

## Instructional Course Lectures

Friday, October 12

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### **IC17: "LOOKING" FOR COMMUNICATION SUCCESS: VISUAL CONSIDERATIONS FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATIONS FOR THE PEDIATRIC PATIENT WITH CEREBRAL PALSY AND CORTICAL VISUAL IMPAIRMENT**

*Katherine L. Clark, MOT, OTR/L, ATP; Lindsay Stutz, MA, CCC-SLP*

Given the high incidence of CVI and visual processing delays among children with CP, understanding how visual and motor deficits impact opportunities for accessing AAC devices and systems is required to improve communication outcomes for these children. This course will illustrate how deficits related to the ability to process complexity and novel or abstract picture symbols, as well as challenges with visual motor coordination, can prevent a child from successfully using AAC systems. Topics will include discussion of the 10 characteristic visual behaviors associated with CVI and how these impact the complex AAC evaluation process. An interdisciplinary approach will be discussed which addresses the critical components of an AAC evaluation, including assessment of functional vision, physical abilities, cognition, and communication. The presentation will focus on how visual preferences, use of functional vision during daily routines, and motor impairments can greatly impact social participation in activities across various environments, and in turn limit opportunities for communication. Common barriers to successful communication identified through the evaluation process will be illustrated. Practical clinical strategies will be provided to address these challenges. Clinical case examples and videos of patients from early intervention through early elementary years will be used to highlight strategies for communicators with varying visual, physical and cognitive abilities.

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### **IC18: HYPOTONIA CARE PATHWAY UPDATE**

*Ginny Pateg, PT, DScPT; Maureen Story, BSR PT/OT; Garey Noritz, MD*

Hypotonia, or low muscle tone, is associated with pediatric disorders with different causes and outcomes. The underlying mechanism causing hypotonia is variable and can reflect genetic, metabolic, or structural disorders. This topic is important because infants with hypotonia often require full medical work-ups to identify the cause. These children could benefit from early intervention, which often requires a diagnosis.

This course will present the clinical care pathway for Hypotonia including the algorithm that was developed by a consortium of international health care professionals.

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### **IC19: TRANSFORMATIVE JOURNEYS INTO ADULTHOOD: BEST PRACTICES TO PROMOTE LIFE SKILLS AND TO RECEIVE EMERGING ADULTS WITH CHILDHOOD ONSET DISABILITIES INTO ADULT CARE**

*Marij Roebroek, PhD; Susan C. Labhard, MSN, RN; Jan Willem Gorter, MD, PhD; Donna Thomson- Parent Advisor; Elisabet Rodby-Bousquet, PhD*



Key goals in a successful journey to adulthood for many individuals with child-onset conditions are learning how to self-manage life and developing the skills to take care of their own health care needs. Parents of youth affected by severe disabilities must cope with their child's condition while maintaining value and dignity. This course will inform on best practices of young adult clinics of USA, Canada, Sweden and the Netherlands. Specific focus is on effective approaches to support young people with disabilities through developmentally appropriate life experiences at regular intervals.

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## **IC20: A MULTIDISCIPLINARY APPROACH TO IMPROVING GAIT IN CHILDREN WITH CEREBRAL PALSY WITH RHIZOTOMY: PATIENT SELECTION, SHORT TERM OUTCOMES AND LONG TERM OUTCOMES.**

*Marcie Ward, MD; Tom Novacheck, MD; Peter Kim, MD, PhD*

To disseminate an evidenced based approach for improving ambulatory function in the pediatric patient with cerebral palsy using a multidisciplinary strategy which explores motion analysis data, safe patient selection for rhizotomy and orthopedic surgery to maximize gait.

This course will cover an evidence based multidisciplinary approach to evaluating the ambulatory patient with cerebral palsy for consideration of selective dorsal rhizotomy using selection criteria predictive of a favorable outcome. The selection criteria will be highlighted and the evaluation process explained. The post-operative rehabilitation of the patient following rhizotomy will be reviewed, as well as, the role of subsequent orthopedic surgical intervention. Finally, the long term outcomes following selective dorsal rhizotomy will be summarized and discussed. Audience response software will be used to collect aggregate participant data for the purpose of adjusting the content to the needs of the audience and to generate collaborative discussion during case presentations.

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## **IC21: LET'S DO A SPINE FUSION! A HANDS-ON LABORATORY INTRODUCTION TO SPINE SURGERY FOR SCOLIOSIS IN CHILDREN WITH CEREBRAL PALSY**

*M. Wade Shrader, MD; Joshua Hyman, MD; Kirk Dabney, M.D.; Mohan Belthur, M.D. FRCSC, FRCS (Tr & Orth)*

This course will present an overview of the technical details involved in a posterior spinal fusion in children with cerebral palsy (CP) and neuromuscular scoliosis. The indications for scoliosis correction in the context of CP will be briefly discussed, as well a review of the outcomes in the literature. The bulk of the course will focus on a hands-on laboratory where participants will be able to place implants (wires, bands, and pedicle screws) in a sawbones model that simulates perform a posterior spinal fusion with modern surgical instrumentations, guided by pediatric orthopedic surgeons.

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## **IC22: BLAZING A TRAIL FOR NEW JOURNEYS THROUGH ADAPTIVE SPORT**

*Gavin Colquitt, EdD; Cynthia Frisina, MA, MBA, CARSS; Jennifer E. Miros, MPT*



Sports can teach sportsmanship, teamwork, social skills, confidence, and risk taking. It is important as medical clinicians to teach/promote adaptive sports skills and physical fitness. All children need to have the chance to learn how to play sports and interact with others. Participation in adaptive sports benefit individuals with CP and other COD by improving their independence through enhanced mental and physical fitness. Also, physical activity in sports can help prevent comorbidities and improve social, psychological, and physical health. Despite the benefits of adaptive sport, many clinics and communities lack the knowledge to create and maintain new programs. We will discuss numerous program formats that we have been piloted and implemented. Various approaches about creating new programs and adaptive sport training with children in all the Gross Motor Function Classification Scale (GMFCS) levels will be discussed and many examples provided. Input will be offered on what has been successful in motivating and enhancing performance among individuals with cerebral palsy and other COD and their families to become energized about being more independent and physically fit through adaptive sports activities.

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## **IC23: DEFINING MALNUTRITION IN CHILDREN WITH CEREBRAL PALSY**

*Richard D. Stevenson, MD; Jodi Wolff, MS, RDN*

The Guidelines for Defining Pediatric Malnutrition, that were endorsed by the American Academy of Pediatrics will be reviewed and used as a framework for the development of a malnutrition definition specific to patients with cerebral palsy. The specific indicators recommended for nutrition assessment in typically developing children will be evaluated for appropriateness of use in children with cerebral palsy, using the literature as a standard. Attendees will participate in case discussions where the current guidelines and the CP specific guidelines will be applied to various clinical scenarios, allowing for application of the proposed CP specific definition.

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## **IC24: Enhancing the Quality of Life for Individuals with Upper Extremity Neuromotor Impairment: An Interdisciplinary Approach**

*Jenny Dorich, B.S., MBA; Jason T. Long, PhD; Kevin Little, MD; Jilda Noel Vargus-Adams, MD, MSc*

This course will present a collaborative approach to evaluating and providing care for children and young adults with upper extremity (UE) neuromotor impairment resulting from cerebral palsy or other etiologies. Our model focuses on a goal of optimizing functional outcomes and quality of life. Case examples will be used to illustrate how our interdisciplinary team utilizes assessments, such as the Canadian Occupational Performance Measure (COPM), to identify family goals and thereafter facilitate a plan of care that employs the expertise of each individual discipline. The roles of the physiatrist, orthopaedic surgeon and occupational therapist within our collaborative framework will be discussed, as well as the supporting role played by the Motion Analysis Lab. The physiatrist will review assessment measures and spasticity interventions. The occupational therapist will discuss applying the COPM to identify family goals and functional assessment of the child performing tasks specific to their goals. The orthopaedic surgeon will highlight the primary surgical options for the upper extremity and how clinical presentation will inform candidacy for surgery. Upper

extremity motion analysis techniques and data will be presented as they relate to surgical planning. Presenters will also discuss team assessment for determining conservative therapeutic interventions and their timing in relation to medical and surgical interventions. Course participants will engage in round table discussions of challenging case scenarios, and will brainstorm ways to integrate a collaborative model in various practice settings.

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## **IC25: Hip health in cerebral palsy: management of hip displacement from surveillance to surgery and beyond**

*Pamela Thomason, B Physio, M Physio; Kate Willoughby, BPhysio, DPhysio; Abhay Khot, FRACS; Kerr Graham, MD, FRCS (Ed), FRACS*

This course will focus on an evidence-informed approach to the management of hip displacement in children and adolescents with CP with the goal of achieving good 'hip health' beyond adolescence and into adulthood for both ambulant and non-ambulant children. It will guide participants in the surveillance continuum from the initiation of a first x-ray and identifying displacement, to monitoring response to intervention and long-term outcomes. The epidemiology of hip displacement will be explored, along with evidence of effectiveness of hip surveillance. Clinical guidelines for hip surveillance will be described including the Australian Hip Surveillance Guidelines for Children with Cerebral Palsy and the newly developed AACPDM Care Pathway. The extended and revised Melbourne Cerebral Palsy Hip Classification System (MCPHCS) will be discussed and evidence of hip outcomes for adolescents and young adults at skeletal maturity will be presented.

An overview of a preventive approach to hip management will be explored through interactive case studies including evidence for non-surgical and surgical approaches. The course will assist participants to maximise multi-disciplinary team planning to prepare the child and family for surgery and to minimize peri-operative risks. The course will assist participants to navigate the challenges of developing and implementing management algorithms while balancing scientific evidence and important child and family factors including management of children for whom the complex nature of their disability extends far beyond the hip.

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## **IC26: Implementing the National Institute of Neurological Disorders and Stroke Common Data Elements Physical Therapy Session Form into the Electronic Record using Improvement Science Methodology**

*Amy F. Bailes, PT, PhD PCS; Mary Anne Lenk, BS*

While cerebral palsy (CP) is the most common diagnosis treated by pediatric physical therapists, little is known about the optimal dose (frequency, intensity, timing, and type) of therapy intervention needed for best outcomes. Determining the optimal dose of physical therapy (PT) for individuals with CP is a national priority given the potential for PT to mitigate health and functional CP-related sequelae. Previous work with the electronic medical record (EMR) and billing code data demonstrates that current documentation



practices are limited and do not include details of intervention that are discrete and discoverable for outcomes research. A recent NIH rehabilitation summit and the American Physical Therapy Association

Academy of Pediatric Physical Therapy have recommended standardizing the way we document dose and the development of a central database for CP. The National Institute of Neurological Disorders and Stroke (NINDS) recently developed CP specific common data elements that are useful to study start up and data sharing. This course will demonstrate how one center incorporated the CP Common Data elements for an individual PT session into their electronic documentation system (EPIC) in order to track service utilization and outcomes.

Standardizing documentation practices can be a daunting task. This course will share quality improvement methods and how they have been utilized to successfully implement the NINDS PT session form into clinical practice within the electronic medical record. The speakers will review quality improvement methods including defining key process measures and drivers, process maps, and failure modes effect analysis.

We will share interventions that were tested using Plan-Do-Study-Act (PDSA) cycles. We will demonstrate how these methods have been integrated into the existing work flow, first with a small sample of clinicians and spread to over 40 physical therapists. Photographs and video cases will be shared to allow audience participation and practice using the electronic record form.

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## **IC27: Navigating the Gray: Clinical Decision-Making with Families and Their Children with Medical Complexity in the Face of Uncertainty**

*Emily J. Goodwin, MD; Kathleen Huth, MD MMSc; Nancy A. Murphy, MD*

To discuss and illustrate approaches to clinical decision-making when evidence is limited. Using an interactive, case-based format, we will review the clinical evidence and shared experience in managing common yet challenging issues in children with disabilities associated with high medical complexity.

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## **IC28: PRACTICAL FOUNDATIONS FOR THE CARE OF A CHILD WITH A TRACHEOSTOMY AND/OR GASTROSTOMY**

*Lisa Letzkus, PhD RN CPNP-AC; James (Jim) Plews-ogan, MD; Susan Almarode, MSN, NNP-BC; Kristen Bray, RRT-NPS,*

Advances in medical care and technology have led to increasing numbers of children with medical complexities living at home. Caring for a child with technology, such as a tracheostomy or a feeding tube can be daunting. Advanced assessment, management strategies and skills are needed to ensure safe care is provided in any clinical setting and at home. This course aims to give participants a hands-on, working knowledge of two technologies common to children with medical complexity.

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## **IC29: SPINAL MUSCULAR ATROPHY: A NEW ERA OF EVALUATION AND TREATMENT**



*Linda P. Lowes, PT, PhD; Lindsay N. Alfano, PT, DPT; Natalie F. Miller, DPT; Megan A. Iammarino, DPT*

Spinal muscular atrophy (SMA) is an autosomal recessive disorder leading to progressive muscle weakness across a spectrum from infantile to adult onset. Historically there has been no treatment to slow or reverse disease progression. In 2016, the first drug, Spinraza (Nusinersen) was approved for the treatment of persons with SMA. Similarly, a promising gene therapy delivering SMN complementary DNA via adeno-associated virus serotype 9 resulted in change to the natural history of SMA type I, with individuals achieving motor milestones outside of historical expectations. We will present the “new natural history” of SMA development seen in treated individuals, highlight the divergence from previous expectations, and identify patient characteristics that are emerging as efficacy modifiers. We will briefly discuss the strengths and weaknesses of current functional outcomes validated in SMA. Patient videos will be used to provide examples of new movement patterns and to illustrate the difficulties with current assessments. Participants will learn to administer a modified assessment that follows the expected development of treated individuals.

Additional videos will be shown to allow the participants to score a “mock assessment” and discuss their selection with the other participants. As a conclusion, we will present considerations for ongoing care and therapeutic interventions.

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### **IC30: SUPPORTING INDIVIDUALS WITH NEURODEVELOPMENTAL DISABILITIES TO BE RESEARCH COLLABORATORS**

*Ariel Schwartz, MSOT; Jessica M. Kramer, PhD*

The disability rights movement and the UN Convention on the Rights of Persons with Disabilities demand that people with disabilities are involved in research concerning them. Participatory action research (PAR) is an approach in which stakeholders are involved in all phases of the research process. PAR is recognized as best practice in the disability community for its potential to provide insights unavailable to non-disabled researchers, increase the accessibility of research processes for other participants with disabilities, and enhance the relevance of research outcomes. Rehabilitation researchers may derive similar benefits from including individuals with neurodevelopmental disabilities (NDD) as co-researchers, yet there is little guidance on how to do so.

We will describe the findings from a literature review on strategies that support PAR for individuals with NDD. We will then discuss how these strategies can facilitate components of PAR essential for a meaningful and successful PAR project; these components include mutual trust, co-researcher ownership of the research process, co-researcher power, and accessibility. Next, we will provide examples of how we used these strategies in our own PAR projects with individuals with NDD and also provide additional examples from the peer-reviewed literature. Attendees will work together to identify how they may use the strategies to implement PAR in a range of rehabilitation research contexts and topics. Next, we will discuss solutions to issues related to feasibility of PAR with individuals with NDD in rehabilitation research, including transportation, funding, IRB approval, scheduling, and determining when and how to involve co-researchers with NDD. At the end of the course, attendees will work in small groups to identify a phase of their research





# Transformative JOURNEYS

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in which they may use the described strategies to increase the involvement of individuals with NDD and discuss feasibility challenges.

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## **IC31: THE CHALLENGE OF COMMUNICATING RESEARCH FINDINGS IN WRITING: CAN A MASTER CLASS EDUCATIONAL APPROACH HELP?**

*Peter L. Rosenbaum, MD; Bernard Dan, MD PhD*

Talking and writing about a topic may seem very similar, but are in fact distinctly different. Because abstracts are often the 'entry point' for having one's work accepted for presentation at conferences, funded by granting agencies, or published in the peer-reviewed literature, the abstract becomes a key element of our representation of our work. The purpose of this course – using a 'master class' teaching approach – is to help people recognize some of the challenges associated with written communication, and identify opportunities to improve that communication.

