IC32: 24 HOUR POSITIONING AND EQUIPMENT MANAGEMENT OF THE COMPLEX NEUROLOGICAL PATIENT ACROSS THE LIFESPAN

Melissa K. Tally, MPT; Elizabeth McCarty, OT

This course will introduce and define the philosophy and goals of 24 hour positioning for individuals with complex neurological presentations. The background of the concepts of 24 hour positioning, as well as references in the literature, will be included. A practical “equipment plan of care” developed at the Perlman Center will be reviewed and suggestions for implementation will be illustrated through use of case studies. The plan of care was designed to be used as a clinical tool to guide equipment considerations throughout the day and across the lifespan. Using such a tool has been helpful for families to understand the broad picture regarding the need for equipment at critical periods in development, as well as a helpful tool for the care team. Positioning for functional participation, including feeding or other daily living tasks, sleep, transportation, and standing, are all part of the 24 hour positioning options. For special circumstances such as when the family and care team are considering surgical intervention a pre-surgical evaluation for seating and positioning will be described Along with examples of successful outcomes and interventions. As patients develop and mature, new challenges arise. Using the concept of 24 hour positioning an equipment plan of care can assist in the decision making and planning for the family and care team.

IC33: AN OVERVIEW AND UPDATE OF EVALUATION AND MANAGEMENT OF PAIN IN PEOPLE WITH CEREBRAL PALSY

Joshua Hyman, MD; Hiroko Matsumoto, MA, PhDc; Heakyung Kim, MD; Daniel Linhares, MD; M. Wade Shrader, MD; David Roye, MD

~20‐60% of people with Cerebral Palsy (CP) have daily pain. Nearly 70% of adults with CP report chronic pain: 33% of these patients are discontent with their pain management. Given its subjective nature, pain evaluation & management is challenging. Many patients with CP have difficulty expressing their pain, adding an extra layer of complexity. As a result, treatment may be inadequate or delayed, leading to an increased burden of care for families, caregivers and the health system. Thus, there is a need for investigation & improvement in the evaluation and treatment of pain in people with CP.

IC34: BOTULINUM TOXIN AND SPASTIC EQUINIS. RE-TREAT OR RETREAT?

Tandy Hastings-Ison, PhD, BAppSci(Physio); Kerr Graham, MD, FRCS (Ed), FRACS; Abhay Khot, FRACS; Barry Rawicki, MB, BS; FAFRM(RACP)
BoNT-A injections have become the standard of care for young children with spastic equinus, despite modest and short-lived effects. There is strong evidence for a decrease in muscle tone but not for objective improvements in gait function, e.g. small improvements in ankle dorsiflexion (foot flat) can be offset by deterioration at the knee especially in children with bilateral involvement. In addition, the only two RCTs investigating injection frequency found no difference in outcomes between injections once per year when compared to 3 times per year. These RCTs align with current animal work, which shows skeletal muscle does not recover from injection by 6 months and that up-regulation of mRNA for inflammation and fibrous tissue repair is evident. A strong argument can be made from clinical and animal studies to inject less frequently, once per annum at most. This workshop will evaluate the evidence, and debate both the merits and shortcomings of BoNT-A protocols for spastic equinus.

IC35: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) EVALUATION AND TREATMENT: AN INTERDISCIPLINARY MODEL

Sherry L. Lanyi, MA; Jessica McCoy, MOT

Completing an AAC evaluation for a patient with motor impairment, such as CP, can be a challenging task that requires the expertise of many people involved in the patient’s care: parent, SLP, OT/PT, and frequently, other specialists or school teams. A one-time clinical AAC evaluation is problematic for those using alternative access because it does not provide enough time to trial different devices and alternative access methods. The model discussed addresses these limitations by using an evaluation series and collaboration with multiple disciplines to allow for effective evaluation of all the patient’s strengths and skills. The patient is seen over 5-6 sequential sessions by both the OT and SLP in co-treat sessions. This interdisciplinary approach allows for enhanced collaboration between therapists, more efficient coordination of resources, and provides the time required to trial alternative access methods, language systems and devices with the patient. Alternative access methods such as switch scanning, head pointing and eye gaze will be discussed. SGD training and implementation post-funding is also approached in an interdisciplinary, multi-session fashion.

The presenters will discuss how the Perlman Center at Cincinnati Children’s Hospital conducts their AAC evaluations and training, including the roles each discipline brings to the evaluation. Case studies will be used to demonstrate the effectiveness of this evaluation process. This course includes resources and hand-outs for considerations for documentation, tips for successful funding, and training on the new SGD (speech generating device) that clinicians will be able to apply to their clinical practice. Presenters will discuss the benefits of this approach as well as some of the challenges faced when using this format.

IC36: CONDUCT MULTI-CENTER CLINICAL RESEARCH WITH THE CEREBRAL PALSY RESEARCH NETWORK

Paul Gross, BA; Jacob Kean, PhD; Michael C. Krue, MD
Attendees will be given an overview of how to work with CPRN to develop, fund and execute a study in conjunction with the sites that are members of CPRN. CPRN supports a variety of study types focused on the diagnosis and treatment of children and adults with CP including multi-center clinical trials, quality improvement, clinical registry analyses and patient-reported outcomes.

Attendees will be led through the process of proposing study concepts to CPRN for approval and development into full applications to funding agencies with CPRN support using exemplars that have recently submitted studies to PCORI and NIH. Researchers will learn what resources are available to strengthen scientific applications including: the development of preliminary data through the CPRN registry; data collection with CPRN and the NINDS CDEs; access to engaged patients and caregivers to participate in study development; the volume of patients accessible through network studies; and CPRN subcommittees and processes to help develop high quality research applications.

IC37: CYCLING FOR PEOPLE WITH CEREBRAL PALSY OR OTHER CHILDHOOD ONSET DISABILITIES

Jennifer E. Miros, MPT; Jennifer Angeli, DPT, PhD

Cycling is an important childhood activity. It is something that is done in neighborhoods and communities throughout the world. Children with cerebral palsy enjoy cycling and this activity can improve their sense of well-being (2). An understanding of the association between mastery of bicycle riding and subsequent health outcomes is beginning to mount. For example, research studies focusing on the use of stationary cycles as an exercise activity for children with CP or other COD have demonstrated gains in function (3, 4). We will summarize the state of evidence on cycling as a therapeutic intervention through literature appraisal and dissemination of associated findings. Principles of non-adapted and adapted cycling, and operational infrastructure for successful bicycling camp endeavors administered in two Midwest academic health centers will be shared. There are many adaptive cycling options if riding a bicycle is not going to be an attainable goal for a person with CP or other COD. All adaptive tricycles are designed so that they do not require significant balance or skilled motor ability on the part of the user. Speakers will also encourage discussion and networking in order to enhance the likelihood that attendees can successfully implement comparable cycling programs in their respective home institutions. This portion of the course will include discussion of funding mechanisms for provision of services and equipment, including charitable appeal and demonstration of medical necessity.

IC38: HYPERTONIA MANAGEMENT IN CEREBRAL PALSY: PAST IDEAS AND LESSONS, CURRENT PRACTICE AND OUTCOMES, FUTURE INNOVATIONS AND POSSIBILITIES

Marcie Ward, MD; Timothy Feyma, MD; Mark Gormley, MD

This course will begin by reflecting on the history of tone management for patients with cerebral palsy and the lessons learned from that practice. Next, the course will summarize current practice trends in tone management including neurosurgical options (rhizotomy and deep brain stimulation) in conjunction with a review of the available evidence evaluating those practices. Finally, the presenters will explore potential
future directions in hypertonia management and consider novel uses for established techniques (such as "palliative rhizotomy"). Focus will be directed at examining the use of neurotoxins and nerve blocks, and neurosurgical interventions including rhizotomy, intrathecal baclofen and deep brain stimulation. Case examples will be presented and audience response software will be used to generate discussion and collaboration.

**IC39: NEW AND EMERGING RESEARCH DIRECTIONS FOR THE MANAGEMENT OF FEEDING AND SWALLOWING DISORDERS IN CP**

*Georgia Malandraki, PhD; Wendelin Burdo-Hartman, MD*

This course will present new and emerging findings on the underlying peripheral and central physiological mechanisms of feeding and swallowing that are implicated in cerebral palsy. Recent evidence, including work the authors are conducting (partially funded by a Pediatric-with-Pete and AACPDM grant), has revealed differentially impaired muscular and neural swallowing activity across CP types and motor involvement levels, providing first insights on adaptive and maladaptive underlying mechanisms for swallowing in CP. These mechanisms can serve as new and more effective evaluation and treatment targets for dysphagia management in CP. The presenters will share these findings and their implications for practice. Then, they will discuss extensively how this new information can be used to shift clinical dysphagia management paradigms from a largely passive compensatory model to a more active skill-based training model focusing on the exact underlying physiological deficits of each child. Case examples from the 2 cerebral palsy clinical research groups the presenters represent will be shared with the audience and the audience will participate in management plan development based on the new knowledge acquired during the course.

**IC40: ON THE JOURNEY TOGETHER TRANSLATING THE GMFCS INTO PRACTICE: CLINICIAN AND CAREGIVER PERSPECTIVES**

*Amy F. Bailes, PT, PhD PCS; Mary E. Gannotti, PT, PhD; Danielle Bellows, PT, MHS, PCS; Michele Shusterman, BA; Jen Lyman, MS*

The Gross Motor Function Classification System (GMFCS) and motor curves can be used to facilitate improved family and caregiver understanding of their child’s current function and prognosis for future motor abilities. However, current evidence suggests that the GMFCS has been used primarily in research with limited use in clinical practice or family centered care. Recent studies report that clinicians most often use the GMFCS as a data point to record in an evaluation rather than as a tool for communicating with families or for clinical decision making. This course will review the literature describing the current use of the GMFCS and available resources for clinicians and families to increase their understanding of gross motor development in CP. We will also share findings from our recent survey of over 300 parents regarding their knowledge and preferences for learning about gross motor information as it relates to their child with CP. Based on our findings from our recent survey, parents on our panel will explore how to deliver realistic and
hopeful information to families regarding their child’s gross motor function classification level using case studies and role playing techniques.

IC41: OPTIMIZING FEEDING AND SWALLOWING IN CHILDREN WITH PHYSICAL AND DEVELOPMENTAL DISABILITIES: A PRACTICAL GUIDE FOR CLINICIANS

Andrea S. Hoffman, MD; Shauna Kingsnorth, PhD; Rebecca Perlin, M.CI.Sc.; Christie Raffaele, B.A.Sc., M.Sc.(OT); Carolyn Li, Bachelor of Science

The workshop will focus on three main areas. The first is to describe the creation of the handbook, highlight the collaborative approach and how expertise was engaged to develop its content and structure. The second is to highlight the Feeding and Swallowing Framework. Thirdly, the presenters will showcase how the handbook can support individual clinicians in taking a multi-disciplinary perspective when approaching feeding and swallowing issues. Presenters will use an interactive, case-based approach to highlight the clinical utility of the handbook, reviewing both evaluation and management.

IC42: ORTHOPAEDIC SURGERY FOR THE SPINE AND LOWER LIMB IN CHILDREN WITH CEREBRAL PALSY

Robert M. Kay, MD; Ken Illingworth, MD

Faculty will discuss state-of-the-art and established evaluation and surgical and non-surgical treatment techniques of spine and lower extremity problems in children with CP. Discussion will focus on common challenges encountered at the spine, hip, knee, long bones, and foot and ankle. Surgical indications and contraindications will be discussed. Emphasis will be placed on common challenges in problem identification and treatment recommendations, and ways to minimize errors and maximize patient outcomes. Content will be based both on the presenters’ clinical expertise and evidence-based review of literature. The presenters will use x-rays, photographs and videos and handouts will be provided. Group discussion of difficult cases and clinical problems will be encouraged.

IC43: PROJECT TEAM: A GROUP INTERVENTION TO TEACH TRANSITION AGE YOUTH WITH DEVELOPMENTAL DISABILITIES TO PROBLEM SOLVE PHYSICAL AND SOCIAL ENVIRONMENTAL BARRIERS TO PARTICIPATION

Jessica M. Kramer, PhD; I-Ting Hwang, MS; Ariel Schwartz, MSOT

A growing body of literature suggests disparities in participation are due to barriers in the physical and social environment. However, existing environment-focused interventions designed to facilitate participation were not explicitly designed for the unique learning and support needs of youth with developmental disabilities (DD) and cognitive impairments.
Project TEAM teaches transition age youth with DDs to identify and resolve physical and social environmental barriers to participation. Project TEAM is a 12-week, theory-driven, multi-component intervention that includes individualized goal-setting, a group curriculum, and peer mentoring. Each intervention component operationalizes theoretical tenets that drive hypothesized changes in youth’s problem-solving skills and participation. Project TEAM incorporates principles of universal design for learning and is accessible to youth with diverse cognitive, sensory, and motor needs.

During this course, attendees will learn about the theories underlying Project TEAM’s design and learn how the intervention manual operationalizes the components that facilitate change. Next, attendees will learn about Project TEAM’s accessible problem solving approach, called the “Game Plan,” and use the Game Plan to complete a case study. Attendees will also review results from a federally funded quasi-experimental study of Project TEAM and discuss strategies for implementing Project TEAM in their practice setting. Attendees will be able to freely access all intervention materials.

**IC44: ROLES OF DISTAL FEMORAL EXTENSION OSTEOTOMY AND PATELLAR TENDON ADVANCEMENT IN THE TREATMENT OF SEVERE PERSISTANT CROUCH GAIT IN ADOLESCENTS AND YOUNG ADULTS WITH CEREBRAL PALSY.**

*Tom Novacheck, MD; Elizabeth R. Boyer, Ph.D.; Jean Stout, PT, MS; Katie Walt, PT, DPT; Libby Weber, MD*

This course will summarize our experience with DFEO+PTA as a treatment for severe crouch gait in individuals with cerebral palsy and will include these topics: 1) a definition and principles of crouch gait, 2) surgical techniques, 3) complications, 4) the role of post-surgical rehabilitation protocols, 5) implications for muscle function and patellar position, and 6) long-term functional and x-ray outcomes. Based on an understanding of the principles, pathology and the nature of the surgeries and rehabilitation, appropriate case examples will illustrate and emphasize treatment.

**IC45: THE YEAR’S TOP 10 ARTICLES ON DEVELOPMENTAL DISABILITIES**

*Nancy A. Murphy, MD; Richard C. Adams, MD*

The top ten clinically relevant articles published in English between Fall 2017 and Summer 2018 will be presented to the audience. Articles will be chosen from the presenters’ personal experiences as well as from searches in Medicine and CINAHL (Current Information in Nursing and Allied Health Literature). Categories from which the articles are typically chosen include the following: attention deficit hyperactivity disorder, autism spectrum disorders, cerebral palsy, congenital syndromes and genetic conditions, intellectual disabilities, spina bifida, and spinal cord and acquired brain injuries. They will be selected using the following criteria: (1) impact on clinical care, (2) scientific merit of the study [strength / validity], and (3) translation to clinical practice. The presenters will summarize the ten articles in reverse order (saving number one for last). Their impact on clinical practice, place in the context of current care, and their implications for future research will be discussed. The audience is encouraged to respond to each article as it is presented. A copy of the references and abstracts will be provided to the attendees.
IC46: PUTTING KNOWLEDGE INTO ACTION: PATHWAYS FOR MAKING CHANGE AND IMPACT

Kelly J Mrklas, MSc, PhD Candidate

Research tells us that “knowing is not enough” when we want to create impact by improving health outcomes, health services and products, and strengthening the health care system.

So how do we get from knowing to doing?

This workshop will provide participants with the basics to develop an implementation strategy for their practice setting. Participants will learn about a practical, systematic, and well-validated approach for moving high quality evidence (e.g., clinical practice guidelines) into action.

The workshop will start with a short background about different types of implementation approaches. Participants will learn about the core components of well-built implementation strategies. Hands-on practice with a well-validated framework will help participants gain experience with strategy development. The workshop will conclude with a tour of high quality resources for developing, executing and evaluating implementation strategies.