BRK 11: ABOUT CEREBRAL PALSY: INTERVENTIONS AND THERAPIES. AN ON-LINE DECISION MAKING RESOURCE
Margaret Wallen, PhD; Abigail Townsend, MPH

Purpose: This session will introduce the cerebral palsy community to About Cerebral Palsy: Interventions and therapies, an on-line resource for people with cerebral palsy and their families, clinicians, and service providers, as well as engage the audience in identifying future content which reflects international clinician and consumer priorities.

Target Audience: People with cerebral palsy, their families, clinicians and service providers; researchers interested in evidence and knowledge translation

Course Summary: About CP: Interventions and therapies provides information on a cross section of interventions including those which address mobility, upper extremity function, communication, sleep, pain and anxiety. Each intervention is briefly described and further details are provided to assist in identifying whether an intervention may be applicable for an individual. Two experts identify and synthesize the best available evidence using a transparent rapid review process. The information and evidence is intended to assist people with cerebral palsy and their families to make informed decisions about effective and appropriate interventions.

Details will be provided of the background to this resource - from topic identification through to web publishing and knowledge translation - and particularly on the evidence-based methodology for developing each intervention topic. In addition to contributing to prioritizing future content, the audience will be invited to share information about similar decision-making resources.

Learning Objective 1: Locate and navigate About CP: Interventions and therapies
Learning Objective 2: Describe the evidence-based rapid review process used to synthesise and grade the best available evidence for About CP: Interventions and therapies
Learning Objective 3: Articulate the international priorities for information and evidence summaries for interventions and therapies for cerebral palsy
Learning Objective 4: Identify additional sources of information about interventions and clinical practice guidelines related to cerebral palsy interventions and therapies
BRK 12: ADVOCATING FOR ADVOCACY: CLINICIAN-PATIENT PARTNERSHIPS FOR ADVOCACY
Edward Hurvitz, MD; Kerstin Sobus, MD, PT

Purpose: The purpose of this session is to provide clinicians practical tools and examples to help them to encourage family members to become involved in organized advocacy.

Target Audience: Clinicians who work with families of individuals with neurodevelopmental disabilities

Course Summary: Families are the key to advocating for the needs of children and adolescents with childhood onset disabilities. Health care professionals, teachers, and others who have a role in the lives of individuals with childhood onset disabilities can advocate, but it is the parents and sibling who have the best day to day life experience and reality of needs of their loved one. We as health care professionals can work with the families to give them the tools to advocate effectively, and to assist with knowledge about who to best collaborate with at the local level, state level and national level. With knowledge of different agencies and parent support groups in the region and state, physician can assist in facilitating advocacy needs. In this session, we will present practical examples and ways that caregivers can work with families to increase their involvement in advocacy.

Learning Objective 1: Describe the need for and the benefits of involving families in organized advocacy
Learning Objective 2: Develop a plan to encourage local and regional advocacy in their area
Learning Objective 3: List several resources that clinicians can use to help families become involved in advocacy.
Learning Objective 4: Discuss how parents with children of similar disability can reach out to other parents for support or share ideas.
Purpose: To describe an approach to the routine care of children with medical complexity (defined by multisystem chronic disease, functional impairment, high health care utilization and high community care needs), through the framework of a newly-developed, evidence-based health surveillance guideline, with a focus on essential components such as family goals of care (including advance directives), preventive care and review of systems.

Target Audience: Health care providers involved in the routine care of children with medical complexity.

Course Summary: Providing preventive care to children with medical complexity is crucial to ensure that family goals are being addressed and important preventive care opportunities are not being missed. However, this is difficult to accomplish and organize due to many factors including multiple chronic diseases, frequent acute illnesses and logistical constraints (limited time for appointments, multiple competing issues, etc.). The instructors will present a novel health supervision guideline as a framework to guide routine care of CMC. Components of the routine evaluation to be presented will include the following: (1) Explicit discussion of the family goals and concerns with implementation and evaluation plan; (2) Evidence-based preventive care review; (3) Anticipatory guidance, including advance directives. Instructors will provide practical examples and demonstrate the implementation of this guideline and techniques to approach each individual section.

Learning Objective 1: Appreciate the unique needs of children with medical complexity with respect to routine and preventive care
Learning Objective 2: Review the current evidence for preventive care in children with medical complexity and the development of an evidence-based health supervision guideline
Learning Objective 3: Develop an approach to the practical and comprehensive review of children with medical complexity in the context of routine outpatient visits
Learning Objective 4: Conduct regular discussions with families of children with medical complexity regarding goals of care and advance directives
BRK 14: CARING FOR THE CAREGIVER: A SKILLS VALIDATION PROGRAM FOR CAREGIVERS OF PEDIATRIC PATIENTS WITH PULMONARY COMPLICATIONS RELATED TO A PRIMARY NEURODISABILITY DIAGNOSIS

Robert Warren, MD; Farrah Jones, BS

**Purpose:** To present the concept of Skills Validation for optimal education of the caregiver providing respiratory care. To review current literature on research into caregiver education. To report the results of our Skills Validation pilot project to assess caregiver knowledge, ability to use respiratory therapy equipment and caregiver satisfaction with this educational approach for ongoing use to maintain proficiency.

**Target Audience:** Physicians, Nurses, Therapists, Educators

**Course Summary:** Patients with pulmonary complications secondary to a primary neurodisability diagnosis are prescribed individually tailored respiratory management plans. These physician prescribed plans, including respiratory medications and devices, are used in the home to maintain pulmonary stability in the patient. The devices can range in complexity from simple inhalation therapy devices to complicated mechanical ventilators. These management plans, as well as many other duties, are carried out in the home daily by caregivers. When medications or devices are first prescribed, initial caregiver education is provided by a respiratory therapist with demonstration, written instructions, and return demonstration from the caregiver. After the initial training, the management plans are only reviewed verbally in the outpatient setting.

The Skills Validation protocol was initiated as a pilot project to improve the quality of follow-up education provided to caregivers. Skills validation is an assessment of the caregiver’s knowledge of their respiratory plan and an opportunity for the respiratory therapist to provide comprehensive instruction when needed. The purpose, frequency of use, order of therapy and possible adverse effects of respiratory medications and devices are all details about which the caregiver should have a clear understanding. Most important in this exercise is the hands on demonstration by the caregiver to the respiratory therapist of their ability to correctly use their equipment. This is done on an outpatient basis and can be repeated semi-annually or annually or upon the caregiver’s request when review of equipment or medications is felt to be needed.

The pilot project was an exercise to evaluate the effectiveness of the Skills Validation process and the caregiver’s response to it. A questionnaire was provided before the exercise to assess the caregiver’s perceived level of confidence in their knowledge of the respiratory management plan and preferred method of receiving education. They then performed the skills validation exercise, using their own equipment, with the respiratory therapist. The same questionnaire was provided after the exercise.

The results documented a need for improved follow up education and a high degree of caregiver satisfaction with the exercise.

**Learning Objective 1:** Understand the challenge to a busy caregiver providing comprehensive care in the home setting in which a major portion is the respiratory therapy management plan

**Learning Objective 2:** Understand the limitations of current caregiver education and the value of precise knowledge of respiratory medications and devices and their use

**Learning Objective 3:** Understand the value of an organized educational instrument such as the Skills Validation protocol and the potential for increased patient stability with its use

**Learning Objective 4:** Understand how the Skills Validation protocol can be tailored to enhance caregiver education regarding any type of clinical management plan
BRK 15: COULD THE SENSORY SYSTEM MAKE A DIFFERENCE IN MOTOR CONTROL FOR CHILDREN WITH HEMIPLEGIC CEREBRAL PALSY?
Sarah Evans, MD; Sahana Kukke, PhD; Andrew Gordon, PhD

**Purpose:** Both constraint induced therapy and intensive bimanual therapy, successful interventions in the treatment of children with hemiplegic cerebral palsy, are repetitive task practice that employ moderate to high dosing (60-90 hours of therapy). Since functional tasks typically include interactions between the hand and the environment, we are interested in exploring another possibility. Can hand-environment interactions during functional tasks be improved by enhancing tactile feedback in children with hemiplegic CP?

**Target Audience:** Physician, Occupational Therapists, Physical Therapists, Parents

**Course Summary:** Typically, children with hemiplegic CP express difficulty in movement. Motor symptoms, including increased muscle tone, and abnormalities of posture and movement, are therefore the main focus of patient concerns and clinical care. However, in addition to the motor impairments, children with CP also have obvious deficits in sensation, including tactile sensation, proprioception, stereognosis, and graphesthesia. Unfortunately, tactile sensory deficits are often overlooked in treatment plans for children with hemiplegic CP. If they are addressed by individual occupational therapists, it is not in a standardized manner, which makes it challenging to assess effects objectively.

Tactile sensory function plays an important role in manual ability. Manipulating objects requires the use of appropriate hand forces, which are calibrated during movement through feedback from cutaneous mechanoreceptors that sense touch, pressure, and vibration. Loss of tactile sensation can clearly lead to motor deficits. When the fingers become numb through anesthesia, reach-to-grasp movements of the hand become irregular and slow. Similarly, some patients who have sensory neuropathy have abnormalities in grip force control with the hand. In the specific case of hemiplegic CP, impaired tactile sensation has been reported to interfere with grasping and other upper limb functional tasks. Due to the powerful impact of tactile sensation on hand movement and function, it is certainly possible that improvements in tactile sensation could have downstream positive effects on fine motor control. The potential role of tactile-focused therapy for motor rehabilitation has been investigated in adults with stroke and dystonia. In this seminar, we will explore what is known about sensory function in children with hemiplegic cerebral palsy, what has been studied and what has not. We will discuss the potential to improve hand function by enhancing tactile sensation.

**Learning Objective 1:** Describe the current literature and research related to sensory function in children with hemiplegic cerebral palsy

**Learning Objective 2:** Suggest the possible contribution of tactile therapy to the function of the paretic hand in children with cerebral palsy

**Learning Objective 3:** Differentiate between visual and tactile learning and the effects of each on the brain

**Learning Objective 4:** Discuss the possible contribution of adding sensory findings to a registry of data about children with cerebral palsy

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BRK 16: ESSENTIAL CHARACTERISTICS OF SUCCESSFUL TRANSITION PROGRAMS FOR ADOLESCENTS AND YOUNG ADULTS WITH CHILD ONSET DISABILITIES: KEY LESSONS FROM TWO EVIDENCE-BASED PRACTICE MODELS
Susan Labhard, MSN; Kathryn Lindstrom, MSN, APRN, CNP

Purpose: To help identify critical components of two transition models that successfully accommodate transition needs of adolescents and young adults with childhood onset disabilities. Providers will learn creative approaches to setting up their program and discover practical solutions to transition challenges applicable to their own clinic setting.

Target Audience: Physicians, APRN's Nurses, Therapists, Social Workers, Counselors and Educators

Course Summary: A comprehensive approach to transition, encompassing medical and social inclusion for adolescents and young adults with childhood onset disabilities, is an important issue for patients, families and providers. This course will illustrate transition challenges and solutions by comparing and contrasting two separate delivery systems-Shriners Hospital Transitions Program and Gillette Transition Clinic. Key components of successful transition development and implementation will be compared and contrasted. Methods to engage adolescents and young adults with special health needs in participating in their healthcare and personal goals will be explored. Participants can expect to come away with creative, practical and evidence-based transition tools for use in the clinical setting.

Learning Objective 1: Understand the importance of a successful transition program for youth with childhood onset disabilities citing evidence-based practice recommendations

Learning Objective 2: Learn about innovative tools and strategies to improve efficiency and effectiveness in providing transition information to patients and families in diverse settings

Learning Objective 3: Participants will explore essential characteristics of successful transition models and take home specific tools and resources which can be shared with their patients/families, clinic providers and staff

Learning Objective 4: Upon completion, participants will be able to identify both barriers and key elements in the development of a successful transition program
Purpose: A review of the evidence related to appropriate therapeutic assessments and interventions for individuals with CP, between 5-25 years of age, who have had Single Event Multi-level Surgery (SEMLS). Currently, there is significant variation in clinical practice as it relates to the therapeutic management of these patients, which will ultimately impact their achievement of maximal functional outcomes. During this presentation, clinicians will be informed of current clinical recommendations for this patient population and how these can be applied to their practice settings.


Course Summary: Single event multi-level surgery (SEMLS) is a preferred intervention amongst orthopedic surgeons to promote improved skeletal alignment and muscle efficiency with the ultimate goal of enhancing function. SEMLS is most effective when supported by physical therapy intervention. Unfortunately, standards or clinical practice guidelines regarding best practice for pre- and post-operative therapy do not exist and that anecdotal reports reflect wide variation in practice. As a result, a systematic review was conducted to establish a clinical practice guideline to support clinicians in management of this patient population so as to be able to achieve maximal outcomes.

Learning Objective 1: Appreciate the inconsistencies in clinical practice related to post-operative PT management of SEMLS patients per findings of this systematic review
Learning Objective 2: Understand evidence-based recommendations as it relates to appropriate clinical assessments and therapeutic interventions
Learning Objective 3: Understand the evidenced-based dosing recommendations for pre-and post-operative of physical therapy intervention during the management of SEMLS patient
Learning Objective 4: Understand gaps in the current evidence as it relates to the pre- and post-operative management of SEMLS patients and appreciate areas for future research in this area
BRK 18: RETINAL SCANNING FOR AUGMENTATIVE COMMUNICATION - WHAT’S ON YOUR MIND?
Aloysia Schwabe, MD; Betsy Furler, MS, CCC-LP

**Purpose:** Technology is now available to facilitate communication in children and adults who have significant motor disability or apraxia utilizing retinal scanning. Often these individuals have a limited ability to use traditional forms of access to communication devices. This session is intended to increase knowledge about the key abilities required that predict potential success with a retinal scanning device and to increase familiarity with mechanisms for trials with these devices and also strategies for obtaining devices for longterm personal use.

**Target Audience:** Speech pathologists, occupational therapists, and physical therapists, physiatrists, neurologists and developmental pediatricians, social workers and nurses

**Course Summary:** This course will provide an overview of the technology utilized for retinal scanning and basic prerequisites for its use. Various etiologies of motor impairment or apraxia which could be barriers to use of traditional forms of augmentative communication will be reviewed. Individual examples of individuals being evaluated will be included along with videos to show optimal positioning strategies. Often times despite having a device on loan, appropriate instruction is lacking or proper positioning is not accomplished which can compromise optimal use of these devices as well. Funding opportunities exist outside of traditional means. Documentation supporting the individual's ability to use the device and its impact on their functioning must be submitted to assist with justification for coverage.

**Learning Objective 1:** Increase knowledge of positive attributes predicting future success with retinal scanning technology as well as barriers

**Learning Objective 2:** Understand that certain individuals will need advanced technology from the beginning to be successful with augmentative communication

**Learning Objective 3:** Review the process for obtaining a device on loan and for permanent use incorporating a variety of funding strategies and providing necessary documentation

**Learning Objective 4:** Be familiar with training and optimal positioning necessary for success and carryover
Purpose: The purpose of this breakfast seminar is to introduce clinicians to the structure, processes and research initiatives of the Cerebral Palsy Research Network (CPRN). CPRN is a collaboration of institutions, clinicians, therapists, researchers and patients/caregivers who seek to improve outcomes for people with CP through high quality clinical research and quality improvement initiatives. The network, which has a clinical cp registry and patient reported outcomes at its core, currently has 18 member sites and plans to expand in 2017. This session will describe the formation and working processes of CPRN, its EMR based data collection tools, how its study groups work, its research agenda including adult outcomes and how new sites can join the network and contribute to its body of research.

Target Audience: Clinicians of every discipline, therapists, researchers and patient advocates

Course Summary: The course will cover the founding and startup period of CPRN with a focus on what is unique about this clinical research network and its CP registry. The working processes for the registry rollout, study planning, data access and publication will be discussed. The course will then proceed to describing each of these areas in more depth with each subsequent presenter describing the data collection tools and processes during a clinic visit or surgical event, a review of the highlights of the CPRN registry common data model and how working groups defined and revise the registry elements and then finally a presentation on the adult outcomes registry for CPRN. Attendees will come away with a good understanding of how CPRN works and how they can prepare their center to be involved in the network in the future.

Learning Objective 1: Understand the current state and future direction of the Cerebral Palsy Research Network

Learning Objective 2: Advocate with their partners in their CP practice to prepare their institution to join the CPRN to gain benefits in the efficiency of their practice and to improve patient outcomes

Learning Objective 3: Define the objectives of the CPRN registry for planning research and finding practice variation to target for quality improvement initiatives

Learning Objective 4: Describe how the CPRN adult outcomes registry can be used to track patient outcomes long term and form the basis for new research on adults with cerebral palsy