IC 14: BACKGROUND, CLINICAL PRESENTATION AND MANAGEMENT OF DYSKINETIC CEREBRAL PALSY: WHERE ARE WE NOW?
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Purpose: This instructional course overviews the clinical presentation and the management of dyskinetic CP based on a systematic review of the literature. Attendees will leave the session with an up-to-date clinical picture of dyskinetic CP and a framework how to manage dystonia and choreoathetosis. The instructional course is built up as a practical and interactive session based on the current scientific findings and illustrated with clinical cases.

Target Audience: most paediatric health care professionals: medical doctors, therapists, kinesiologists, orthotists

Course Summary: Dyskinetic Cerebral Palsy (CP) is the second largest group of children with CP. In dyskinetic CP, dystonia and choreoathetosis are dominantly present and are commonly known as complex and difficult to evaluate. This makes the management of dyskinetic CP challenging. In depth evaluation and understanding of dystonia and choreoathetosis are vital for targeted medical interventions and rehabilitation in order to improve in daily life activities and quality of life. In a first part, participants will be introduced in dyskinetic CP. Definitions and classification of dystonia and choreoathetosis will be overviewed as well as background, neuroimaging insights and functional profile in motor function with special attention for the discrimination between dystonia, chorea and athetosis. In a second part, evaluation measures and new insights on the function, activity and participation ICF levels will be overviewed. In a third part, medical and non-medical management of dystonia and choreoathetosis and effects on daily life activities will be discussed in an interactive way by using several case studies.

Learning Objective 1: Understand the background, neuroimaging, functional profile of dyskinetic CP
Learning Objective 2: Describe definitions and classification of dystonia, choreoathetosis and dyskinetic CP
Learning Objective 3: Recognize clinical patterns of secondary dystonia and choreoathetosis in dyskinetic CP
Learning Objective 4: Implement a framework of medical and non-medical management of dystonia and choreoathetosis in dyskinetic CP
IC 15: CLINICAL TOOLS FOR ASSESSMENT OF SELECTIVE VOLUNTARY MOTOR CONTROL IN PATIENTS WITH SPASTIC CEREBRAL PALSY: SELECTIVE CONTROL ASSESSMENT OF THE LOWER EXTREMITY (SCALE) AND TEST OF ARM SELECTIVE CONTROL (TASC)

Marcia Greenberg, MS, PT; Kristin Krosschell, MA, DPT, PT, PCS; Loretta Staudt, MS, PT; Theresa Moulton, PhD, DPT

**Purpose:** To instruct experienced clinicians in the use and administration of two standardized clinical tools for assessment of selective voluntary motor control (SVMC) in patients with spastic cerebral palsy: SCALE (Selective Control Assessment of the Lower Extremity) and TASC (Test of Arm Selective Control). The reliability and validity of SCALE and TASC have been established (Fowler et al. Dev Med Child Neurol, 2009; Krosschell et al, Conference proceedings, AACPDM, 2015). The tools and their clinical and research applications will be presented.

**Target Audience:** This course is designed for clinicians evaluating patients with cerebral palsy in their practice and individuals conducting research on the clinical or functional characteristics of children and adults with cerebral palsy.

**Course Summary:** The role of SVMC assessment in clinical practice and research will be discussed. The relationship of SVMC to other impairments such as strength and spasticity will be explored. The SCALE and TASC tools will be presented for each joint and the patient positioning, examiner instructions and score sheets will be explained. The criteria for each SVMC grade will be described, providing participants with the knowledge and skill to independently assess SVMC of the upper and lower extremity. Participants will have an opportunity to use the tools to assess joints on a variety of videotaped patient examples exhibiting a range of SVMC. Discussion and feedback on the participants’ skills will be provided. The use of SCALE and TASC scores in research and clinical decision making will be discussed.

**Learning Objective 1:** Become familiar with the purpose, content and administration of SCALE and TASC clinical tools for evaluation of selective voluntary motor control (SVMC)

**Learning Objective 2:** Develop skill in scoring of SCALE and TASC

**Learning Objective 3:** Increase knowledge of the literature, clinical relevance and research regarding SVMC

**Learning Objective 4:** Understand the role of SVMC assessment in clinical decision-making, research and evidence-based practice
Purpose: To review the evidence around prevention, surveillance and treatment of osteoporosis and fragility fractures in children with mobility restrictions while providing practical strategies to translate knowledge into practice.

Target Audience: Physicians, Nurses, Physical therapists, Dietitians, Parents

Course Summary: Children with physical disabilities and mobility restrictions are at increased risk for developing osteoporosis. Approximately 20% of children and young adults with cerebral palsy who cannot walk independently develop fragility fractures. Fractures can cause significant pain and impairment, and impact family functioning. It is important for caregivers and care providers to know how to identify those at risk, and how to improve bone density and possibly prevent fragility fractures in these children. We will review the evidence around prevention, surveillance and treatment of osteoporosis and fragility fractures in children with mobility restrictions. Emphasis will be paid to the evaluation of bone density and treatment options. A clinical practice guideline and tools to facilitate translation of this knowledge into practice will be provided. The presenters will prompt participants to engage in discussion about challenges in their own clinical practice, specifically around monitoring vitamin D levels, use of DXA scans, and decision making around the use of bisphosphonates. We will also discuss the evidence regarding use of vibration to improve bone density. Attendees are encouraged to bring cases that they have encountered for group discussion. This workshop will help attendees understand who is at risk, how to evaluate and how to treat low bone mineral density in children with physical disabilities.

Learning Objective 1: Identify key components of the prevention and evaluation of low bone mineral density in children with physical disabilities

Learning Objective 2: Develop skill in implementing nutrition based interventions for preventing and treating low bone mineral density in children with disabilities

Learning Objective 3: Understand how bone density is measured in patients with disabilities and what the measurements mean

Learning Objective 4: Understand the evidence for treatment with bisphosphonates and practical issues around their use
IC 17: HOW DO WE KNOW IF WE ARE MAKING A DIFFERENCE? DEVELOPING EVALUATIONS FOR ONGOING QUALITY IMPROVEMENT IN SERVICES FOR CHILDREN WITH DISABILITIES
Lesley Wiart, PhD; Virginia Wright, PhD, MSc, PT

**Purpose:** This course will lead the audience through the process of developing systematic outcome and process evaluations for improving child and family care.

**Target Audience:** Physicians, Occupational and Physiotherapists, Speech and Language Therapists, Nurses

**Course Summary:** This course will lead participants through an overview of developing process and outcome evaluations for quality improvement. Specifically we will address how quality frameworks and program models can guide evaluation development, the engagement of families in evaluations, and how to identify meaningful outcomes and measurement tools. Participants will discuss their own program processes and outcomes to facilitate learning. We will also discuss the pros and cons of various methods of data collection (i.e., surveys, focus groups, individual interviews and standardized outcome measures) including how these methods can be used in pragmatic ways within health care organizations. Finally, we will share reporting strategies to increase staff engagement and support change for improvement.

**Learning Objective 1:** Understand a systematic process for developing evaluation plans

**Learning Objective 2:** Appreciate how to collect and use quantitative and qualitative data in a pragmatic way for quality improvement

**Learning Objective 3:** Understand criteria for selecting outcome and process measures to be used in program evaluations

**Learning Objective 4:** Appreciate how evaluation data can be used for continuous quality improvement
IC 18: LET’S DO A HIP OSTEOTOMY! A HANDS-ON LABORATORY INTRODUCTION TO THE SURGICAL SKILLS OF A VARUS DEROTATIONAL OSTEOTOMY

M. Wade Shrader, MD; Benjamin Shore, MD, MPH, FRCSC; David Scher, MD; Walter Truong, MD; Jennifer Laine, M.D.

Purpose: This course will present an overview of the technical details involved in a varus derotational osteotomy (VDRO) in children with cerebral palsy (CP) and neuromuscular hip dysplasia. The indications for hip reconstruction in the context of CP will be briefly discussed, as will 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 perform a VDRO on a saw-bones model with modern surgical instrumentations, guided by pediatric orthopedic surgeons.

Target Audience: Physicians, Occupational and Physical Therapists, Nurses

Course Summary: This course will provide an introductory level discussion of hip osteotomies for children and adolescents with cerebral palsy (CP) and neuromuscular hip dysplasia. The pathophysiology, prevalence, treatment indications, and outcomes of hip surgery for dysplasia in CP will be briefly presented. The step-by-step surgical details of a varus derotational osteotomy (VDRO) will be presented didactically with photographic and videographic details of actual surgical procedures. The laboratory portion of the course will allow participants to perform a VDRO on a sawbones model, including femoral osteotomy and hardware implantation, utilizing the cannulated blade-plate (saw bones and hardware donated by Orthopediatrics). Pediatric orthopedic surgeons will be on hand to assist and take participants through the hands-on surgical procedure.

Learning Objective 1: Discuss the prevalence of neuromuscular hip dysplasia in patients with CP
Learning Objective 2: Understand the surgical indications for hip reconstruction in the context of neuromuscular hip dysplasia in patients with CP
Learning Objective 3: List the technical steps involved in the surgical technique of a VDRO
Learning Objective 4: Perform a simplified VDRO surgical procedure on a saw-bones simulation model
IC 19: PHYSICAL THERAPY FOR ADULTS WITH CEREBRAL PALSY: IS IT WORTH IT TO STAND?
Britta Schwartzhoff, DPT; Natalie Goodrich, DPT, PCS

**Purpose:** To promote evidence based physical therapy treatment planning for adults with cerebral palsy. This course will present research and clinical applications of static and dynamic weight bearing activities for therapeutic exercise and health promotion.

**Target Audience:** This presentation is to assist clinicians, patients and their families.

**Course Summary:** Research continues to reveal the harmful effects of a sedentary lifestyle on the general population. Individuals with cerebral palsy are already at high risk for accelerated aging and functional mobility declines are also subject to these effects. This course will focus on the role of physical therapy for adults of all ages, with emphasis on cerebral palsy. Emphasis will be on current research regarding the benefits of weight bearing activities throughout the lifespan with and without a disability. Attendees will be introduced to decision making and interventions used at Gillette Lifetime Specialty Healthcare, including static and dynamic forms for use in adulthood, as well as adaptive equipment to support these activities.

**Learning Objective 1:** Identify patient characteristics that indicate lower extremity weight bearing as a therapeutic intervention

**Learning Objective 2:** Describe key benefits and applications of static lower extremity weight bearing

**Learning Objective 3:** Describe key benefits and applications of dynamic lower extremity weight bearing

**Learning Objective 4:** Identify funding opportunities and barriers to achieve weight bearing activities throughout the lifespan.
IC 20: PROVIDING HOLISTIC CARE FOR PATIENTS WITH NEUROMUSCULAR DISORDERS
Garey Noritz, MD; Linda Lowes, PhD

Purpose: This course will review specific considerations for practitioners who care for patients with neuromuscular diseases, particularly Duchenne muscular dystrophy (DMD) and Spinal Muscular Atrophy (SMA). While many of the challenges faced by these patients are similar to those with other childhood disabilities, there are specifics of care for DMD and SMA with which the practitioner must be familiar.

Target Audience: Physicians and therapists who care for patients with DMD or SMA

Course Summary: This course will review the genetics and pathophysiology of DMD and SMA, and then turn to specific scenarios and recommendations for clinical care. Chief among these are cardiopulmonary care and support; other topics that will be covered include management of corticosteroid complications, nutrition and bowel issues; bone health; and prevention and treatment of nephrolithiasis. We will discuss orthopedic and rehabilitative aspects of care, as well as issues of transition to adult providers. We will close with an overview of current trials to treat DMD and SMA.

Learning Objective 1: Understand the genetics and pathophysiology of DMD and SMA
Learning Objective 2: Develop expertise in the holistic medical care of children and adults with these disorders
Learning Objective 3: Develop expertise in the habilitative and rehabilitative care of children and adults with these disorders
Learning Objective 4: Understand ongoing trials of therapies for DMD and SMA.
IC 21: ROLES OF DISTAL FEMORAL EXTENSION OSTEOTOMY AND PATELLAR TENDON ADVANCEMENT IN THE TREATMENT OF SEVERE PERSISTENT CROUCH GAIT IN ADOLESCENTS AND YOUNG ADULTS WITH CEREBRAL PALSY

Jean Stout, PT, MS; Michael Schwartz, Ph.D.; Katie Walt, DPT; Libby Weber, MD; Tom Novacheck, MD

**Purpose:** This course will discuss the principles, biomechanics, and treatment of crouch gait using distal femoral extension osteotomy and patellar tendon advancement (DFEO+PTA) in individuals with cerebral palsy. Post-operative rehabilitation protocols and long-term outcomes of treatment will also be addressed.

**Target Audience:** Pediatric orthopaedists, physiatrists, physical therapists, and biomechanists who encounter children with cerebral palsy and crouch gait in their clinical practice.

**Course Summary:** 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) biomechanical modeling of the procedures, 3) surgical techniques, 4) complications, 5) Long-term functional and x-ray outcomes, 6) the role of post-surgical rehabilitation protocols. Based on an understanding of the principles, pathology and the nature of the surgeries and rehabilitation, appropriate case examples will illustrate and emphasize treatment.

**Learning Objective 1:** Discuss the etiologic factors of severe crouch gait in adolescents & young adults with cerebral palsy

**Learning Objective 2:** Describe the current biomechanical models of the DFEO+PTA surgeries and their contribution to the understanding of surgical indications

**Learning Objective 3:** Identify one or more operative- or post-operative care insights and the common pitfalls they are designed to avoid

**Learning Objective 4:** Compare long-term case vs. control functional outcomes of DFEO+PTA surgery across the entire spectrum of the ICF domains
IC 22: TEAM MANAGEMENT IN SPINAL FUSION FOR CHILDREN WITH CEREBRAL PALSY, GMFCS 4/5 'EVIDENCE INFORMED CLINICAL PRACTICE GUIDELINES'
Irene Dietz, MD; Mohan Belthur, MD, FRCSC, FRCS (Tr & Orth); Ranjit Varghese, MBBS, MS, MHScE; Gina Rempel, MD; Lisa Cantore Letzkus, RN, MSN, CPNP-AC, CCRN; Holly Roach, OTR, ATP

Purpose: This course will present “Evidence-informed Clinical Practice Guidelines” for team-based pre-operative evaluation, perioperative support and post-surgical care for children GMFCS level 4/5 undergoing spinal fusion for scoliosis. Integrating family goals as well as the medical team care elements improves pre-op monitoring and decision-making for timing of surgical intervention in this complex group of children.

Target Audience: Physicians, Nurses, Occupational and Physical Therapists, Respiratory Therapists, Dieticians, Families

Course Summary: Spine deformity is common in children with neurodevelopmental disabilities especially cerebral palsy. Surgical intervention presents management challenges to their families and care teams because of the complex interplay of co-occurring conditions. Decreased pulmonary function, inadequate nutrition, seizures, infection and immunodeficiency, coagulopathies, decreased mobility, communication and cognitive difficulties may all be present. Protocol-based care has been shown to successfully decrease the number of days on mechanical ventilation, improve mortality from sepsis, reduce costs of hospitalization, and reduce the incidence of drug-resistant bacterial infections. A high-risk spine protocol helps patients by having dedicated professionals in multiple specialties focusing on all aspects of a patients care in the pre, intra and postoperative phases. This course will present the current knowledge informing providers for children with NM disorders in this process.

Learning Objective 1: Identify modifiable risk factors and co-occurring conditions including airway, pulmonary, cardiac, nutritional, musculoskeletal, and psychosocial issues should be evaluated and treated before undergoing high-risk spine surgery

Learning Objective 2: Understand how dedicated multidisciplinary team involved throughout the pre-, intra-, and postoperative periods improves patient outcome

Learning Objective 3: Integrate how protocol-based care in spine surgery may lead to reduced complications and better outcomes with reduced length of stay and overall improved patient outcomes

Learning Objective 4: Discuss how shared decision-making and adequate preparation of the family before surgery improves outcomes
IC 23: THE IMPLICATIONS OF CORTICAL VISUAL IMPAIRMENT ON SOCIAL INCLUSION
Christine Roman, PhD; Alisha Waugh, BS, PT

Purpose: The purpose of this instructional course is to provide information on methods to improve social and learning inclusion outcomes for individuals who have cortical visual impairment (CVI). Cortical visual impairment is the leading cause of visual impairment in children in developed countries but is a condition that is often misunderstood or worse, ignored in school and rehabilitation settings. This presentation will be used to demonstrate proper measurement (The CVI Range-reliable and valid assessment of CVI functional vision developed by Roman) and and interventions of the unique visual and behavioral characteristics associated with CVI and then, how these interventions can be used in school and community settings to increase and enhance opportunities for successful inclusion.

Target Audience: The presentation is appropriate for all pediatric practitioners (PT, OT, educators, MDs, vision specialists) who provide community or individual support to individuals with CVI.

Course Summary: This course will provide 1) A brief overview of CVI including causes and the unique visual and behavioral characteristics associated with CVI. 2) Methods that are used to assess the degree of affect of the CVI characteristics. 3) A description of the distinct obstacles to inclusion experienced by individuals with CVI. These obstacles are made more difficult due to the fact that children with CVI generally have little or none of the facial manifestations associated with ocular forms of visual impairment. The visual impairment of individuals with CVI exists in the posterior visual pathways and processing areas and therefore it is not "worn on the face". Additionally, children with CVI frequently have multiple and complex additional needs (CP, seizures, speech/language needs, etc.) and may not be seen as educationally visually impaired. Therefore, their lack of social or inclusion success may unfortunately may be assigned to conditions other than vision. Because children with CVI do not have typical access to their visual world, they are often disenfranchised from opportunities for inclusion. 4) Examples will be provided to illustrate social and inclusion interactions "before" CVI-specific supports, and "after" CVI-specific supports are implemented. 5) Parent perspective and multi-disciplinary approaches will be shared to demonstrate how these supports for inclusion occur as part of a daily approach rather than a separate therapy. A question and answer time will be provided.

Learning Objective 1: Describe the 10 visual and behavioral characteristics associated with cortical visual behavior
Learning Objective 2: Describe the relationship between proper assessment of functional vision and selection of intervention methods and supports
Learning Objective 3: Describe the unique challenges to social, learning, and community inclusion experienced by individuals with CVI
Learning Objective 4: Describe methods to facilitate and measure increased social, learning, and community inclusion for individuals with CVI
IC 24: THE YEAR’S TOP TEN ARTICLES ON DEVELOPMENTAL DISABILITIES
Richard Adams, MD; Nancy Murphy, MD

Purpose: To present summaries of the ten most intriguing articles on developmental disabilities published in the past year (2015 to 2016), and to encourage discussion about them by participants.

Target Audience: Physicians, nurses, and others who treat children with developmental disabilities and want to keep abreast of the latest evidence-based, scientific findings that have the greatest translational impact on care. Cross disciplinary participation is welcome and encouraged. The articles selected are generally grounded in a medical context; however, the articles should be relevant to those whose practices are focused on children and youth with disabilities.

Course Summary: The top ten clinically relevant articles published in English between Autumn 2015 and Summer 2016 will be presented to the audience. Articles will be chosen from the presenters’ personal experience 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, cerebral palsy, Down syndrome, Intellectual Disabilities, spina bifida, and spinal cord injury. 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 various practice settings.

Learning Objective 1: Discuss the major conclusions of each of the ten articles presented
Learning Objective 2: Identify areas in which additional research is needed
Learning Objective 3: Evaluate the utility of each of the articles for their own clinical practice
Learning Objective 4: Be inspired by the presentations to seek articles on their own
IC 25: TOXIN- SAFE TERRITORY FOR BOTH PATIENTS AND PROVIDERS
Ed Wright, MD; Deborah Gaebler-Spira, MD; Colin Hovinga, Pharm D; Clifton Bergfeld, JD; Ana-Marie Rojas, MD

Purpose: Residency, fellowship and apprentice training with mentors, meeting podium presentations, scientific publications, and experience are primary influencers on the practice of botulinum toxin injections and vary throughout the world. The influences of industry, regulatory agencies, and litigation are less considered contributors to practice but are an increasingly important in system based competency. The purpose of the course is to highlight and update the practice usage patterns subsequent to the 2009 FDA “boxed warning” and provide an interactive forum with legal and pharmaceutical professionals to improve patient and provider safety.

Target Audience: Physicians and other providers who inject or influence patient decision making regarding botulinum toxin injections

Course Summary: Botulinum toxin injections for hypertonia have a 25 year history of use in Cerebral Palsy with the first presentation at AACPDM in 1992. Since then many countries have approval by their respective drug regulatory agencies, however at doses lower than commonly used in practice. In the United States there is frequent “off label” usage in pediatric cerebral palsy. Dose escalation occurred rapidly in the late 90’s and 2000’s which was prior to the recognition of the systemic effects that prompted product label changes and several dosing safety studies. Following a brief review of this history and the medico legal climate, current practices around dosing, consent, documentation, injection techniques, identifying and reporting of adverse events will be explored through an interactive, anonymous poll of participates. Regulatory awareness, documentation practices and litigation around toxins will be reviewed by a hospital lawyer/physician team. Systemic spread reports, risks and responses and accessing regulatory safety data will be presented by a Pharmacology PHD/physician team.

Learning Objective 1: Understand issues around patient and practice safety related to neurolytics use
Learning Objective 2: Understand the roles of federal regulatory agencies relative to the pharmaceutical industry and the practice of healthcare.
Learning Objective 3: Understand the treatment options and outcomes of systemic botulism.
Learning Objective 4: Understand the current variable use and practice of neurolytic injections