

Thursday, April 19, 2018

# Maximizing Function and Ability in CP

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Cerebral Palsy Research Consortium  
of Michigan 6th Conference



RADIOLOGY BUILDING  
Michigan State University

*A research collaboration of Michigan State University, University of Michigan, and Wayne State University*

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

Community members interested in CP research are invited to attend these conferences as part of the vital partnership of medical scientists and the community of individuals with CP in the research enterprise. Indeed, CPRCoM researchers are interested in and experienced with participatory action research, which involves the community in planning and implementation of research. Michigan is a site for the Cerebral Palsy Research Network, a CP registry that will allow families to participate in CP related research.

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

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## ACKNOWLEDGEMENTS

**MICHIGAN STATE  
UNIVERSITY**



**WAYNE STATE  
UNIVERSITY**



### KEYNOTE SPEAKERS:

Keynote speaker Peter Rosenbaum  
and all our speakers, panelists and presenters

### CONFERENCE ORGANIZERS:

Edward Hurvitz  
Steven Korzeniewski  
Madeleine Lenski  
Nigel Paneth  
Seth Warschausky

### BOOKLET AND PROGRAM:

Ann Cook  
Mark Watrich

*Photos: Thanks to Piotr, Daneel and Dora and families for the wonderful photos*

### FINANCIAL AND COLLEGIAL SUPPORT:

University of Michigan, Department of Physical  
Medicine & Rehabilitation  
Michigan State University, Department of  
Epidemiology and Biostatistics  
Wayne State University

**CONFERENCE AGENDA**

- 8:00**                    **Registration and continental breakfast**
- 8:30**                    **Welcome**  
Edward Hurvitz
- 8:35 - 9:35**            **CP RESEARCH METHODOLOGY (Paneth, moderator)**
- The MOBAND cohort - the best new resource for studying the etiology of CP**  
Nigel Paneth
- Exploring the probability of gonadotropin involvement in protection against CP-related brain injury**  
Tammy Movsas
- Pre-Pregnancy and Early Gestation Antecedents of CP**  
Steven Korzeniewski
- Baby Wiggles and Early Identification**  
Jennifer Larson
- 9:35**                    Break and poster session
- 10 - 10:45**            **PERINATAL AND EARLY LIFE RESEARCH (Lenski, moderator)**
- Expression of inflammation-related gene S100A9 in newborn bloodspots can differentiate CP from healthy controls: a preliminary study**  
Sok Kean Khoo
- Unlocking Potential in Children with Multiple, Severe Disabilities: Does Power Mobility Training Generate Neural Plastic Changes in the Brain?**  
Lisa Kenyon
- Predicting Communication Function in Individuals with Cerebral Palsy**  
Mary Jo Cooley Hidecker
- 10:45**                    Break and poster session
- 11:15 - 12:15**        **KEYNOTE**
- CP and the ICF: How a simple framework is making a BIG difference!**  
Peter Rosenbaum
- 12:15 - 2:00**            Lunch
- CP Families Together: From Functioning to Living**  
Dawn Krause
- 2:00 - 3:15**            **CP IN ADULTS (Cooley Hidecker, moderator)**
- Aging trajectories of chronic noncommunicable diseases in cerebral palsy**  
Mark Peterson

**Skeletal metabolism and cerebral palsy**

Daniel Whitney

**Cognitive Assessment Through Assistive Technology:  
From switches to Brain-Computer Interfaces**

Jane Huggins

**Mobile Technologies for Self-Management of Health and  
Independence - Unlocking their potential**

Michelle Meade

**MSU Adaptive Sports & Recreation Club: Creating Inclusive  
and Integrated Physical Activity Environments for Individuals  
with Cerebral Palsy**

Piotr Pasik

**3:15** Break and poster session**3:30 Q & A PANEL:**Peter Rosenbaum, Edward Hurvitz, Seth Warschausky,  
Mary Jo Cooley Hidecker and Nigel Paneth (moderator)**The Cerebral Palsy Research Network**

Edward Hurvitz

**NIH/NINDS common data elements for cerebral palsy**

Seth Warschausky

**Question and answer for panel****4:30 A Chance to Dance**

Daneel Proshlyakov and Dora Ivkovich

**5:00 Adjourn**

Edward Hurvitz



*With a flourish:  
Daneel dancing the foxtrot with Dora, leader of "A Chance to Dance"*



### **MARY JO COOLEY HIDECKER, PHD, MS, MA, CCC-A/SLP**

Mary Jo Cooley Hidecker, Ph.D., M.S., M.A., CCC-A/SLP, is an Assistant Professor in the Division of Communication Disorders at the University of Wyoming. After completing her M.S. in Epidemiology from Michigan State University, Mary Jo is happy to continue her affiliation as a speech-language pathologist and audiologist with Dr. Nigel Paneth's research team. Mary Jo leads the on-going development of the Communication Function Classification System (CFCS) which was "born" during her post-doctoral fellowship in MSU's Department of Epidemiology and Biostatistics.



### **JANE HUGGINS, PHD**

Dr. Huggins trained in computer engineering and biomedical engineering at Carnegie Mellon University and the University of Michigan in Ann Arbor. She completed a clinical Rehabilitation Engineering Internship at the University of Michigan. She is a founding member of the University of Michigan Direct Brain Interface Laboratory, which she has led since 2007. Her current focus is making EEG-based brain-computer interfaces practical for people who need them, both for communication and for cognitive assessment. Dr. Huggins is a founding member of the board of directors of the Brain-Computer Interface Society and serves on the editorial board for the journal Brain-Computer Interfaces. Outside the lab, Dr. Huggins enjoys knitting, horseback riding, birdwatching, cooking, and being Mom to her two school-age children.



### **EDWARD HURVITZ, MD**

Edward A. Hurvitz, MD is Professor and Chair, James W. Rae Collegiate Professor of the Department of Physical Medicine and Rehabilitation at Michigan Medicine, University of Michigan in Ann Arbor, Michigan, USA. He is a pediatric rehabilitation medicine specialist who provides clinical care and performs research related to children with disabilities and adults with pediatric onset disabilities, particularly cerebral palsy. He has co-authored several papers related to adolescents and adults with cerebral palsy including several related to health and fitness in CP, and to motor control in adults with CP. Dr. Hurvitz is co-director of the Cerebral Palsy Research Consortium of Michigan, which promotes research related to CP by sharing expertise, collaborating, and assisting with recruitment. He is on the Leadership Team for the Cerebral Palsy Research Network, a national effort to create a registry for cerebral palsy. He co-leads the International Cerebral Palsy Health Promotion Group.



### **LISA K. KENYON, PT, DPT, PHD, PCS**

Dr. Kenyon is an Associate Professor in the Department of Physical Therapy at Grand Valley State University in Grand Rapids, Michigan. Dr. Kenyon heads the Grand Valley Power Mobility Project, an inter-professional research project that provides power mobility training for children with multiple, severe disabilities. Dr. Kenyon presents internationally on topics related to pediatric physical therapist practice and has published multiple journal articles and book chapters pertaining to topics in pediatrics.



### **SOK KEAN KHOO, PHD**

Sok Kean Khoo received her B.S. and M.S. degrees in applied biology and physiology from the University of Science Malaysia. Her Ph.D. in fisheries genetics was obtained from the Tokyo University of Marine Science and Technology. She completed her postdoctoral training in cancer genetics at the Van Andel Research Institute and subsequently was promoted to Associate Director for the Laboratory of Germline Modification & Cytogenetics and later Laboratory Director for the Genomic Microarray Technology Core. She then obtained a Distinguished Associate Professor contract position in the Department of Cell and Molecular Biology (CMB) at Grand Valley State University (GVSU) in 2013. She became a tenure-track Associate Professor in CMB at GVSU in 2016. Dr. Khoo has more than 20 years of research experience in molecular genetics and genomics, studying various cancers and neurological diseases. Her current research focuses on developing translational biomarkers for Parkinson's disease and understanding the molecular etiology of cerebral palsy.



### **STEVEN KORZENIEWSKI, PHD**

I am an Associate Professor in the Department of Obstetrics and Gynecology at the Wayne State University School of Medicine (WSUSOM). With a broad background in studying maternal & child health, my specific training and expertise are in the key area of epidemiology, "a fundamental science for translating discoveries into population health benefits (pg. 522 PubMed id. 20688899)". My research seeks to identify early antecedents of major pregnancy complications, and determine mechanistic pathways linking them to damage to developing brain structure or function, with the end goal of developing clinical/therapeutic interventions to reduce population-level disease burden. I am particularly interested in what appears to be modulation of inflammation-related phenomena by neurotrophin/angiogenesis-regulating processes in association with malplacentation-related pregnancy complications and their offspring neurodevelopmental sequelae. Since 2005, I have published four original studies, four reviews, four book chapters and two commentaries each focused on cerebral palsy.



### **DAWN KRAUSE, BA**

Dawn Krause has BAs from Michigan State University in Eastern European History and International Political Science. She is a research administrator at the University of Michigan Department of Physical Medicine & Rehabilitation. Her son William was diagnosed with lissencephaly and cerebral palsy at the age of 4 months and given a two-year life expectancy; he passed away on 11-5-15 at age 11. Dawn has testified in Congress and lobbied in Washington, D.C. with NCART (National Coalition for Assistive & Rehab Technology). She currently has three bills going through the Michigan state Senate with regards to pediatric do-not-resuscitate (DNR) orders and DNRs in an educational setting. She is married to Ted, a professor at Central Michigan University, and she has two other children: Grant (16) and Gabby (11). Dawn lives in Saline with her family.



### **JENNIFER LARSON, PHD**

Dr. Jennifer Larson is a Board Certified Clinical Neuropsychologist and a Clinical Assistant Professor at the University of Michigan in the Department of Physical Medicine and Rehabilitation. She provides comprehensive outpatient neuropsychological assessments to diverse and complex child clinical populations of various ages with a broad spectrum of developmental, medical, and neurological disorders. Her research interests include the motor and executive systems and their interactions with development, outcomes research for children born prematurely, and the clinical utility of neuropsychological measures and methods.



### **MICHELLE MEADE, PHD**

Michelle A. Meade, Ph.D. is an Associate Professor with tenure in the University of Michigan (UM) Department of Physical Medicine and Rehabilitation. As a rehabilitation psychologist, she conducts research with, provides clinical services to, and advocates for individuals with SCI and other physical disabilities. Dr. Meade is the Principal Investigator (PI) and Director of the UM Rehabilitation Engineering Research Center (RERC) Technology Increasing Knowledge: Technology Optimizing Choice (TIKTOC) which is focused on developing and evaluating mobile technologies to enhance health management and independence among adolescents and young adults with disabilities. She has also served as a PI, co-investigator or consultant on other grants from the federal government and private foundations, including the University of Michigan SCI Model Systems and a Department of Defense study looking at resilience among individuals with SCI. Her primary research interests focus around self-management and enhancing health and participation, and reducing health care disparities and costs, among individuals with disabilities through the identification of modifiable factors, the development and validation of culturally relevant interventions, and the implementation of tailored dissemination and knowledge translation strategies. Dr. Meade is a fellow of the American Psychological Association (APA) and the President-elect of Division 22 (Rehabilitation Psychology) of APA in addition to serving as Treasurer of the Section of Psychologists, Social Workers and Counselors (PSWC) in the Academy of Spinal Cord Injury Professionals (ASCIP) and as a member of the Editorial Board for Topics in Spinal Cord Injury Rehabilitation.



### **TAMMY Z MOVSAS, MD, MPH**

Dr. Tammy Movsas has an undergraduate degree in Biochemistry and Molecular Biology from Harvard University, an MD degree from Washington University School of Medicine in St Louis and an MPH in epidemiology from University of Michigan. She is board certified in both Ophthalmology and Preventive Medicine and has completed fellowships in neuro-ophthalmology, pediatric ophthalmology and perinatal epidemiology. She is the Founder and Director of ZRI, the Medical Director of Midland County Dept of Public Health and Clinical Associate Professor of Pediatrics and Human Development at MSU.





### **NIGEL PANETH, MD, MPH**

Dr. Paneth is a pediatrician and perinatal and developmental 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 and the causes and consequences of brain injury in premature infants.



### **PIOTR JOZEF PASIK, MA, MS CANDIDATE**

I am a first generation immigrant with a physical disability who navigates the American Dream using a mobility scooter. Living in a largely inaccessible world has made me into a natural problem-solver, able to easily adapt to various circumstances. As a minority in disability, I embrace all forms of human diversity, and actively advocate for equality, inclusion and social justice. I am an optimist with a progressive perspective that is uniquely balanced and guided by the Roman Catholic faith passed on to me by my Polish ancestors. 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. I have traveled extensively; living, working, and studying abroad are experiences that have contributed to my global viewpoint and cross-cultural competence. Born to college-educated parents, I value academics and understand the impact of education on quality of life. Through a range of employment opportunities, I have honed my leadership and entrepreneurial skills, excelling in the areas of student development and program management. Using excellent written and oral communication skills to network, I have repeatedly illustrated a unique ability to identify, obtain, and maximize resources to pioneer successful initiatives that facilitate cross-campus synergy and create meaningful applied learning experiences that benefit all involved.



### **MARK PETERSON, PHD**

Dr. Mark Peterson is on faculty at the University of Michigan (UM)-Medicine, Department of Physical Medicine and Rehabilitation, and an active member in the UM Neuroscience Graduate Program, Institute for Health Policy and Innovation, Michigan Center of the Demography of Aging, and the Michigan Institutes for Data Science. Mark's federally-funded research is designed to study muscle physiology and metabolic health/regulation among individuals with neurodevelopmental and acquired disabilities (e.g., cerebral palsy, spinal cord injury, age-related frailty, etc.), and to examine the effectiveness of targeted exercise interventions in these populations. Mark has published over 80 peer review papers and book chapters in leading medical, public health, and sports science journals, in the field of exercise physiology and on topics related to muscular strength optimization for enhancing metabolic health, improving function and cognitive capacity, increasing life-expectancy, and maximizing athletic performance. Dr. Peterson is recognized as a Fellow of the American College of Sports Medicine (ACSM), and is certified with

distinction, as a strength and conditioning specialist through the National Strength and Conditioning Association (NSCA).



### **PETER ROSENBAUM, MD, FRCP(C)**

Peter Rosenbaum, M.D., FRCP (C) joined the faculty of McMaster University in July 1973 and has been a Professor of Pediatrics since 1984. He held an inaugural Tier 1 Canada Research Chairs (2001- 2014). In 1989, Peter co-founded the award-winning CanChild Centre for Childhood Disability Research, a health system-linked research unit now recognized world-wide for its research and dissemination activities.

Peter has held more than 80 peer-reviewed research grants and is a contributing author to over 330 peer-reviewed journal articles and book chapters. He has been an invited lecturer and keynote speaker in 30 countries. He co-authored “Cerebral Palsy: From Diagnosis to Adult Life” (2012), and co-edited “Life Quality Outcomes of Children and Young Adults with Neurological and Developmental Conditions” (2013) with Dr. Gabriel Ronen. In 2016, he and colleagues published a book on ethical dilemmas in developmental medicine.

Peter has been a graduate supervisor or committee member at the Universities of Oxford, Utrecht, Witwatersrand, and Toronto in addition to McMaster. From 2012-14 he was a consultant to UNICEF’s Expert Consultation on the Collection of Data on Children with Disabilities. His awards include the Ross Award from the Canadian Pediatric Society (2000); an Honorary Doctor of Science degree, Université Laval (2005); the AACPDM’s first Mentorship Award (2007) and its Lifetime Achievement Award (2014). In 2015, he received the inaugural Holland Bloorview Medal of Excellence for “outstanding achievement and leadership in making positive global advancements in the field of childhood disabilities. In October 2017 he was honoured by the University of Haifa with the university’s Carmel Award of Merit in recognition of his lifetime achievements in childhood disabilities research.



### **SETH WARSCHAUSKY, PHD**

Seth Warschausky, Ph.D. is a Professor and pediatric neuropsychologist in the Department of Physical Medicine and Rehabilitation at the University of Michigan. He is Director of the university’s NIH-CTSA Neurodevelopmental Assessment Core that supports pediatric clinical trials. Dr. Warschausky is a Consulting Editor for Rehabilitation Psychology, the Journal of Pediatric Rehabilitation Medicine, and the Journal of the International Neuropsychological Society. He serves on the Science Advisory Council of the Cerebral Palsy Foundation. Recently, Dr. Warschausky served as a member of the NIH/AACPDM Common Data Elements workgroup for Cerebral Palsy.



### **DANIEL G. WHITNEY, PHD**

Daniel G. Whitney, PhD: Dr. Daniel Whitney is a research fellow in the Department of Physical Medicine and Rehabilitation at the University of Michigan. He received his PhD in Applied Physiology studying musculoskeletal pathophysiology in children with cerebral palsy under the supervision of Christopher M. Modlesky, PhD, at the University of Delaware. Dan's research interests include lipid, musculoskeletal and neuromuscular pathophysiology and chronic disease clustering in those with cerebral palsy.

## **PREDICTING COMMUNICATION FUNCTION IN INDIVIDUALS WITH CEREBRAL PALSY**

Mary Jo Cooley Hidecker

Several birth characteristics and developmental language milestones have been predictive of later communication performance for children with cerebral palsy. These characteristics and milestones should trigger referrals for communication evaluations, including speech, language, hearing, and/or augmentative and alternative communication.

## **COGNITIVE ASSESSMENT THROUGH ASSISTIVE TECHNOLOGY: FROM SWITCHES TO BRAIN-COMPUTER INTERFACES**

Jane Huggins

Too often, tests of cognitive function rely on speech, pointing, or other types of physical function to demonstrate cognition. This makes many such tests inaccessible to people with severe speech and movement impairments. Studies at the University of Michigan are investigating adapted cognitive testing using assistive technology to provide access to standard cognitive assessments. Current assistive technologies for this purpose include pressure switches, head pointers, and scanning. Research efforts are also underway to use brain-computer interfaces for cognitive assessment.

## **THE CEREBRAL PALSY RESEARCH NETWORK**

Edward Hurvitz

The Cerebral Palsy Research Network (CPRN) has been developed to improve outcomes for people with cerebral palsy through high quality clinical research and quality initiatives. It includes over 20 clinical sites around the country who are working toward using the electronic medical record to collect uniform data, which is sent to a central data processing center. The network includes physicians, therapists, and patient advocates who work together to develop study questions and methods. Over 1500 patients have already been entered into the database. This presentation will briefly review the methodologies, examine some of the early findings and discuss a research agenda recently developed through a conference funded by a PCORI grant led by CPRN and CP NOW, an advocacy organization.

## **UNLOCKING POTENTIAL IN CHILDREN WITH MULTIPLE, SEVERE DISABILITIES: DOES POWER MOBILITY TRAINING GENERATE NEURAL PLASTIC CHANGES IN THE BRAIN?**

Lisa K. Kenyon (Co-authors: John Farris, Naomi J. Aldrich)

Research suggests that children with multiple, severe disabilities may benefit from power mobility use even though they may never become independent power wheelchair users. But what are the benefits of power mobility training and use in this population? Are these children able to learn and develop functional skills through power mobility use? Electroencephalography (EEG) has been proposed as a way to understand the possible neural correlates of skill acquisition and to provide information about the effectiveness of rehabilitation interventions. This session will provide an overview of our work exploring the impact of power mobility training on the spectra of EEG activity in children with multiple, severe disabilities.

## **EXPRESSION OF INFLAMMATION-RELATED GENE S100A9 IN NEWBORN BLOODSPOTS CAN DIFFERENTIATE CP FROM HEALTHY CONTROLS: A PRELIMINARY STUDY**

Sok Kean Khoo

Increased inflammation-related proteins in blood are known to associate with increased risk of cerebral palsy (CP). Previously, using gene expression microarray on newborn bloodspots, we found genes in the fetal inflammatory response syndrome gene set most differentially-expressed between CP and its matched controls. One of the highest differentially-expressed genes was S100A9 (S100 calcium-binding protein A9). S100A9 codes for S100A9, a calcium- and zinc-binding protein which regulates the inflammatory processes and immune response. Here, we used quantitative real-time PCR to compare S100A9 gene expression in newborn bloodspots of 74 CP and 68 healthy controls (HC). S100A9 expression was significantly up-regulated in CP compared to HC ( $P = 0.000845$ ), showing that S100A9 can distinguish CP from HC in newborn bloodspots.

## **PRE-PREGNANCY AND EARLY GESTATION ANTECEDENTS OF CP**

Steven Korzeniewski

My talk will focus on the inter-relationships among factors that appear to raise the risk of cerebral palsy (CP) and its correlates. In large-part the focus will be on pre-conception and early gestation risk factors, but I will also link these exposures to later occurring CP antecedents (i.e., obstetric disorders) because this has major implications for study design and inference about CP causality.

## **CP FAMILIES TOGETHER: FROM FUNCTIONING TO LIVING**

Dawn Krause

Cerebral Palsy Families Together of Michigan was founded in March of 2015 by Dr. Edward Hurvitz and Dawn Krause. CPFTOM is a (pending) 501c3 that provides Michigan-based families of children with cerebral palsy, adult mentors, and caregivers with support, education, and advocacy. Under the direction of Dr. Edward Hurvitz, President Dawn Krause, and Vice-President Brian Hagler, the board represents a broad range of expertise from both University of Michigan and Michigan State University, with decades of collective experience in caring for medically complex children. Their mission is centered on the belief that leading-edge pediatric research, increased awareness, and education will lead to new treatments of CP, thereby improving the lives of impacted children and their families. Currently there are over 350 members and one of the biggest achievements to date is a large equipment closet. Future plans include working with local representatives on advocacy projects and fundraising.

## **BABY WIGGLES AND EARLY IDENTIFICATION**

Jennifer Larson

At present cerebral palsy (CP) is the most common cause of physical disability in childhood affecting 2-2.5 per 1000 live births. A diagnosis of CP is typically made between the 12 and 24th month of life; however, recent systematic reviews have found that CP can be reliably identified in high-risk infants prior to 6 months corrected age using the General Movement Assessment (GMA). Early identification of children at highest risk for developing CP allows for early intervention, which has shown to be promising in improving motor and cognitive. The aim of this presentation is to provide information on the GMA and its role in early identification of CP in high risk infants.

## **MOBILE TECHNOLOGIES FOR SELF-MANAGEMENT OF HEALTH AND INDEPENDENCE - UNLOCKING THEIR POTENTIAL**

Michelle Meade

Adolescents and young adults with disabilities represent a diverse and often underserved group with unique needs, strengths, challenges, experiences, and skills. Mobile technology - including sensors, apps, games, and other innovations - represent an opportunity to include and engage this group and their family members so as to better address their needs and support their transitions to health self-management and independence.

The potential benefits associated with mobile technology, though, are likely to be lost if development and innovation do not occur in a space where there is an opportunity for shared understanding and discussion. The processes of development and innovation cannot occur in silos; they must be informed by the knowledge and expertise of individuals with disabilities and their families. Also relevant and bringing their own challenges are the systems, structures, and processes associated with healthcare, educational, and employment environments in which the technology needs to be embedded - or at least interacted with.

It was for this reason that the Technology Increasing Knowledge: Technology Optimizing Choice (TIKTOC) Rehabilitation Engineering Research Center (RERC) at the University of Michigan (UM) decided to use its state of the science conference as an opportunity to bring together a diverse mix of researchers, clinicians, and developers as well as representatives from disability organizations, funding agencies, and business, insurance, and technology-related companies to consider how best to integrate mobile technology into systems and lives. This event, Facilitating Health Self-Management and Independence among Adolescents and Young Adults with Disabilities identified best practices and the state of the science as related to mobile technology applications for individuals with physical, cognitive, and developmental disabilities in the areas of Engagement and Tailoring, Innovation, Research, Integrating technology into health care, and Sustainability and technology transfer.

This presentation will review the highlights and recommendations from this State of the Science Conference. In doing so, the presenter will reinforce how to unlock the potential of mobile technology to optimize health management and participation outcomes for individuals with CP and other disabilities.

### **EXPLORING THE PROBABILITY OF GONADOTROPIN INVOLVEMENT IN PROTECTION AGAINST CP-RELATED BRAIN INJURY**

Tammy Z Movsas

The human fetus is exposed to the placental hormone, human chorionic gonadotropin (hCG) throughout its intrauterine development. hCG can cross the blood-brain barrier, and hCG receptors exist in fetal brains. Thus, it is plausible that hCG may be involved in fetal neurodevelopment. Given that almost 90% of the cerebral palsy-associated brain injuries occur in utero or at the time of birth, Dr. Movsas and colleagues hypothesized that high levels of hCG exposure to the fetus at the time of brain insult may be protective against the later development of cerebral palsy. Dr. Movsas will provide evidence that hCG has strong neuroprotective properties capable of decreasing the injury of immature neurons in vivo and in vitro and discuss the likelihood of the involvement of hCG in protection against CP-related brain injury during human development.

### **THE MOBAND COHORT: THE BEST NEW RESOURCE FOR STUDYING THE ETIOLOGY OF CP**

Nigel Paneth

Most studies that look for the underlying causes of CP must rely on medical records of pregnancy and early life, or maternal recollections of exposures that took place in pregnancy. To study the early origins of CP prospectively, that is, starting before CP was diagnosed, ideally, from early in pregnancy, has been very difficult. In fact, it has only been undertaken once, in the very influential National Collaborative Perinatal Project, which looked at risk of CP in 55,000 US pregnancies born 1959-1966, followed to age seven. That study showed how infrequently birth troubles led to CP, dismissing the myth that all CP was due to obstetrical malpractice. With a prevalence of about 3/1,000 live births, even that huge study had fewer than 200 children with CP.

But in the late 1990's and early 2000's, Norway and Denmark each undertook a study of 100,000 pregnancies. The data has now been combined into one cohort of 200,000 children from MoBa (Mothers and Babies in Norway) and DNBC (The Danish National Birth Cohort) and that cohort is referred to as MOBAND. By linking to the CP registries of both countries, nearly 500 children with CP have been identified in MOBAND.

The cohorts are rich repositories of real-time pregnancy and perinatal data, including interviews with mothers in pregnancy on nutrition, illnesses, psychosocial stress and much more, as well as archived urines and blood specimens from pregnancy, including cord blood at delivery.

MOBAND would like to see investigators interested in what causes CP develop specific hypotheses that can be tested in the database. Information on how to get involved will be presented in Dr. Paneth's talk.

### **MSU ADAPTIVE SPORTS & RECREATION CLUB: CREATING INCLUSIVE AND INTEGRATED PHYSICAL ACTIVITY ENVIRONMENTS FOR INDIVIDUALS WITH CEREBRAL PALSY**

Piotr Jozef Pasik

Research suggests that physical activity improves physical health, facilitates psychological wellness, fosters social inclusion, and enhances academic performance. However, due to an increased likelihood of a sedentary lifestyle that is dictated by their respective disability contexts, individuals with physical disabilities are at a higher risk for secondary physical health conditions, depression, as well as social isolation. Additionally, this population faces individual, societal, and environmental level barriers to quality physical activity opportunities, further compromising their overall quality of life. In light of this, well organized wheelchair sport and adaptive recreation programs that take into account important disability considerations are needed in order to develop, facilitate, and sustain healthy physical activity behaviors among this population. Key to achieving such outcomes is the establishment of a needs based motivational climate in adapted physical activity settings. Rooted in Self-Determination Theory and Achievement Goal Theory, the MSU Adaptive Sports & Recreation Club is an example of such an inclusive and integrated physical activity environment, serving to further MSU's Land Grant legacy by diversifying education and making it more accessible for able-bodied students and individuals with disabilities respectively.

## **AGING TRAJECTORIES OF CHRONIC NONCOMMUNICABLE DISEASES IN CEREBRAL PALSY**

Mark Peterson

While the incidence of cerebral palsy (CP) has remained stable in recent years, the mortality rate of children with CP has declined substantially, suggesting that adults with CP represent a growing population whose health status and healthcare needs are poorly understood. This expansion of the aging CP population has led to a diversification of cardiometabolic disease morbidity, including increased prevalence of aging-related multimorbidity and musculoskeletal frailty. Decrements in muscle mass and strength are typically considered the primary contributing factors of gross motor decline in adults with CP; however, it is likely that these changes are actually the direct consequence of years spent accumulating extremely sedentary lifestyles. These modifiable behaviors lead to substantially increased risk of multiple chronic disease processes, such as obesity, diabetes, hypertension, asthma, and stroke. We have recently completed two studies which represent a substantial addition to the current body of literature pertaining to: (1) predictors of multimorbidity in middle-aged adults with CP, and (2) characterization of the longitudinal trends and disease free survival of chronic noncommunicable diseases such as diabetes, hypertension, hypercholesterolemia, osteoporosis, pulmonary disease, arthritis, etc., in large samples of adults with CP. This session will highlight the need for a lifespan approach to improve screening and tailoring of interventions to preserve function and cardiometabolic health, increase longevity, and improve overall quality of life in the CP population.

## **CP AND THE ICF: HOW A SIMPLE FRAMEWORK IS MAKING A BIG DIFFERENCE!**

Peter Rosenbaum

The World Health Organization's International Classification of Functioning, Disability and Health – published in 2001 and affectionately known as ‘the ICF’ – provides a framework for health for everyone. Although still not well enough known and used, this integrated biopsychosocial approach has generated considerable interest from people in the field of childhood disability. A whimsical adaptation of the ICF – the ‘F-Words in childhood disability’ – has captured the attention, and stimulated the imaginations, of families and colleagues around the world. In this talk I will take listeners on a tour of the ICF and F-words, and share some of the ‘sights and sounds’ of this amazing – and emerging – journey of discovery. Listeners will leave with access to a fascinating array of useable resources.

## **NIH/NINDS COMMON DATA ELEMENTS FOR CEREBRAL PALSY**

Seth Warschausky

Dr. Warschausky will briefly describe the NINDS CDE process and content, discuss the potential use of CDEs in registry development and research, and comment on implications for the electronic medical record (EMR).

## **SKELETAL METABOLISM AND CEREBRAL PALSY**

Daniel G. Whitney

Cerebral palsy (CP) arises from damage or malformation of the developing brain leading to neuromuscular dysfunction and low levels of physical activity. Inadequate mechanical loading likely initiates poor skeletal development in children with CP, but subsequent alterations, such as expansion of fat within bone marrow, may further impede musculoskeletal acquisition in an independent manner. This talk will outline the composition and structural deficits of the skeleton in children with CP, and skeletal disease profiles in adults with CP as a function of age.

## **USE OF VIRTUAL REALITY TECHNOLOGY ON IMPROVING BALANCE AND FUNCTIONAL MOBILITY IN AN ADOLESCENT WITH CEREBRAL PALSY: A CASE REPORT**

Zubek, J., Busik J. and Denis Proshlyakov

The purpose of the prospective case report is to determine the impact of a commercially available virtual reality gaming system (HTC VIVE™) to enhance the home rehabilitation efforts of a male adolescent with Spastic Diplegia Cerebral Palsy, GMFCS level III, after recent lower leg fracture and surgery. All sessions took place at the patient's home in a safe environment and monitored by his parents and home aides. Intervention: The patient participated in daily home sessions and tracked his consistency using a daily marking grid provided by the therapist. Each session began with visual tracking exercises coupled with dynamic standing balance to improve chasing speed within the game itself. From here, the patient was assisted into a homemade "ski rig" to affix the distal limbs during play. The patient would play the immersive game "Space Pirate Trainer," cued as necessary to maintain upright posture throughout. Outcomes: Session data collected includes 1. Total time standing during initial game play, 2. Points achieved during initial game play, and 3. Total time playing game. Other measures include postural control and sway assessments as well as functional mobility using the Edinburgh Visual Gait Analysis (EVGA). Home visits were followed up at weeks 3 and 6 during the intervention phase. Discussion and Conclusion: Initially, patient compliance with the home based regimen was slow to start, but improved after addition of a daily record for consistency. Motivation was measured by the number of times the patient had to be reminded to participate in his daily VR rehab sessions. These reminders decreased by 70%. The EVGA scale showed a reduction of 4 points by week 3 which indicates a clinically meaningful improvement in functional mobility (Robinson, LW et al. 2017).



## EXHIBITS:

- A Chance to Dance
- Euro-Peds National Center for Intensive Pediatric PT, Pontiac, MI
- Team Rehab Pediatric Physical Therapy, Bingham Farms, MI
- University of Michigan Pediatric Rehabilitation Center, Ann Arbor, MI
- CPRCoM: Cerebral Palsy Research Consortium of Michigan
- CEEP Study: Conductive Education Evaluation Project, Michigan State University

## POSTERS:

- **Clinical variables and newborn blood spots gene expression analysis for cerebral palsy.**  
Brooke Armistead MS; Madeleine Lenski MSPH; Nigel Paneth, MD, MPH;  
Sok Kean Khoo, PhD
- **Prenatal Polyunsaturated Fatty Acids, Inflammation, and Cerebral Palsy: A study within MOBAND-CP**  
Diana K Haggerty, MS; Nigel Paneth, MD MPH; AJ Wilcox MD PhD
- **The impact of power mobility training on EEG activity in children with multiple, severe disabilities: a pilot study.**  
Lisa K. Kenyon, PT, DPT, PhD, PCS; John Farris, PhD; Naomi J Aldrich, PhD;  
Joshua Usoro, MSE; Samhita Rhodes, PhD
- **Providing power mobility access and training using a tongue-activated access method: a case report.**  
Lisa K. Kenyon, PT, DPT, PhD, PCS; John Farris, PhD; Tonya Calkins, PT, DPT;  
Paige Niles, PT, DPT; Stacey Omiljan, PT, DPT
- **A home-based body weight supported treadmill training program for children with cerebral palsy: a pilot study.**  
Allie Visser, PT, DPT; Marci Wesman, PT, DPT; Sango Otieno, PhD;  
Lisa K. Kenyon, PT, DPT, PhD, PCS
- **Pediatric power mobility training methods: a systematic review.**  
Lisa K. Kenyon, PT, DPT, PhD, PCS; Courtney Peterson, Pt, DPT; Lisa Hostnik, PT, DPT;  
Rachel McElroy, PT, DPT; John Farris, PhD
- **A school-based intervention to improve fitness and function in severe cerebral palsy: a pilot study.**  
Carol Daly, PT, DPT, PCS; Connie Haneline, PT, DPT; Suzanne Johannes, PT, MPT; Julie Middleton, PT, DPT; Lisa K. Kenyon, PT, DPT, PhD, PCS
- **Conductive Education Evaluation Project (CEEP): Phase II**  
Madeleine Lenski MSPH; Deborah Weiland MSN; Nigel Paneth, MD, MPH
- **Maternal and newborn infections and risk of cerebral palsy: a case-control study of Michigan children**  
Kathryn Thornton, DMD, MPH; Madeleine Lenski, MSPH; Nigel Paneth MD
- **Use of Virtual Reality Technology on Improving the Quality of Lower Extremity Movement in an Adolescent with Cerebral Palsy: A Case Report.**  
John Zubek DPT; Julia Busik PhD
- **Cerebral palsy by subtype, topography and impairments: A reliability study by maternal interviews and physician reports.**  
Edward Jados, BS, MHA; Madeleine Lenski, MSPH; Nigel Paneth MD, MPH
- **IPAAR: An adaptive test of phonological awareness for children with speech production difficulties**  
Ryan P. Bowles, PhD; Lori E. Skibbe, PhD; Gary A. Troia, PhD; Sarah Goodwin, PhD; Haruka Konishi, PhD

