

Amy F. Bailes, PT, PhD

Quality Improvement Director

Division of Occupational Therapy and Physical Therapy, Cincinnati Children's Hospital Medical Center, Associate Professor, Department of Rehabilitation, Exercise and Nutrition Sciences, University of Cincinnati.

Steve Wisniewski, PhD

Data Coordinating Center Principal Investigator

Vice Provost, Budget and Analytics
Co-Director, Epidemiology Data Center
University of Pittsburgh

CP Research Network Participating Centers

Al duPont/Nemours Children's Hospital | Wilmington, Delaware

SITE INVESTIGATOR

Wade Shrader, MD, Professor of Orthopedic Surgery and Pediatrics, BOD and First Vice-President of The American Academy for Cerebral Palsy and Developmental Medicine.

ALTERNATE SITE INVESTIGATOR

Kenneth Rogers, PhD, ATC, Program Manager - Research

SITE CLINICAL RESEARCH COORDINATOR

Parma (Ellie) Montufar Wright, BA, Nemours Children's Hospital.

Akron Children's Hospital | Akron, Ohio

SITE INVESTIGATOR

Micah Baird, MD, Director, Division of Pediatric Physiatry, Medical Director of Rehabilitation, Co-director of Myelodysplasia Clinic at Akron Children's Hospital.

ALTERNATE SITE INVESTIGATOR

Adam Bartlett, MD, Physical Medicine & Rehabilitation at Akron Children's Hospital.

Boston Children's Hospital | Boston, Massachusetts

SITE INVESTIGATOR

Benjamin Shore, MD, MPH, FRCSC, Associate Professor of Orthopedic Surgery at Harvard Medical School, Director of the Cerebral Palsy Program.

ALTERNATE SITE INVESTIGATOR

Stacey Cook, MD, PhD; Medical Director, Outpatient Complex Care at Boston Children's Hospital; Instructor, Harvard Medical School.

The Campbell Foundation/Le Bonheur Children's Hospital | Memphis, Tennessee

SITE INVESTIGATOR

William C. Warner, Jr, MD, Professor of Orthopedic Surgery at University of Tennessee-Campbell Clinic, Pediatric Orthopedic Surgery, Co-Director CP/Neuromuscular Clinic.

ALTERNATE SITE INVESTIGATORS

Leslie N. Rhodes, DNP, PPCNP-BC, Pediatric Nurse Practitioner, ULPS Cerebral Palsy/Neuromuscular Clinic, Le Bonheur Children's Hospital, Assistant Professor at University of Tennessee Health Science Center, College of Nursing- Health Promotion and Disease Prevention.

David Spence, MD, Assistant Professor of Orthopedic Surgery, University of Tennessee-Campbell Clinic, Pediatric Orthopedic Surgery, Co-Director CP/Neuromuscular Clinic.

SITE CLINICAL RESEARCH COORDINATOR

Karen Romer, BSN, RN, Research Nurse Coordinator, The Campbell Foundation.

Children's Hospital Colorado | Aurora, Colorado

SITE INVESTIGATOR

Joyce Oleszek, MD, Pediatric Rehabilitation Medicine at Children's Hospital Colorado, Professor of Physical Medicine and Rehabilitation at University of Colorado School of Medicine.

ALTERNATE SITE INVESTIGATOR

Wendy Pierce, MD, Assistant Professor of Physical Medicine and Rehabilitation at the University of Colorado School of Medicine.

Cristina Sarmiento, MD, Pediatric & Adult Rehabilitation Medicine at Children's Hospital Colorado and UC Health, Assistant Professor of Physical Medicine & Rehabilitation at University of Colorado School of Medicine.

Children's of Alabama | Birmingham, Alabama

SITE INVESTIGATOR

Cynthia Wozow, DO, Assistant Professor of Rehabilitation Medicine at University of Alabama at Birmingham.

ALTERNATE SITE INVESTIGATORS

Byron Lai, PhD, MS, Assistant Professor of Pediatric Rehabilitation Medicine at University of Alabama at Birmingham.

Brandon Rocque, MD, Assistant Professor in the Pediatric Division of the University of Alabama at Birmingham Dept of Neurosurgery.

SITE CLINICAL RESEARCH COORDINATOR

Anastasia Arynchyna, MPH, CCR, Research Manager of Pediatric Neurosurgery

Children's Mercy Hospital | Kansas City, Missouri

SITE INVESTIGATOR

Rose Gelineau-Morel, MD, Pediatric Neurologist, Clinical Assistant Professor of Pediatrics, University of Kansas School of Medicine and University of Missouri – Kansas City.

ALTERNATE SITE INVESTIGATOR

Kathryn Keeler, MD, Pediatric Orthopedic Surgeon, Assistant Professor of Orthopedic Surgery, University of Kansas School of Medicine

SITE CLINICAL RESEARCH COORDINATOR

Dante Kyle

CP Research Network Participating Centers

Cincinnati Children's Hospital and Medical Center | Cincinnati, Ohio

SITE INVESTIGATORS

Amy F. Bailes, PT, PhD, PT III, Division of Occupational Therapy and Physical Therapy, Cincinnati Children's Hospital Medical Center, Associate Professor, Department of Rehabilitation, Exercise and Nutrition Sciences, University of Cincinnati.

Charles B. Stevenson, MD, Faculty Neurosurgeon at Cincinnati Children's, Associate Professor at the University of Cincinnati.

ALTERNATE SITE INVESTIGATOR

James McCarthy, MD, Pediatric Orthopedic Surgeon, Professor, University of Cincinnati Orthopedic Surgery

SITE CLINICAL RESEARCH COORDINATOR

Gina Rolle

Columbia University | New York City, New York

SITE INVESTIGATOR

Jason Carmel, MD, PhD, Pediatric Neurologist, Director, Weinberg Family Cerebral Palsy Center.

SITE CLINICAL RESEARCH COORDINATOR

Kirsten Carlberg, MPH

Gillette Children's Specialty Healthcare | St. Paul, Minnesota

SITE INVESTIGATOR

Tom F Novacheck, MD, Pediatric Orthopedic Surgeon, Medical Director Integrated Care Services, Professor of Orthopedics, University of Minnesota.

ALTERNATE SITE INVESTIGATOR

Angela Sinner, DO, Pediatric Rehabilitation Medicine Physician, Co-Director of Inpatient Rehabilitation, Member of American Board of Physical Medicine and Rehabilitation.

SITE CLINICAL RESEARCH COORDINATOR

Jennifer Carpenter, PTCB, Clinical Research Coordinator at Gillette Children's Specialty Healthcare.

Lurie Children's Hospital | Chicago, Illinois

SITE INVESTIGATOR

Jeffrey Raskin MS, MD, Pediatric Neurosurgeon, Assistant Professor of Neurological Surgery (Pediatric Neurological Surgery), Northwestern University Feinberg School of Medicine

SITE CLINICAL RESEARCH COORDINATOR

Klaudia Dziugan

Nationwide Children's Hospital | Columbus, Ohio

SITE INVESTIGATORS

Laurie Glader, MD, Medical Director of Cerebral Palsy Program and Section Chief of the Division of Complex Care at Nationwide Children's Hospital.

Garey Noritz, MD, Pediatrician, Internist, Section and Division Chief of the Complex Health Care Program, Professor of Pediatrics at The Ohio State University College of Medicine, Director of the Comprehensive Cerebral Palsy Program at Nationwide Children's Hospital. Principal Investigator, CP Research Network Clinical Registry.

Jeffrey Leonard, MD, Chief of Neurosurgery, Co-Director of Neuro-Oncology, Professor of Neurosurgery at the Ohio State College of Medicine.

EPILEPSY STUDY PI

Adam Ostendorf, MD, Pediatric Neurologist, Assistant Professor of Clinical Pediatrics and Neurology at The Ohio State University College of Medicine.

Oklahoma Children's Hospital | Oklahoma City, Oklahoma

SITE INVESTIGATOR

Virendra Desai, MD, Pediatric Neurosurgeon, Assistant Professor in the Department of Neurosurgery at the OU College of Medicine.

ALTERNATE SITE INVESTIGATOR

Joanna Gernsback, MD, Pediatric Neurosurgeon, Assistant Professor in the Department of Neurosurgery at the OU College of Medicine.

Phoenix Children's Hospital | Phoenix, Arizona

SITE INVESTIGATOR

Michael Kruer, MD, Director, Cerebral Palsy & Pediatric Movement Disorders Program at the Barrow Neurological Institute, Phoenix Children's Hospital, Associate Professor, Child Health, Cellular & Molecular Medicine, Neurology, and Genetics at University of Arizona College of Medicine – Phoenix.

ALTERNATE SITE INVESTIGATOR

Mohan Belthur, MD, Pediatric Orthopedic Surgeon, Clinical Assistant Professor in the Department of Child Health at the University of Arizona College of Medicine.

CP Research Network Participating Centers

Primary Children's Hospital | Salt Lake City, Utah

SITE INVESTIGATOR

Robert Bollo, MD, MS, FAANS, FACS, FAAP, Pediatric Neurosurgeon, Surgical Director of the Pediatric Epilepsy Program at Primary Children's Hospital

ALTERNATE SITE INVESTIGATOR

Allison Oki, MD, Physical Medicine & Rehabilitation at Primary Children's Hospital.

SITE CLINICAL RESEARCH COORDINATOR

Allison Ludwick, MSc, Clinical Research Coordinator at the University of Utah School of Medicine.

Rady Children's Hospital | San Diego, California

SITE INVESTIGATOR

Pritha Dalal, MD, Physical Medicine & Rehabilitation, Rehabilitation Medicine Specialist at Rady Children's Hospital Cerebral Palsy Center, Concussion Specialist at Rady Children's Hospital Sports Medicine Department, Assistant Clinical Professor at UC San Diego Department of Orthopedic Surgery.

ALTERNATE SITE INVESTIGATOR

Andrew Skalsky, MD, Physical Medicine & Rehabilitation, Division Chief of Rady Children's Rehabilitative Medicine, Rehabilitation Medicine Specialist of at Rady Children's Hospital Cerebral Palsy Center, Associate Clinical Professor of Pediatrics at UC San Diego.

SITE CLINICAL RESEARCH COORDINATOR

Alyssa Wieand, BS, Clinical Research Coordinator at Rady Children's Hospital.

St. Louis Children's Hospital | St. Louis, Missouri

SITE INVESTIGATOR

Bhooma Aravamuthan, MD, DPhil, Assistant Professor of Neurology at Washington University School of Medicine.

SITE CLINICAL RESEARCH COORDINATOR

Kelsey Steffen, Pediatric Neurology

Seattle Children's Hospital | Seattle, Washington

SITE INVESTIGATOR

Kristie Bjornson, PT, MS, PhD, Pediatric Physical Therapist, Professor of Developmental Medicine- Pediatrics at the University of Washington and Seattle Children's Hospital Research Institute.

SITE CLINICAL RESEARCH COORDINATOR

Deborah Grenard, BS, C-MPH, Clinical Research Coordinator for Developmental Medicine at Seattle Children's

Shirley Ryan Ability Lab | Chicago, Illinois

SITE INVESTIGATOR

Tim Krater, MD, Pediatric Physical Medicine and Rehabilitation, Instructor of Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine.

ALTERNATE SITE INVESTIGATOR

Ana-Marie Rojas, MD, Pediatric Physical Medicine and Rehabilitation, Assistant Professor of Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine.

SITE CLINICAL RESEARCH COORDINATORS

Bangning Yu, MD, PhD, Clinical Trial Program Manager of Pediatric Neurosurgery at McGovern Medical School.

SickKids | Toronto, Ontario Canada

SITE INVESTIGATOR

Unni Narayanan, MBBS, MSc., FRCS (C) Professor, Department of Surgery & Rehabilitation Sciences Institute, Division of Orthopedic Surgery

SITE CLINICAL RESEARCH COORDINATOR

Ashley Ferkul, PMP

Texas Children's Hospital | Houston, Texas

SITE INVESTIGATOR

Sruthi Thomas, MD, PhD, Physical Medicine & Rehabilitation, Assistant Professor at Baylor College of Medicine

ALTERNATE SITE INVESTIGATOR

Aloysia Schwabe, MD, Physical Medicine & Rehabilitation, Associate Professor of Physical Medicine and Rehabilitation at Baylor College of Medicine, Faculty Senator of Baylor College of Medicine.

UCSF Benioff Children's Hospitals | Oakland, California

SITE INVESTIGATOR

Ravinder Brar, MD, MPH Pediatric Orthopedic Surgeon, Associate Professor of Orthopedic Surgery at University of California San Francisco

ALTERNATE SITE INVESTIGATOR

Kate Sigford, MD, Associate Professor of Rehabilitation in the Department of Orthopedic Surgery at University of California San Francisco

CP Research Network Participating Centers

University of Michigan Medical Center | Ann Arbor, Michigan

SITE INVESTIGATOR

Edward Hurvitz, MD, Professor and Chair of the Department of Physical Medicine and Rehabilitation at Michigan Medicine/The University of Michigan, James W. Rae Collegiate Professor in Physical Medicine and Rehabilitation.

ALTERNATE SITE INVESTIGATORS

Angeline Bowman, MD, Clinical Assistant Professor of Pediatric Rehabilitation Medicine at Michigan Medicine/The University of Michigan.

Noelle Whyte, MD, Clinical Assistant Professor, Orthopedic Surgery at Michigan Medicine/The University of Michigan.

University of Texas Health Science Center | Houston, Texas

SITE INVESTIGATOR

Manish N. Shah, MD, FAANS William Devane Distinguished Professor and Associate Professor in the Division of Pediatric Neurosurgery, Director of the Texas Comprehensive Spasticity Center, McGovern Medical School and Children's Memorial Hermann Hospital.

ALTERNATE SITE INVESTIGATORS

Stacey Hall, DO, Assistant Professor of Pediatric Rehabilitation Medicine, Department of Physical Medicine and Rehabilitation and Pediatrics, McGovern Medical School, Medical Director of Pediatric Rehabilitation Medicine at UTHealth-Houston and TIRR Memorial Hermann

Surya Mundluru, MD, Assistant Professor of Orthopedics at McGovern Medical School and Children's Memorial Hermann Hospital

Christine Hill, PT, Physical Therapist at the Department of Pediatric Surgery-Neurosurgery at the University of Texas Health Science Center.

University of Virginia Health System | Charlottesville, Virginia

SITE INVESTIGATOR

Valentina Intagliata, MD, Developmental Pediatrician, Associate Professor of Neurodevelopmental and Behavioral Pediatrics at University of Virginia.

ALTERNATE SITE INVESTIGATOR

Rich Stevenson, MD, Developmental Pediatrician, Professor of Pediatrics at the University of Virginia, Head of the Division of Neurodevelopmental and Behavioral Pediatrics at the University of Virginia.

Cerebral Palsy Research Network Data Coordinating Center

University of Pittsburgh | Pittsburgh, Pennsylvania

DATA COORDINATING CENTER PRINCIPAL INVESTIGATOR

Stephen Wisniewski, PhD, Co-Director, Epidemiology Data Center, Vice Provost of Budget and Analytics

BIostatistician

Wendy King, PhD, Associate Professor in the Department of Epidemiology at the University of Pittsburgh Graduate School of Public Health

DIRECTOR SYSTEMS DEVELOPMENT

Jeffrey Martin, MBA, Department of Epidemiology at the University of Pittsburgh Graduate School of Public Health

ASSISTANT DIRECTOR SYSTEMS DEVELOPMENT

Michael Kania, Department of Epidemiology at the University of Pittsburgh Graduate School of Public Health

DATA MANAGER

Theresa M. Sax, Department of Epidemiology at the University of Pittsburgh Graduate School of Public Health

PROJECT MANAGER

Mary Martinez, Department of Epidemiology at the University of Pittsburgh Graduate School of Public Health

Cerebral Palsy Research Network Board of Directors

David Browdy, MBA

Director

Vice President and Chief Financial Officer, Fred Hutchinson Cancer Center. Former VP and CFO of Utah Health

Paul Gross

President

CEO and Co-Founder, CPRN, Former Chairman, Hydrocephalus Association, Co-Founder, Hydrocephalus Clinical Research Network, Co-Founder, Adult Hydrocephalus Clinical Research Network

Aisha Morrison, MPA, CFRE

Director

Former Director of Development at the AIDS Alliance

Garey Noritz, MD

Director

Clinical Registry Principal Investigator, Leader of Non surgical Registry Elements Task Force, Director of Complex Care at Nationwide Children's Hospital

Michele Shusterman

Director (non voting)

Co-Founder, CPRN
Director of Education and Engagement
Former Executive Director of CP NOW
Author, CPDailyLiving.com

Richard Smith

Treasurer

Executive Director, Bay Area Outreach & Recreation Program (BORP), Former Executive Director, CompassPoint, CEO, Support Centers of America, Assistant Treasurer, Piedmont Education Foundation, President, Ed Roberts Campus

Scientific Advisory Board

Diane Damiano, PT, PhD

Physical Therapist, Chief of the Functional and Applied Biomechanics Section in the Rehabilitation Medicine Department, National Institute of Health Clinical Center in Bethesda Maryland, President of the American Academy of Cerebral Palsy and Developmental Medicine.

Michael Dean, MD, MBA

Associate Dean for Clinical Research at University of Utah Health, Chief of the Division of Pediatric Critical Care at the University of Utah, Medical Director of the Pediatric Intensive Care Unit at Primary Children's Hospital, Professor and Vice Chairman for Research in the Department of Pediatrics at the University of Utah School of Medicine, Director of the Clinical Trials Office in the Department.

Deborah Hirtz, MD

Pediatric Neurologist, Professor of Neurological Sciences at the University of Vermont School of Medicine, Burlington, Vermont, Professor of Pediatrics at the University of Vermont School of Medicine, Former Program Director in the Office of Clinical Research National Institute of Neurological Disorders and Stroke.

John Kestle, MD

Surgeon, Professor of Neurosurgery at the University of Utah College of Medicine, Salt Lake City, Utah, Vice Chair of Clinical Research at the University of Utah, Chairman and Co-Founder, Hydrocephalus Clinical Research Network.

Iona Novak, PhD, MSc, BAppSc

Occupational Therapist, Professor at the University of Sydney, Sydney, Australia, Manager of the Strategic Development of Research into the Prevention and Cure of Cerebral Palsy and Supports the Australian Cerebral Palsy Register.

Steering Committee

The Steering Committee reports to the CEO and oversees the operations and strategic direction of the network. Volunteer members serve three-year terms.

STEERING COMMITTEE MEMBERS

Amy F. Bailes, PT, PhD
Quality Improvement Director
CP Research Network
Cincinnati Children's Hospital

Kristie Bjornson, PT, MS, PhD
Scientific Research Director
CP Research Network
Seattle Children's Hospital

Jason Carmel, MD, PhD
Columbia University

Laurie Glader, MD
Nationwide Children's Hospital

Paul Gross, BA
President & CEO, CP Research Network

Edward Hurvitz, MD
University of Michigan Medical Center

Jeff Leonard, MD
Nationwide Children's Hospital

Michele Shusterman, BA
Co-Founder, CP Research Network

Unni G. Narayanan, MBBS, MSc, FRCS(C)
SickKids Hospital

Yvonne Wu, MD, MPH, University of California San Francisco

Education Committee

The Education Committee supports the Education Coordinator by reviewing network educational materials available on the CPRN website.

COMMITTEE MEMBERS

Jensine' Clark, MD
University of Cincinnati

Noelle Whyte, MD
University of Michigan

Mohan Belthur, MD
Phoenix Children's Hospital

Neena Marupudi, MD
Children's Hospital of Michigan

Rich Stevenson, MD
UVA Children's Hospital

Standard Operating Procedures Subcommittee

The Standard Operation Procedures Subcommittee revises and maintains the governance of the network operating procedures.

COMMITTEE MEMBERS

Kristie Bjornson, PT, MS, PhD
Seattle Children's Hospital

Paul Gross, BA
CP Research Network CEO

Tim Krater, DO
Shirley Ryan Ability Lab

Arianna Trionfo, MD
Al duPont Hospital

Richard Stevenson, MD
University of Virginia

Amanda Whitaker, MD
Shriners Children's Hospital

Manuscript Review Subcommittee

The Manuscript Review Subcommittee is responsible for reviewing and approving manuscripts, presentations and posters representing the work of CPRN to improve quality and increase acceptance of CPRN developed content.

COMMITTEE MEMBERS

Jeffery Leonard, MD
Subcommittee Chair
Nationwide Children's Hospital

Michael Kruer, MD
Subcommittee Vice Chair
Phoenix Children's Hospital

Diane Damiano, PT, PhD
National Institute of Health Clinical Center

Mary Gannotti, PT, PhD
University of Hartford

Edward Hurvitz, MD
University of Michigan Medical Center

Garey Noritz, MD
Nationwide Children's Hospital

Jason Rhodes, MD
Children's Hospital Colorado

Brandon Rocque, MD
Children's of Alabama

Scientific Review Subcommittee

The Scientific Review Subcommittee is responsible for reviewing protocols and applications for CPRN to improve quality studies submitted to and by CPRN.

COMMITTEE MEMBERS

Kristie Bjornson, PT, MS, PhD
Seattle Children's Hospital
Subcommittee Chair

Benjamin Shore, MD, MPH
Boston Children's Hospital
Subcommittee Vice Chair

Amy F. Bailes, PT, PhD
Cincinnati Children's Hospital

Robert Bollo, MD
University of Utah

Diane Damiano, PT, PhD
National Institutes of Health

Deborah Hirtz, MD
University of Vermont

Jeff Leonard, MD
Nationwide Children's Hospital

Angela Sinner, DO
Gillette Children's Specialty Hospital

Richard Stevenson, MD
University of Virginia

Community Action Committee

The Community Action Committee provides feedback to the leadership and investigators on research priorities and programs.

COMMITTEE MEMBERS

John Borland

Lisa Barton Diller

June Isaacson Kailes

Fayza Jaleel

Brittany Kessy

Jodi Kreschmer

Nina Miller

Karen Pleasant

Carol Shrader

Peter Turner

Duncan Wyeth

Christina Youngblood

Annual Meetings

September 23, 2015*	Austin, TX
September 23, 2016	Hollywood, Florida
September 13-16, 2017	Montreal, QC, Canada
May 31- June 1, 2018	Houston, Texas
October 9-13, 2018	Cincinnati, Ohio
May 2-3, 2019	Ann Arbor, Michigan
May 7-8, 2020	Zoom
April 28-29, 2021	Zoom
May 5-6 2022	Chicago, Illinois
* Informational Meeting	

Externally Funded Grants

2022-2023	Mary Gannotti, PT, PhD Adults with cerebral palsy: patient reported outcome registry enrollment Academy of Pediatric Physical Therapy \$28,000
2022-2024	Bhooma Aravamuthan, MD, DPhil Creation of a standardized motor exam video registry for people with cerebral palsy Pediatric Epilepsy Research Foundation \$100,000
2021-	Unni Narayanan, MBBS, MSc, FRCS(C) CPCHECKlist American Academy for Cerebral Palsy and Developmental Medicine \$25,000
2020-	Unni Narayanan, MBBS, MSc, FRCS(C) Shared Decision Making Canadian Institute for Health Research \$100,000 (CDN)
2020-2022	Edward Hurvitz, MD Grip Strength American Academy of Physical Medicine and Rehabilitation \$10,000

2019–2023	1R01NS106298	Michael Kruer, MD Genomic insights into the neurobiology of cerebral palsy National Institute of Neurological Disorders and Stroke	\$2,500,000
2018–2020		Adam Ostendorf, MD Enhancing a Multidisciplinary Research Network for Research and Quality in Epilepsy and Cerebral Palsy Pediatric Epilepsy Research Foundation	\$200,000
2016–2017	4380-CPNF	Paul Gross PCORI Engagement Award Patient-Centered Outcomes Research Institute	\$49,665

Internally Funded Grants

2022		Elizabeth Boyer, PhD Consequences of Falls	
2020-2021		Bhooma Aravamuthan, MD, DPhil Community Attitudes Toward a CP Diagnosis	
2019-2021		Bhooma Aravamuthan, MD, DPhil, Darcy Fehlings, MD, Paul Gross, Michael Kruer, MD, Jonathan Mink, MD, PhD, Michele Shusterman Research CP Dystonia Edition	
2019-2021		Kristen Allison, PhD, CCC-SLP Speech and Language Predictors	
2019-		Paul Gross CP Community Registry (CP-CORE): A Patient-Powered Registry	
2018-2021		Paul Gross Spasticity Practice Variation	
2016-		Garey Noritz, MD Cerebral Palsy Clinical Registry	
2016-		Mary Gannotti, PhD Adult Wellbeing and Pain	

Publications

1. Gross, P. H., Bailes, A. F., Horn, S. D., Hurvitz, E. A., Kean, J., & Shusterman, M. (2018). Setting a patient-centered research agenda for cerebral palsy: A participatory action research initiative. *Developmental Medicine & Child Neurology*,60(12), 1278–1284. doi: 10.1111/dmcn.13984
2. Hurvitz, E. A., Gross, P. H., Gannotti, M. E., Bailes, A. F., Horn, S. D. (2020). Registry-based Research in Cerebral Palsy: The Cerebral Palsy Research Network. *Physical Medicine and Rehabilitation Clinics of North America*, Volume 31, Issue 1, 185–194. doi: 10.1016/j.pmr.2019.09.005
3. Gross, P. H., Gannotti, M. E., Bailes, A. F., Horn, S. D., Kean, J., Narayanan, U. G., Oakes, J., Noritz, G. (2020). Cerebral Palsy Research Network Clinical Registry: Methodology and Baseline Report. *Archives of Rehabilitation Research and Clinical Translation*, Volume 2, Issue doi: 10.1016/j.arrct.2020.100054
4. Bailes, A. F., Kean, J., Gross, P. H., Narayanan, U. G., Noritz, G., Hurvitz, E. A., Leonard, J., Shusterman, M., Gannotti, M. E. (2021). The cerebral palsy research network: Building a learning health network for cerebral palsy. *Journal of Pediatric Rehabilitation Medicine*, vol. 14, no. 2, pp. 161-171. doi: 10.3233/PRM-210011
5. Aravamuthan, B.R., Shusterman, M., Green Snyder, L., Lemmon, M.E., Bain, J.M., Gross, P.H. For Simons Searchlight; For the Cerebral Palsy Research Network (2022). Diagnostic preferences include discussion of etiology for adults with cerebral palsy and their caregivers. *Developmental Medicine & Child Neurology*,64(6), 723– 733. doi: 10.1111/dmcn.15164
6. Gilbert, L.A, Fehlings, D.L., Gross, P.H., Kruer, M.C., Kwan, W., Mink, J.W., Shusterman, M., ARavamutha, B.R., and the Cerebral Palsy Research Network Dystonia Study Group (2022). Top 10 research themes for dystonia in CP, A community-driven research agenda. *Neurology Aug 2022*, 99 (6) 237-245. doi: 10.1212/WNL.0000000000200911
7. Ostendorf, A.P., Axeen, E.T., Eschbach, K., Fedak Romanowski, E., Morgan, L.A., Gross, P.H., et al. For the Cerebral Palsy Research Network (2022). Epilepsy and proxy-reported health-related quality of life in children and young people with non-ambulatory cerebral palsy. *Dev Med Child Neurol*. 2022; 00: 1-7. doi: 10.1111/dmcn.15336
8. Shrader, M.W., Gross, P.H., Bailes, A.F., Whitaker, A.T. (2022). Hip surveillance for patients with cerebral palsy in the United States. *J Pediatr Rehabil Med*. 2022; 15(1):25-30. doi: 10.3233/PRM-220013
9. Bollo, R.J., Gross, P.H., Rocque, B.G., Browd, S.R., Raskin, J.S., Leonard, J.R., Albarqawi, L., Bailes, A.F. (2023). A multicenter initiative to reduce intrathecal baclofen pump surgical site infection: a Cerebral Palsy Research Network quality improvement project. *J of Neuro* 24 February 2023. Doi: 10.3171/2023.1.PEDS22368

Presentations

1. Paul Gross: *From Anxiety to Impact - Focusing Parental Energy on Advancing Research*, Making a Difference Award, AACPDM General Session, Austin, Texas, October 22, 2015.
2. Paul Gross & Yvonne Wu: *Cerebral Palsy Research Funding in the United States: Past, Present, and Future*, AACPDM Breakfast Seminar, Austin, Texas, October 23, 2015.
3. Executive Committee: *Joining CPRN*, AACPDM Side Meeting, Hollywood, Florida, September 20-14, 2016.
4. Mary Gannotti & Debbie Thorpe: *The Cerebral Palsy Research Network Adult Registry*, AACPDM Community Forum, September 20-14, 2016.
5. Michele Shusterman & Paul Gross: *Patient and Family Perspectives on Common Therapies and Interventions*, AACPDM Breakfast Seminar, Hollywood, Florida, September 22, 2016.
6. Paul Gross, Garey Noritz, Amy Bailes, Mary Gannotti: *The Cerebral Palsy Research Registry, Patient Reported Outcomes and Collaborative Research Effort*, AACPDM Breakfast Seminar, Hollywood, Florida, September 23, 2016.
7. Paul Gross: *Community Participation in Registries and Research*, AACPDM Community Forum, Hollywood, Florida, September 24, 2016.
8. Paul Gross: *How to Join CPRN*, AACPDM Side Meeting, Montreal, QC, Canada, September 13-16, 2017.
9. Garey Noritz, Donnie Clark, Natalie Miller, Paul Gross, Jacob Kean, Linda Lowes: *The Cerebral Palsy Research Network: Initial Data Collection*, AACPDM Free Paper, Montreal, QC, Canada, September 15, 2017.
10. Paul Gross & Robert Bollo: *Quality Improvement Through the Cerebral Palsy Research Network*, AACPDM Breakfast Seminar, Montreal, QC, Canada, September 15, 2017.
11. Paul Gross & Jacob Kean: *Joining CPRN*, AACPDM Side Meeting, Cincinnati, Ohio, October 9-13, 2018.
12. Garey Noritz, Jacob Kean, Kristie Bjornson, Paul Gross: *Report from the Cerebral Palsy Research Network*, AACPDM Free Paper, Cincinnati, Ohio, October 11, 2018.
13. Paul Gross, Amy Bailes, Michele Shusterman, Ed Hurvitz: *Research CP: Results from a Community-Based Research Prioritization Project*, AACPDM Breakfast Seminar, Cincinnati, Ohio, October 11, 2018.
14. Paul Gross, Jacob Kean, Michael Kruer: *Conduct Multi-Center Clinical Research with the Cerebral Palsy Research Network*, AACPDM Instructional Course, Cincinnati, Ohio, October 13, 2018.
15. Paul Gross: *From Anxiety to Impact: Focusing Parental Energy on Advancing Research*, CP Grand Rounds, Al duPont Hospital, Wilmington, DE, November 1, 2018
16. Ed Hurvitz: *The Cerebral Palsy Research Network*, Frederick J. Fischer Pediatric Orthopaedic Lectureship, Danto Auditorium- Frankel Cardiovascular Center, Ann Arbor, MI, April 12, 2019.
17. Garey Noritz: *Report from the Cerebral Palsy Research Network- 2019*, AACPDM Poster, Anaheim, CA, September 17, 2019 <https://doi.org/10.1111/dmcn.14354>

18. Adam Ostendorf: *Epilepsy Prevalence, Treatment and Intractability in the Cerebral Palsy Research Network Cohort*, AACPDM Free Paper, Anaheim, CA, September 17, 2019 <https://doi.org/10.1111/dmcn.14353>
19. Jeffrey Leonard: *A Descriptive Study of Surgical Interventions for Cerebral Palsy Patients in the Cerebral Palsy Research Network Registry*, AACPDM Poster, Anaheim, CA, September 17, 2019 <https://doi.org/10.1111/dmcn.14354>
20. Robert Bollo: *A Prospective, Multi-Center Initiative to Reduce Intrathecal Baclofen Pump Surgical Site Infection: A Cerebral Palsy Research Network Quality Improvement Project*, AACPDM Poster, Anaheim, CA, September 17, 2019 <https://doi.org/10.1111/dmcn.14354>
21. Mary Gannotti: *Pain Experiences Among Aging Adults with Cerebral Palsy: Leveraging the Cerebral Palsy Research Network Community Registry for Patient Reported Outcomes*, AACPDM Free Paper, Anaheim, CA, September 17, 2019 <https://doi.org/10.1111/dmcn.14353>
22. Paul Gross, Kristie Bjornson, D Fehlings, Jacob Kean, S Robinson, Joline Brandenburg: *Practice Variation in Treatment of Spasticity in Children with Spastic Diplegic CP in North America*, AACPDM Poster, Anaheim, CA, September 17, 2019 <https://doi.org/10.1111/dmcn.14354>
23. Paul Gross and Mary Gannotti: *How to Engage Patients in Research and Garner Patient-Reported Outcomes Using the CPRN Community Registry*, AACPDM Annual Meeting, Anaheim, CA, September 17, 2019
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