BRK 1: CHILDREN WITH MEDICAL COMPLEXITY: A UNIQUE POPULATION WITH UNIQUE NEEDS
Nancy Murphy, MD; Rishi Agrawal, MD, MPH; Laurie Glader, MD; Eric Levey, MD

Purpose: Children with medical complexity (CMC) have conditions associated with chronic, complex medical and functional impairments. They experience co-occurring conditions which require management by multiple medical, rehabilitative and educational specialists, and they demonstrate the highest needs for coordinated and goal-directed care based on partnerships between parents and providers. Participants in this interactive session will gain insights into the identification of CMC and an understanding of approaches to their care that support the highest value of healthcare delivery for these children and their families.

Target Audience: All healthcare providers concerned with the care of children with complex chronic conditions, including physicians, therapists, nurses, administrators, educators and researchers, are encouraged to participate. All skill levels will be addressed.

Course Summary: Children with medical complexity are characterized by high medical fragility and complexity, with multi-organ system involvement, technology-dependencies, functional impairments and high psychosocial complexity. It is estimated that they compromise 1% of the total pediatric population, yet account for 30% of pediatric healthcare utilization. We will define CMC, identify their unique needs for coordinated and goal-directed care, provide a conceptual approach to care planning and illustrate value-based approaches to their care.

Learning Objective 1: Define children with medical complexity (CMC)
Learning Objective 2: Discuss the unique needs of CMC and their families
Learning Objective 3: Illustrate the use of goal-directed care in guiding shared-decision making and care planning for CMC
Learning Objective 4: Understand value-based care and how to maximize value for this unique population of children
BRK 2: CUTTING EDGE MANAGEMENT OF CHILDREN WITH EPILEPSY
Dave Clarke, MBBS; Mark Lee, MD, PhD; Maureen Nelson, MD; Jeffrey Titus, PhD

Purpose: The purpose of this course is to highlight the common presence of an epilepsy diagnosis in children with other types of disabilities, and to address the proper evaluation and management of epilepsy. The most current approach to evaluation and diagnosis will be presented, as well as the logical steps in treatment. This will include classic and nontraditional treatments, such as medications, vagus nerve stimulator, dietary options, and medical marijuana. The newest surgical options will be shown, including laser ablation. Rehabilitation interventions at all steps of involvement will be reviewed.

Target Audience: Pediatricians and pediatric subspecialists, psychologists, nurses, therapists, educators

Course Summary: This course will highlight the frequent concomitant presence of epilepsy with other pediatric disabilities. Evaluation of type of epilepsy will be presented, which will lead to discussion of optimal therapeutic approaches. These will include diet, medications, vagus nerve stimulator, medical marijuana and other non-traditional substances, and neurosurgery, both open brain and laser ablation. Neuropsychological evaluation and advanced imaging techniques including magnetoencephalogram (MEG) will be presented, and their role in treatment decision-making will be discussed. Rehabilitation interventions throughout the course of care will be reviewed.

Learning Objective 1: Describe the through and orderly evaluation of seizures in a child
Learning Objective 2: Refine the medical management of seizures in a child, including those with multiple diagnoses
Learning Objective 3: Describe the usefulness of imaging and neuropsychological testing in a child with special needs and seizures
Learning Objective 4: Determine which children are appropriate for nontraditional treatment approaches
Purpose: Elucidate the process of defining key ingredient of an intervention focusing on cognitive change co-emerging with motor problem-solving. Describe the process for quantifying how interventions differ and demonstrate the use of a tool designed to establish the fidelity of the specific intervention for motor-based problem-solving.

Target Audience: Researcher and therapist interested in discussing methods for describing an intervention and quantifying the use of an intervention in research and practice.

Course Summary: Families, therapists, and researchers want the ability to compare intervention protocols to determine the best approach for a specific child’s needs. However, our ability to compare interventions and determine efficacy requires documentation of the intervention with a clear description of strategies, components, or principles. Although recent evidence clearly links motor skill development with cognitive change, few motor interventions explicitly translate this linkage. A new clinical trial (START-Play) is underway to explore the effects of motor based problem solving on developing cognitive skill in infants with neuromotor disorders. The process of identifying the key ingredients of our targeted intervention which differentiate it from other interventions will be described in this presentation. These “key ingredients” serve to pinpoint critical factors of our specific intervention that may directly affect outcomes.

In this breakfast seminar the presenters will discuss ways to identify the key ingredients of your intervention and how documenting the key ingredients can improve your ability to describe and compare your intervention, measure dose, fidelity, and engagement. Specific dimensions of fidelity in the START-Play clinical trial that will be discussed include adherence, dosage, quality of intervention delivery, and therapist, parent, and child engagement. Examples of the use of these factors to document successful intervention training prior to initiating a protocol, and maintenance of fidelity components during an intervention or clinical trial will be provided. Attendees will be asked to share their experiences with measuring fidelity of an intervention, and discuss strategies for documenting fidelity, the cost/benefit of measuring fidelity in clinical trials, comparative effectiveness research, and within clinical practice.

Learning Objective 1: Create examples of definitions for key ingredients of a specific intervention that distinguishes the intervention from "usual care" or a previous approach

Learning Objective 2: Understand the cognitive and motor components and fidelity measures of the START-Play intervention, different approaches to achieving fidelity, and discuss the pro and cons of utilizing each of these approaches

Learning Objective 3: Discuss methods for achieving fidelity and maintaining a given level of fidelity of an intervention over time

Learning Objective 4: Examine and evaluate examples of fidelity to critique for use in a given intervention
BRK 4: ENHANCING FUNCTIONAL PERFORMANCE IN CHILDREN WITH CORTICAL VISUAL IMPAIRMENT
Karen Harpster, PhD, OTR/L; Patricia Gribben, OTR/L

Purpose: Cortical visual impairment (CVI) impacts every aspect of a child’s life. Children with CVI are not visually curious and have difficulty processing the world around them. Without intervention, children with CVI avoid using their vision which negatively impacts their functional performance. A recent study showed that 95% of the children who received intervention exhibited clinically significant changes in their visual abilities following treatment (1). This seminar will describe interventions that can be implemented in order to enhance visual attention and accordingly, improve functional performance in individuals with CVI.

Target Audience: Physicians, Therapists, Nurses, Caregivers

Course Summary: Cortical visual impairment (CVI) is the leading cause of bilateral visual impairment in children in developed countries (2-3) and in children under the age of five years (4). This presentation will provide an overview of the current evidence supporting pediatric CVI intervention and assessment. The presenters will briefly introduce the CVI Range, an assessment utilized for children with CVI and the 3 severity levels associated with the CVI Range (5).

Key environmental and task adaptations, including effective toy selection will be shared through picture and video-based examples. Caregiver involvement is essential in order to implement a successful treatment plan for children with CVI. Strategies that assure active participation of a care provider will be discussed. Approaches to treatment will be illustrated through case studies. Participants will leave this session empowered with practical and generalizable information that will ensure an empirical and experientially-validated plan of care for children with CVI. The session will conclude with the development of a CVI therapy network, in order to enhance the practice of therapists and researchers who seek to collaborate and learn from one another.

Learning Objective 1: Describe the current body of evidence for therapeutic interventions for individuals with CVI
Learning Objective 2: Explain environmental and task adaptations that should be implemented for children with CVI to improve functional performance
Learning Objective 3: Develop a treatment plan for individuals with CVI that promotes occupation-based functional skills
Learning Objective 4: Describe how to actively involve the caregiver into the treatment sessions
Purpose: To share with attendees the impetus for intervention approaches that enhance physical activity, the evidence supporting running for children with physical disability, the operational realization of the BeWell Running Program, and the early results of these efforts.

Target Audience: physical therapists, occupational therapists, physiatrists, orthopaedic surgeons, athletic trainers, clinic administrators

Course Summary: This course will present current evidence behind exercise and participation in leisure activities for children with physical disabilities with particular attention to cerebral palsy. Specific discussion will focus on running as a therapeutic endeavor as well as a contributor to improved quality of life. Running has been associated with improved physiological function in children with disability (2-7). Children participating in running programs have reported lower levels of pain, fatigue, and deconditioning (2, 5, 7). Moreover, running has also been associated with improved emotional well-being (2, 5), higher self-esteem (3, 6), and improvements in classroom behaviors (3). Running is safe and convenient (2), and can contribute to long-term health (1, 3, 6). In this course, we will discuss the development of BeWell Running, a 5K training program offered through collaboration between a tertiary care hospital’s Physical Therapy Department and Cerebral Palsy Clinic.

Key drivers for the program’s operational success will be reviewed, including discussion of community collaboration and institutional support. Program outcomes including participant changes in exercise tolerance and physical activity will be shared. The course will emphasize learnings and insights for others considering pilot wellness efforts and will include our strategies for program growth.

Learning Objective 1: Acknowledge the importance of physical activity for children with physical disability.

Learning Objective 2: Summarize the evidence in support of running programs for children with physical disability

Learning Objective 3: Identify operational processes associated with preliminary program successes

Learning Objective 4: Develop a plan for the implementation of targeted physical activity program in local, clinical practice
BRK 6: HYPOTONIA: WHAT IS IT AND WHAT CAN WE DO ABOUT IT?
Ginny Paleg, BS, MPT, PT, DScPT; Mark Romness, MD

**Purpose:** Clinicians evaluate and treat children with hypotonia and yet there exists no valid definition, reliable measurement tool or universal agreement on where hypertonia fits within the cerebral palsy spectrum.

**Target Audience:** Therapists, Physicians, nurses, teachers and caregivers of children with hypotonia

**Course Summary:** This session will begin with what has been suggested as definitions and etiology of hypotonia in the infant, toddler and school aged child. Dr. Romness will review medical issues, diagnosis and prognosis. Dr Paleg will present a review of evidence informed PT and OT interventions as well as a novel outcome measure. She will explore the use of the GMFM and MACS for children with hypotonia.

**Learning Objective 1:** Explain why the current definition of hypotonia is inadequate

**Learning Objective 2:** List three tests which should be considered when a physical evaluates a child with hypotonia of unknown etiology

**Learning Objective 3:** List four common clinical findings in hypotonia

**Learning Objective 4:** Discuss three evidence based interventions which should be considered by OPTs and OTs for children with hypotonia
BRK 7: MOVING FROM HEURISTIC TO PRECISION APPROACHES TO TREAT AND PREVENT CHRONIC DISEASES IN ADULTS WITH CEREBRAL PALSY
Mark Peterson, PhD; Edward Hurvitz, MD

**Purpose:** Prevalence of lifestyle-related chronic conditions is significantly increased in adults with cerebral palsy (CP). This session will cover the fundamental differences between classic heuristic approaches to handle symptom management among children, adolescents, and young adults with CP, versus 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 this population.

**Target Audience:** Physicians; Medical Students; Physical and Occupational Therapists; Researchers; Parents

**Course Summary:** While the incidence of CP has remained stable in recent years, the mortality rate of children with CP has declined, suggesting that adults with CP represent a growing population whose health status and healthcare needs are poorly understood. Premature declines in function among adults with CP may occur as a result of early and accelerated muscle atrophy and weakness, beyond that which is expected for typically-developed adults. Evidence confirms that children and adults with CP have less lean body mass, greater relative adiposity, and lower fitness and physical activity participation. Although decrements in muscle mass and strength are typically considered the primary contributing factors of gross motor decline in this population, it is conceivable 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 a study which represents a substantial addition to the current body of literature pertaining to characterizing the link between risk factors and prevalence of chronic diseases among a large, clinic-based sample of individuals with CP.

**Learning Objective 1:** Describe the risk of chronic diseases in adults with cerebral palsy compared to the general population

**Learning Objective 2:** Develop an approach to clinical care of the adult with cerebral palsy that includes greater attention to chronic disease risk, sedentary behavior and physical activity

**Learning Objective 3:** Discuss the need for population surveillance of chronic health risks in individuals with cerebral palsy

**Learning Objective 4:** Identify and discuss relevant risk factors for chronic conditions in CP, and offer guidance for lifestyle interventions to prevent losses of function and disease, and to improve quality of life.
BRK 8: NEUROORTHOPEDIC MANAGEMENT OF RETT SYNDROME
M. Wade Shrader, MD; Mohan Belthur, MD, FRCSC, FRCS (Tr & Orth); Michael Kruer, MD, PhD

Purpose: This course will present an overview of the management of patients with Rett Syndrome. The speakers will discuss the genetics, pathophysiology, and diagnosis of Rett syndrome. The initial treatment strategies, surgical indications, and the orthopedic surgical treatment of patients with Rett Syndrome will also be presented.

Target Audience: Physicians, Occupational and Physical Therapists, Nurses

Course Summary: This course will provide an introductory level discussion of orthopedic impairments of children with Rett Syndrome, and the typical orthopedic surgical procedures that may be required in the care of those children. The impact of these deformities and surgeries on the patient and their family will be discussed within the context of the International Classification of Functioning, Disability and Health (ICF). A review of the genetics, pathophysiology, diagnosis, and prognosis of Rett Syndrome will be discussed. Surgical indications will be presented for the typical orthopedic deformities in patients with Rett Syndrome. Surgical management will be discussed thoroughly, including postoperative management.

Learning Objective 1: Discuss the pathophysiology and diagnosis of Rett Syndrome
Learning Objective 2: Understand the orthopedic impairments of Rett Syndrome and the principles of non-operative management
Learning Objective 3: Understand the typical orthopedic surgical procedures that children with Rett Syndrome undergo, including spine fusion and the typical outcomes that can be expected
Learning Objective 4: Gain understanding of the impact of Rett syndrome on the patients and their families
BRK 9: PATIENT AND FAMILY PERSPECTIVES ON COMMON CP THERAPIES AND INTERVENTIONS
Michele Shusterman, BA; Paul Gross, BA

**Purpose:** To share survey data (N=1132) collected on patient and family perspectives related to common therapies/interventions for CP with a focus on decision making. This data was gathered to inform the scope of a planned large scale observational trial to aid families in surgical decision making that was submitted to the Patient Centered Outcomes Research Institute. We will review the demographics of the population surveyed and further characterize them by type of CP, GMFCS level, co-morbidities and the intervention choices they considered and made. We will share both quantitative and qualitative information about their intervention decisions, experience and outcomes assessment.

**Target Audience:** Clinicians both surgical and medical, therapists, educators, researchers.

**Course Summary:** In this course we will review and analyze data collected from a Spring 2015 community survey collected via Survey Monkey that was distributed via social media outlets that support the CP Community. There were 1132 respondents who answered questions about common therapies and interventions, their experience with them, how well prepared families felt making these decisions and their satisfaction with the outcomes. We will also review patient and family perspectives on the timing of the surgery, along with the options that were presented alongside the treatment/intervention they ultimately pursued.

**Learning Objective 1:** Learn the decision-making of respondents regarding common treatments used to treat various conditions seen in the CP population

**Learning Objective 2:** List the most difficult treatment/intervention decisions facing individuals with CP and/or their families

**Learning Objective 3:** Understand what made treatment/intervention decisions difficult for the population surveyed

**Learning Objective 4:** Understand the interventions and therapies that the patient families feel have the best outcomes in their minds including alternative interventions and therapies
BRK 10: PATIENT-SPECIFIC MODELLING: INCORPORATING ADVANCES IN MEDICAL IMAGING TO BETTER INFORM MUSCULOSKELETAL MODELS
Lee Barber, PhD; Chris Carty, PhD; Morgan Sangeux, PhD

**Purpose:** The main learning objectives of this workshop are to communicate to the broader clinical community the latest advances in musculoskeletal modelling for children with movement disorders and to discuss the clinical utility of musculoskeletal modelling.

**Target Audience:** Clinicians, researchers and allied health professionals with an interest in clinical motion analysis.

**Course Summary:** The workshop will be divided into three sections, each followed by an opportunity for questions and discussion.

Section 1: EOS is a new medical imaging modality based on ultra-low-dose bi-plane x-rays. It is designed to estimate deformities of the spine and lower-limbs in three-dimensions. EOS is one of the few medical imaging modalities to provide the accurate positions of the markers used in gait analysis with respect to the skeleton in standing. It is now used at The Royal Children’s Hospital, Melbourne, together with gait analysis to derive patient-specific musculoskeletal models and to inform surgical planning for children with lower-limbs torsional deformities.

Section 2: MRI can be used to image bone and soft tissues (muscle, ligament, cartilage) and using specific software routines we can merge information from MRI with 3D motion capture allowing patient specific representation of bone deformities and muscle pathways. The immediate advantage is insight into muscle-tendon lengths, the velocity dependency of muscle-tendon lengthening and the impact of bony deformity during walking.

Section 3: Freehand 3D ultrasound can localize specific muscles, tendons and joints and enable 3D structural rendering and measurement of position, volume and length. Recent advances in ultrasound image integration and processing techniques now allows to better quantify how muscle and tendon design might be coupled to function in vivo. Morphology of the muscle and tendon can be visualized with real-time ultrasound making it possible to measure how muscles work during controlled movements and functional tasks such as walking.

**Learning Objective 1:** Recognize current innovative technologies that enhance patient-specific musculoskeletal model
**Learning Objective 2:** Understand the advantages and limitations of patient-specific musculoskeletal model
**Learning Objective 3:** Communicate to the broader clinical community the latest advances in musculoskeletal modelling for children with movement disorders
**Learning Objective 4:** Discuss the clinical utility of musculoskeletal modelling