

CPRCoM

7th Biennial Meeting

Babies, Brain and Behavior in CP



Out into the world in the Mini-Explorer

Sponsored by CPRCoM - Cerebral Palsy Research Consortium of Michigan

ISTB (Interdisciplinary Science Technology Building)
Michigan State University

Wednesday, October 19, 2022

A big thank-you to the families of our adorable cover photo friends

ABOUT US



Cerebral Palsy Research Consortium of Michigan (CPRCoM) brings together scientists, health professionals, and community partners to promote research and develop new knowledge about cerebral palsy. As part of this growing network, researchers are collaborating on studies of CP causes, treatments, function, and outcomes, with the aim of making progress in prevention and improving the lives of individuals and families affected by CP.

In fall 2007, building on active research programs and clinical strengths at universities and medical centers in Michigan, and with enthusiastic backing from United Cerebral Palsy in Lansing, a group of colleagues initiated discussion to develop collaborations across institutions that could advance CP research. Our first conference, aptly named “Cerebral Palsy: Toward Collaborative Research in Michigan”, took place March 18, 2008 at the University of Michigan with about 50 attendees, hosted by Dr Edward Hurvitz. Internationally prominent researchers, including Michigan’s Drs Hurvitz, Nigel Paneth and Seth Warschausky, and Dr Mindy Aisen of United Cerebral Palsy Research and Educational Foundation (UCPREF, now CPIRF), presented up-to-date research findings, with Dr Aisen’s keynote highlighting funding challenges for CP research. This initial meeting generated new questions, connections and inspiration to work together.

Two months later, Michigan State University hosted the Werner workshop on Adults with CP. The meeting paid tribute to Arnold Werner, a well-loved MSU psychiatrist with CP who urged us to learn more about aging with CP, and featured exciting presentations by Michigan clinicians and disability spokespeople. The workshop was attended by almost 100 clinicians, community members with CP, and researchers to specifically address issues in adults. Subsequently the Consortium has organized biennial conferences, rotating sites between MSU, UM and Wayne State University, and funded by our Michigan academic institutions, industry sponsors, and non-profit organizations. In addition to Dr Aisen in 2008, keynote speakers have included Dr Janice Brunstrom-Hernandez from Washington University, Saint Louis, in 2010; Dr Roberto Romero from NIH Perinatology Research Branch in

2013; and joining us in 2015, Dr Jaime Slaughter-Acey from Drexel University and Dr Marshalyn Yeargin-Allsopp from Centers for Disease Control in Atlanta, and in 2018, Dr. Peter Rosenbaum from McMaster University.

Community members interested in CP research are invited to attend these conferences as part of the vital partnership of medical scientists and the CP community in the research enterprise. Indeed, in addition to conferences, the consortium has developed a CP research registry at University of Michigan to enable people with CP who want to contribute to research to be contacted about upcoming studies.

We welcome you to join us in CPRCoM's efforts for professional, educational, community and family engagement in CP research.

ACKNOWLEDGEMENTS

KEYNOTE SPEAKER

Bernard Dan MD, PhD Paediatric neurologist. Professor of Neurophysiology and Developmental Neurology; Editor-in-Chief of Developmental Medicine & Child Neurology

CONFERENCE ORGANIZERS

Edward Hurvitz, Lisa Kenyon, Steven Korzeniewski, Madeleine Lenski, Nigel Paneth, Seth Warschausky

- Madeleine Lenski, Conference organizer
- Mark Watrich, Program Design
- Financial and administrative support: University of Michigan, Department of Physical Medicine & Rehabilitation; Michigan State University, Department of Epidemiology and Biostatistics, and Arnold Werner Fund.

CONFERENCE AGENDA

8:30 **CONTINENTAL BREAKFAST**

9:00 **WELCOME**

Dr Nigel Paneth, MD, MPH
University Distinguished Professor Emeritus, Michigan
State University

Session I BRAINS and BABIES

9:05 **PediaTrac: A novel method to monitor and screen
infant-toddler development and longitudinal
surveillance**

Dr Renée Lajiness-O'Neill, PhD
Professor of Psychology, Eastern Michigan University

9:17 **ORIGIN: The Organization for Imaging Genomics in
Infancy, Who We Are and What We've Learned**

Dr Rebecca Knickmeyer, PhD
Associate Professor in Pediatrics and Human
Development and Interim Chief of Neuroengineering at
the Institute for Quantitative Health Sciences and
Engineering at Michigan State University.

- 9:29 **I-ACQUIRE: An Early Look at Early Intervention for Neonatal Stroke**
- Dr Jessica Prunte, MD
Assistant Professor, Physical Medicine and Rehabilitation,
University of Michigan.
- 9:41 **In Quest of On Time Mobility for Children with Cerebral Palsy**
- Dr Lisa Kenyon, PT, DPT, PhD, PCS
Professor, Physical Therapy and Athletic Training, Grand
Valley State University
- 9:56 **Is the prevalence of Cerebral Palsy decreasing?**
- Dr Nigel Paneth, MD, MPH
Emeritus University Distinguished Professor of
Epidemiology and Biostatistics and Pediatrics and Human
Development, Michigan State University
- 10:10 - 10:25 **BREAK and POSTERS**

Session II BEHAVIOR and COMMUNICATION

- 10:25 **Update on Cerebral Palsy Diagnosis**
- Dr Steven Korzeniewski, PhD
Associate Professor, Family Medicine and Public Health
Sciences, Wayne State University

- 10:37 **CFCS - Communication Function Classification System:
Ten years later**
- Dr Mary Jo Cooley Hidecker, PhD, CCC-A/SLP
Associate Professor, Communication Sciences & Disorder,
University of Kentucky
- 10:49 **Challenges and Strategies when Introducing Children
with Cerebral Palsy to Brain-Computer Interface
Assistive Technology**
- Dr Jane Huggins, PhD
Associate Research Scientist, Physical Medicine &
Rehabilitation, Assistant Research Scientist, Biomedical
Engineering
Director, University of Michigan
- 11:02 **Break**
- 11:15 **KEYNOTE “The emperor’s old clothes: who is helped
by calling cerebral palsy CP?”**
- Dr Bernard Dan, MD, PhD
Professor of Neurophysiology and Developmental
Neurology, Université Libre de Bruxelles, Belgium; Editor-
in-Chief of Developmental Medicine
- 12:15 **Lunch**

Session III ADULTS and CP

1:15 **Patient Reported Outcomes in Adult CP: The MyCP registry**

Dr Edward Hurvitz, MD
James W. Rae Collegiate Professor and Chair, Physical
Medicine and Rehabilitation, University of Michigan

1:20 **Bone development, fracture risk, and post-fracture consequences for individuals with cerebral palsy**

Dr Daniel Whitney, PhD
Assistant Professor, Physical Medicine and Rehabilitation,
University of Michigan

Session IV CP and COMMUNITY

1:45 **Impact of Adaptive/Wheelchair Sports on the Quality of Life of Individuals with Cerebral Palsy**

Piotr Pasik, MA
Instructor, Kinesiology, and leader of MSU Adaptive
Sports and Recreation Club, Michigan State University

- 2:00 **VOICES from the Community**
- 1. Duncan Wyeth, MA**
- “Beyond his expiration date”!
- Retired Executive Director, Michigan Commission on Disability Concerns; Adjunct Faculty Member Counseling, Educational Psychology & Special Education, Michigan State U. Community member “CP Research Network”
- 2. Karen Weinstein, BS**
- “Think outside the box”
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- 2:25 **BOOK RAFFLE**
- (Signed ELGAN book) Dr Nigel Paneth
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- 2:30 **ADJOURNMENT**
- Dr Edward Hurvitz, Professor and Chair, James W. Rae Collegiate Professor of Physical Medicine and Rehabilitation, U of Michigan
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- 2:40 **STAY FOR “QUESTION & ANSWERS”**
- with Dr Bernard Dan, MD, PhD

HISTORY

- ❖ Oct 19, 2022: MSU. Babies, brain, and behavior.
Keynote: Bernard Dan
- ❖ Feb 17, 2021: ZOOM. Zooming through the lifespan.
- ❖ Apr 19, 2018: MSU. Maximizing ability and function.
Keynote: Peter Rosenbaum
- ❖ Mar 25, 2015: UM. CP in 3D.
Keynote: Marshalyn Yeargin-Allsopp
- ❖ Jan 30, 2013: WSU. On the cutting edge.
Keynote: Roberto Romero
- ❖ Oct 19, 2010: MSU. Developing multicenter collaborations.
Keynote: Janice Brunstrom-Hernandez
- ❖ May 12, 2008: MSU. Arnold Werner workshop on adult CP.
Keynote: Mindy Aisen
- ❖ Mar 13, 2008: UM. Toward collaborative research.

SPEAKERS



Bernard Dan, MD, PhD

Bernard Dan is a professor of developmental neuroscience at the Université Libre de Bruxelles, Belgium. He received his MD (1992) and PhD (2002) from Université Libre de Bruxelles. He works at Inkendaal Rehabilitation Hospital. He is also the Editor-in-Chief of the internationally respected journal *Development Medicine and Child Neurology (DMCN)*, specializing in scientific articles on childhood disability. He was the first recipient of the Elsass Foundation Research Prize for research on cerebral palsy.



Mary Jo Cooley Hidecker, PhD, CCCA/SLP

Mary Jo Cooley Hidecker, PhD, CCCA/SLP, Associate Professor at the University of Kentucky, studies cerebral palsy and communication disorders. She leads the development of the Communication Function Classification System (CFCS) which categorizes communication performance at the activity/participation level of the World Health Organization's International Classification of Functioning, Disability and Health (ICF).



Jane E. Huggins, PhD

Dr. Huggins received her B.S. in Computer Engineering with a Biomedical Engineering option and an Art Minor from Carnegie Mellon. She received a M.S. in Bioengineering, a M.S.E. in Computer Engineering, and a Ph.D. in Biomedical Engineering from the University of Michigan in Ann Arbor. She completed a clinical Rehabilitation Engineering Internship. While working on her dissertation, she founded the University of Michigan Direct Brain Interface Laboratory with Dr. Simon Levine. Dr. Huggins has been the director of the University of Michigan Direct Brain Interface Laboratory since 2007.

Her current focus is making EEG-based brain-computer interfaces practical for people who need them. Dr. Huggins was a founding member of the board of directors of the Brain-Computer Interface Society. She is a co-editor-in-chief of the journal Brain-Computer Interfaces. Outside the lab, Dr. Huggins enjoys knitting, birdwatching, cooking, and being Mom to her children, now in college.



Edward A. Hurvitz, MD

Edward A. Hurvitz, M.D., is Professor and Chair, and James W. Rae Collegiate Professor, Department of Physical Medicine and Rehabilitation (PM&R) at Michigan Medicine, the University of Michigan. He trained in Pediatric physiatry at the University of Michigan. He leads the Adults with Pediatric Onset Disability group at Michigan, which has published extensively on areas such as risk and prevention of chronic disease, fracture risk and outcomes, and prevalence of mental health issues. Dr. Hurvitz co-founded and co-directs the Cerebral Palsy Research Consortium of Michigan and the International Cerebral Palsy Health Promotion Group, and is a member of the research steering committee of the Cerebral Palsy Research Network



Lisa K. Kenyon, PT, DPT, PhD, PCS

Dr. Kenyon is a Professor in the Department of Physical Therapy and Athletic Training at Grand Valley State University in Grand Rapids, Michigan. She heads the Grand Valley Power Mobility Project, an inter-professional research and service project providing power mobility training and use for children 6 months to 26 years-old who are not traditionally considered to be candidates for power mobility use, and presents internationally on topics related to pediatrics. She currently serves on the Editorial Committee for the Wheelchair Skills Program and on the Pediatric Specialty Council of the American Board of Physical Therapy Specialties.



Rebecca Knickmeyer, PhD

Rebecca Knickmeyer has 20+ years' experience working at the cutting-edge of cognitive developmental neuroscience. She received her PhD in Experimental Psychology from the University of Cambridge (U.K.) in 2005 and completed her postdoctoral training in the Neurodevelopmental Disorders Research Center at the University of North Carolina at Chapel Hill. She is currently an Associate Professor in the Department of Pediatrics and Human Development at Michigan State University and Interim Chief of Neuroengineering in MSU's Institute for Quantitative Health Sciences and Engineering. The goal of Dr. Knickmeyer's lab is to identify genes and molecular pathways associated with altered brain development in infancy and early childhood through the integration of pediatric neuroimaging with cutting-edge techniques in genomics, metagenomics, and analytical chemistry. She has a particular interest in mechanisms underlying sexual differentiation of the brain and the microbiome-gut-brain axis. She is the author of over 80 scientific publications including manuscripts in high impact journals such as Science, PLOS Biology, and Biological Psychiatry. She is founder and director of ORIGIN (the Organization for Imaging Genomics in Infancy), a working group of the ENIGMA Consortium (Enhancing NeuroImaging Genetics through Meta-Analysis), serves on the editorial board of Molecular Autism, and belongs to numerous professional organizations including the Society for Neuroscience and the American College of Neuropsychopharmacology.



Steven J. Korzeniewski, PhD

With a broad multidisciplinary research background, my specific training and expertise are in epidemiology. I investigate the antecedents, correlates and sequelae of hypertension across the lifespan; my special interests are in placental malperfusion, related pregnancy disorders and offspring neurodevelopmental and cardiovascular disorders.



Renée Lajiness-O'Neill, PhD

Renée Lajiness-O'Neill, PhD, is a licensed clinical psychologist and neuropsychologist. She earned her doctoral degree from Brigham Young University with a dual specialization in Neuropsychology and Child Clinical psychology. She completed her internship in Clinical Psychology at Primary Children's Medical Center in Salt Lake City, Utah followed by a Postdoctoral Fellowship in Clinical and Research Neuropsychology in the Department of Psychiatry at Michigan Medicine. She is currently a Professor of Psychology in the Department of Psychology at Eastern Michigan University and an Adjunct Research Professor in the Department of Physical Medicine and Rehabilitation at Michigan Medicine. Dr. Lajiness-O'Neill specializes in the assessment of neurodevelopmental (e.g., learning, ADHD, autism spectrum, language) and acquired disorders of childhood. Her research focuses on development and validation of assessment methods to characterize neurobehavioral development. She is currently project director/principal investigator of a National Institutes of Health (NIH) R01 multisite, longitudinal grant ("PediaTrac: Web-based Measure to Screen and Track Early Developmental Trajectories") for which her team is developing and validating a web-based tool to identify risk trajectories of neurodevelopmental

disorders (e.g., autism, cerebral palsy) and related developmental psychopathologies. She is also Project Director/Principal Investigator of a National Science Foundation (NSF Major Research Instrumentation) grant award for which her team is developing electroencephalography (EEG) methods for infancy and toddlerhood studies.



Nigel Paneth, MD, MPH

Nigel Paneth is a pediatrician and epidemiologist whose research addresses the causes and prevention of childhood neurodevelopmental handicap, and especially their relationship to events in pregnancy and the perinatal period. He has a special interest in the epidemiology of cerebral palsy, the major motor disorder of childhood in terms of frequency and severity, and also on the causes and consequences of perinatal brain injury.



Piotr Pasak

I am a first-generation immigrant with a physical disability - cerebral palsy - who navigates the American Dream using a mobility scooter. Living in a largely inaccessible world has made me into a natural problem-solver, easily adapting to various circumstances. As a minority in disability, I embrace all forms of human diversity, and actively advocate for equity, inclusion and social justice. Although I value independence and self-sufficiency, at times, I find myself dependent on others, and in this process, have learned to form positive relationships quickly. An avid soccer fan and player, I am passionate about disability focused physical health and psychological wellness initiatives. Living, working, studying and competing abroad are experiences that have contributed to my

global viewpoint and cross-cultural competence. I value academics and understand the impact of education on quality of life, and have grown into a proficient leader and entrepreneur, excelling in both student development as well as program management. My work aims at increased understanding of disability via the provision of meaningful applied learning experiences, and contributions to qualitative research in Adapted Physical Activity.



Dr. Jessica Prunte, MD

Dr. Jessica Prunte attended medical school at Michigan State University, College of Human Medicine, and completed her residency training in PM&R at the University of Colorado in 2016. She also completed a Pediatric Rehabilitation Medicine fellowship at the Shirley Ryan AbilityLab (formerly Rehabilitation Institute of Chicago) in 2018. Dr. Prunte's clinical responsibilities include outpatient rehabilitation management of children with Cerebral Palsy, Spina Bifida, and other neurologic or musculoskeletal conditions affecting development. Her research interests include the early identification of Cerebral Palsy and early intervention to improve outcomes.



Karen Weinstein, BS

My name is Karen Weinstein. I have spastic left hemiplegic cerebral palsy. I grew up on the west coast and have lived in Michigan for 25 years. I have a bachelor of science degree in social science with an emphasis in psychology and child development with a minor in special education. I taught preschool for 15 years. I was a single foster to adopt mom. I am extremely active in my community and enjoy helping others whenever I can.



Dan Whitney, PhD

Dan Whitney, PhD, is an Assistant Professor in the Department of Physical Medicine & Rehabilitation at the University of Michigan. Dan's translational research focuses on understanding musculoskeletal pathology and how it impacts healthful aging for individuals with pediatric-onset disabilities across the lifespan.



Duncan Wyeth

Duncan Wyeth was born in 1946 and diagnosed with cerebral palsy in 1947. His parents rejected a very negative prognosis that would have placed him in an institution. They were his first advocates and modeled for him the advocacy skills that have served him so well throughout his life. He attended his neighborhood schools before state and federal laws mandated inclusion. Duncan attended MSU and then taught in junior and senior high schools. His employment and volunteer activities have included the directorship of a Center for Independent Living, Consumer Activities for the national office of United Cerebral Palsy, the Client Assistance Program within Michigan Rehabilitation, and Executive Director of the Michigan Commission on Disability Concerns. As adjunct faculty at MSU, Duncan taught Disability Studies. He currently serves as a member of the MI DNR Accessibility Advisory Council and the Cerebral Palsy Research Network. In his sporting life, Duncan competed in the 1988 Seoul and 1992 Barcelona Paralympics and was elected to represent his peer athletes with disabilities at the 1996 Atlanta Games and for eight years on the US Olympic Committee Board of Directors.