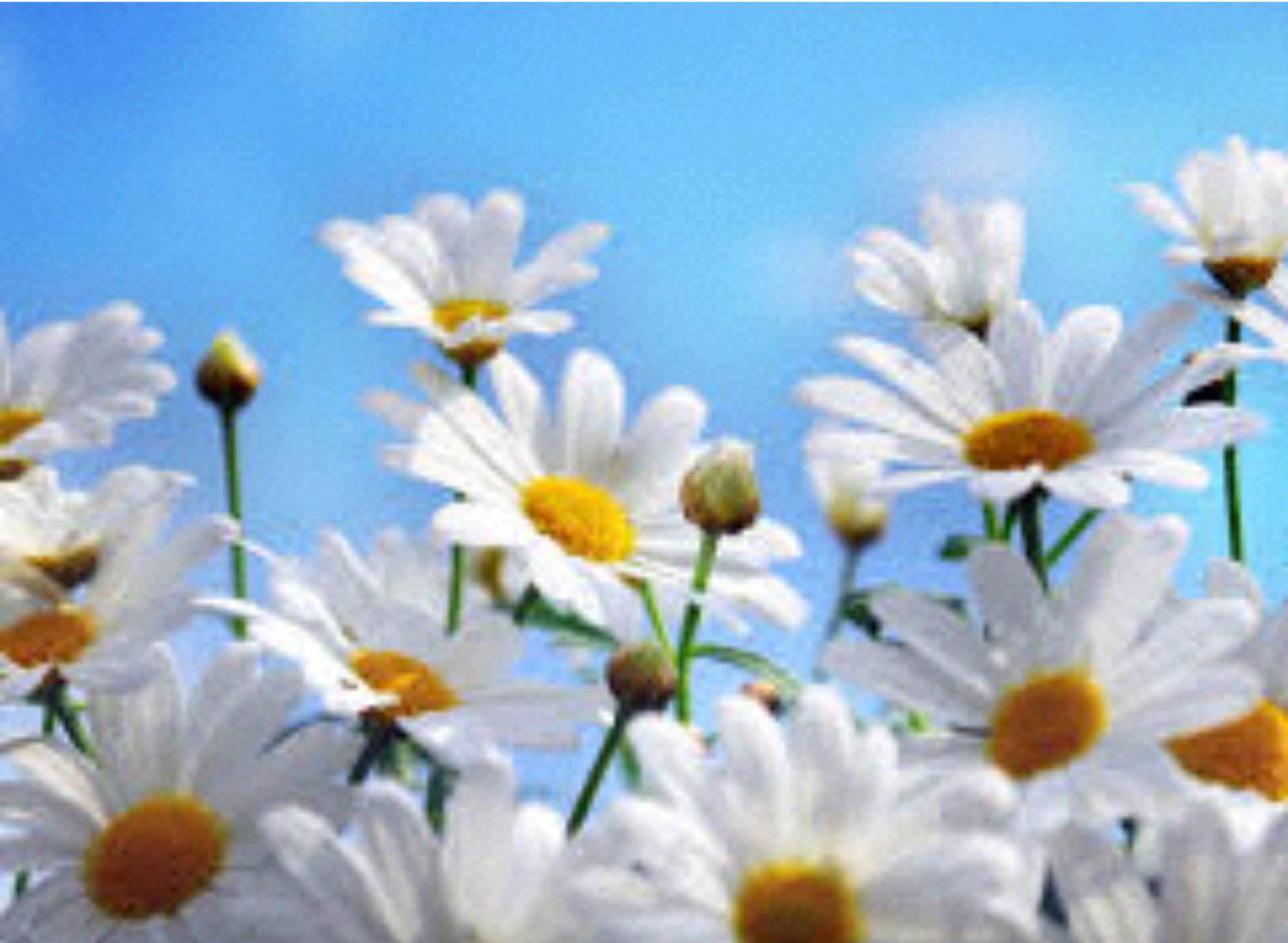
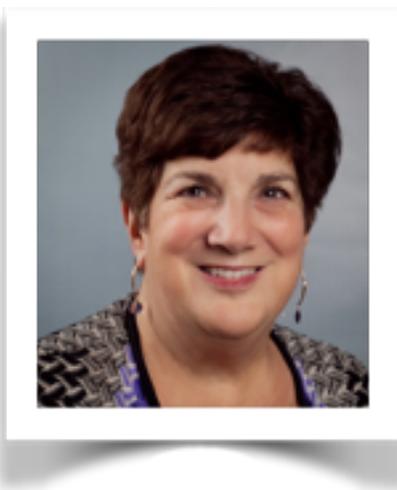


ACNN Currents



# Summer Edition 2015





## President's Message

Happy SUMMER!

It's hard to believe that Summer is here but I for one am happy to say goodbye to Winter and all the snow. I would like to thank all the Board Members, Committee Chairs and Committee members who volunteered many hours in 2014 to ensure a wonderful Conference in October. We had another successful conference with informative presentations and opportunities to network with colleagues across the country. I look forward to working with this year's Board of Directors as we move forward in 2015.

We continue working with the Child Neurology Society who is our management company. We just completed the membership renewal process which began in January. If you have not renewed your membership it's not too late. There are advantages to being a member. As a member you can network with other child neurology nurses and you receive a lower rate for the annual meeting. We are continuing to upgrade the new website. You can now access our website through a link on the CNS website front page. Look for more information to come.

We are in need of more committee members and Chairs to help with the programs we do throughout the year. Please consider being part of a committee, an organization is only as good as its members.

If you are thinking about having a conference or workshop in your area ACNN has a small startup allowance to help with your conference. These is a great way to have a program closer to home to assist other nurses in the field who are unable to attend the annual conference. Please check the website for more details.

I encourage everyone to take an active role in our organization. Each of you has a gift to share with others so don't be afraid to nominate a colleague or yourself. We also have some funding for small research projects that you may be thinking about doing. Your Board of Directors and the committees are here to help you succeed.

I wish you a healthy and successful 2015 as you continue working with children and families living with neurologic disorders to improve their lives.

Sincerely,

Kathy O'Hara

ACNN President

[kohara@mcvh-vcu.edu](mailto:kohara@mcvh-vcu.edu)



# 44th Child Neurology Society Annual Meeting, Gaylord National Resort & Convention Center, National Harbor, MD



## Agenda for 2015 ACNN Conference Program October 6-9, 2014

### Tuesday, October 6

**7:00 pm -9:00 pm - ACNN Welcome Reception (Nurses Only)**

### Wednesday, October 7

**7:00 am – 8:00 am – Registration and Continental Breakfast**

**8:00 am – 8:15 am – Welcome and Introduction**

**8:15 am – 9:00 am – Janet Bruckner Keynote Speaker, Pain Management in the Paediatric Neurology Patient**

Nancy Santilli, PNP, MN, FAAN

**9:00 am – 9:45 am – Concussion in the Pediatric Population**

Elaine Philipson, MS, PPCNP-BC

**9:45 am – 10:00 am – Break**

**10:00 am – 10:45 am – *Understanding the Ketogenic Diet in the Treatment of Epilepsy***

Elaine Philipson, MS, PPCNP-BC

**10:45 am –11:30 am – *ESES (Electrical Status Epilepticus of Slow-wave Sleep) - Beyond Landau-Kleffner Syndrome***

Rhonda Werner, MS, RN, APNP, PCNS-BC

**11:30 am – 12:00 pm – Awards Presentation and Annual Business Meeting**

**12:00 pm – 1:00 pm – Lunch**

**1:00 pm – 1:30 pm – 2015 *Clinical Practice Award - Nemours Neurology Headache Program***

Tara Pezzuto, APRN, MSN, PCNS

**1:30 pm– 2:30 pm – *I Feel Dizzy; A Clinical Approach to Evaluation***

Mona Jacobson, MSN, CPNP-PC

**2:30 pm – 2:45 pm – Break**

**2:45 pm– 3:30 pm - *Utilizing Patient Engagement to Improve Decision Making in Pediatric Onset Multiple Sclerosis***

Lisa Duffy, PhD, RN, CPNP, CNRN, MSCN

**3:30 pm – 4:15 pm – *X-linked Creatine Transporter Disorder-A Tale of 3 Brothers***

Carolyn Zook Lewis, RN, MSN, CPNP-DC, PMHS

**Thursday, October 8**

**12:00 pm – 12:45pm – Lunch – SIG and Table Discussions**

**12:45 pm – 1:15 pm - *Febrile Seizures...To Treat Or Not To Treat, That Is The Question***

Lauren Siebrase, MSN, FNP-C

**1:15 pm– 1:45 pm - *You Never Told Me She Would GO BALD!” Addressing the anxieties and fears of parents, patients, and providers when encountering medication related hair thinning/hair loss with commonly used pediatric neurology drugs***

Bethany Hutchinson, MSN, RN, CPNP, PPCNP-BC

**1:45 pm – 2:15 pm – *Evaluation and Treatment Management of Childhood Epilepsy Syndromes***

Lauren Siebrase, MSN, FNP-C

Lai Brooks, DNP, FNP-BC

***Annual Fun Run/Walk***

TBA

**Friday, October 9**

**12:00 pm – 12:45 pm – *Lunch***

**12:45 pm – 1:30 pm – *Up in Smoke: Cannabis for Pediatric Epilepsy***

Maureen Sheehan, RN MS CPNP

**1:30 pm – 2:30 pm – *Fetal Surgery for Myelomeningocele: The UNC Experience***

Gretchen Delametter, RN, MSN, CPNP-AC, CNS



## **Conference Platform Presentation Abstracts**

**Presentation: Concussion in the Pediatric Population**

**Date: Wednesday, October 7**

**Time: 9:00 am-9:45 am**

**Presentation Title:** Concussion in the Pediatric Population

**Author with Credentials:** Elaine Philipson, MS, PPCNP-BS

**Abstract:**

There has been increased awareness regarding the potential impact of concussion in the pediatric population among both healthcare providers and laypersons. However, this awareness has not always lead to clarity in how to best manage the short or long-term consequences on concussion. Though concussions occur in multiple types of settings and effect all age groups, research and guidelines have focused primarily on concussions occurring during sports. Key organizations involved with concussion care and research have published updated guidelines in the last few years with recommendations based on their review of available evidence. The focus of this talk will be to provide an update on the understanding of concussion injury, to describe the clinical and educational manifestations of concussive injury and to provide an overview of the most recent guidelines regarding concussion management.

**Learning Objectives:**

1. Describe the public health burden of concussion in children
2. Describe the historical perspective on concussion
3. Describe the physiologic injury that occurs with concussion
4. Discuss how the guidelines are operationalized in schools and healthcare settings

**Impact Statements:**

1. Providing very current patient/family teaching regarding the understanding of concussion injury, the specific risks in teenagers with concussion and how to best support the healing process
2. Utilize most recent Concussion Guidelines to guide clinical decision-making.
3. Effectively and safely help children transition back to normal functioning after concussive injury

**Presentation: Understanding the Ketogenic Diet in the Treatment of Epilepsy**

**Date: Wednesday, October 7**

**Time: 10:00 am-10:45 am**

**Presentation Title:** Understanding the Ketogenic Diet in the Treatment of Epilepsy

**Author with Credentials:** Elaine Philipson, MS, PPCNP-BC

**Abstract:**

The ketogenic diet is known to be an effective nonpharmacologic treatment for individuals with epilepsy since it was first used in the 1920's. It has been shown that more than 50% of

the individuals started on the diet will respond favourably and experience a decrease in seizure frequency of at least 50%. Some achieve total seizure freedom, even in cases of intractable epilepsy or in those who have failed numerous medication trials. Though the mechanism of action is not fully understood it is vital that nurses caring for patients using this diet for seizure control understand the concepts that can make or break the success of the diet in the home. Yet, despite this, most nurses have little training in the metabolic pathways that provide the foundation for helping families start and maintain this complex diet. This presentation will review the essential metabolic pathways, discuss how the body responds to the diet change and how we monitor ongoing ketosis and other labs in managing these patients. We will review the disorders that the ketogenic diets have been particularly beneficial in treating. The presentation will also discuss the different types of ketogenic diets, the restrictions involved in each and the current thinking regarding how to provide ongoing management for these patients.

**Learning Objectives:**

1. Discuss how the Ketogenic Diet (KD) changes metabolism in the human body
2. State how KD has been and is being used in the treatment of epilepsy
3. Describe the types of KD's and how they differ
4. Describe "typical diet initiation process
5. Describe ongoing outpatient management & concerns

**Impact Statements:**

1. Understanding the metabolic foundation for how the ketogenic diet changes energy production and usage in the body
2. Being able to determine which children may benefit most from starting the KD
3. Making clinical decisions regarding medications, illness events and breakthrough seizure within the limits of the type of KD the individual child is on
4. Understanding the scope of challenges faced by family who provide the KD to their children

**Presentation: ESES (Electrical Status Epilepticus of Slow-wave Sleep) - Beyond Landau-Kleffner Syndrome****Date: Wednesday, October 7****Time: 10:45 am-11:30 am****Presentation Title:** ESES (Electrical Status Epilepticus of Slow-wave Sleep) - Beyond Landau-Kleffner Syndrome**Author with Credentials:** Rhonda Roell Werner, MS, RN, APNP, PCNS-BC**Abstract:**

In 1957, Landau and Kleffner first reported acquired aphasia in a subset of children with epilepsy. Over the last 60 years, hundreds of children with Landau-Kleffner syndrome have

been identified. As more children with concurrent language regression and epilepsy have been identified, it has become clear that there have been different interpretations of the electrical status epilepticus of slow wave sleep (ESES) EEG pattern; as well as the presentation and outcomes of these children are not always clear. A survey completed by members of the Child Neurology Society and American Epilepsy Society published in 2013 demonstrated that only 27% of the 137 members who responded to the survey felt that language regression was required for a diagnosis of ESES. A variety of treatment modalities have been used for the management of ESES/CSWS including antiepileptic medications, i.e. valproate, valproate combined with ethosuximide, benzodiazepines, and sulthiame (which is not available in the United States), immune modulation, and epilepsy surgery. However, responses to therapeutic interventions have been variable. To increase the knowledge base of my nursing colleagues, the current understanding of ESES based on a review of the literature will be presented. Since at my institution a number of patients have been identified and treated for ESES, case studies will be used to review the treatment options and outcomes for ESES. In addition to patients with classic ESES, a number of patients have also been treated who have a focal ESES pattern on EEG. This population has not been well described in the literature. A research study to examine the differences between classic ESES and focal ESES has been implemented. Preliminary data from this study will also be presented.

**Learning Objectives:**

1. Describe ESES and its impact on patients
2. Identify therapies that may be used in the treatment of ESES

**Impact Statements:**

1. Describe ESES and its impact on patients
2. Identify therapies that may be used in the treatment of ESES

**Presentation: Clinical Practice Award - Nemours Neurology Headache Program****Date: Wednesday, October 7****Time: 1:00 pm-1:30 pm****Presentation Title:** Clinical Practice Award - Nemours Neurology Headache Program**Author with Credentials:** Tara Pezzuto, APRN, MSN, PCNS**Abstract:****Learning Objectives:**

1. Understand what makes our practice innovative
2. Understand how it has impacted our patients / families and neurology clinic.
3. Understand how it has financially impacted our practice

**Impact Statements:**

1. Practice innovation
2. Outreach to the community
3. Financial impact

**Presentation: I feel dizzy; a clinical approach to evaluation****Date: Wednesday, October 7****Time: 1:30 pm- 2:30 pm****Presentation Title:** I feel dizzy; a clinical approach to evaluation**Author with Credentials:** Mona Jacobson, MSN, CPNP-PC**Abstract:**

I feel dizzy; a clinical approach to evaluation Many patients being seen in neurology have complaints of dizziness. The issue is sorting out what is meant by dizziness and then sifting through the myriad of conditions that have dizziness as a presenting problem. This presentation will discuss how to approach a patient with dizziness with emphasis in determining what is meant by dizziness. Once dizziness is defined then history and presenting signs and symptoms will be discussed to aid in formulation of a likely diagnosis. There will be case examples highlighting evaluation and diagnosis of dizziness. Topics that will be covered in the context of differential diagnosis include but not limited to: pre syncope/syncope, vertigo, migraines, seizures, psychogenic etiology and postural orthostatic tachycardia syndrome (POTS). Since the focus of this presentation will be evaluation, treatment will only be covered briefly so this will not fulfill any pharmacology requirements.

**Learning Objectives:**

1. Define dizziness and associated symptoms
2. Identify differential diagnoses related to presenting symptom of dizziness
3. Apply algorithm to evaluation of dizziness

**Impact Statements:**

1. Diagnosis of dizziness.
2. Use of an algorithm in determining differential diagnosis related to presenting complaint of dizziness

**Presentation: Utilizing Patient Engagement to Improve Decision Making in Pediatric Onset Multiple Sclerosis****Date: Wednesday, October 7****Time: 2:45 pm-3:30 pm****Presentation Title:** Utilizing Patient Engagement to Improve Decision Making in Pediatric Onset Multiple Sclerosis

**Author with Credentials:** Lisa Duffy, PhD, RN, CPNP, CNRN, MSCN

**Abstract:**

**Aims:** The purpose of this study was to gain knowledge that can be applied to the development of a decision support tool to better aid families of children and adolescents with pediatric onset multiple sclerosis (POMS) in the decision-making process surrounding disease-modifying therapy. This study utilizes the approach supported by PCORI of engaging patients in each phase of the research process to help improve patient outcomes. The specific aim of this study was to describe the experience of decision making related to the use of disease-modifying therapy in patients with POMS and their parents. **Methods:** Focus groups were conducted with four populations; 1) young adolescents ages 12 to 15 years with POMS, 2) adolescents ages 16 to 18 years with POMS, 3) young adults ages 19 to 24 years with POMS, and 4) parents of children ages 12 to 24 years who have a diagnosis of POMS. Participants were recruited from a pediatric MS clinic at an urban quaternary academic medical center. **Results:** Data collection is currently ongoing. Analysis of the data obtained from the focus groups will include: • Field notes about the environment, and participant observation, context, and tone will be added • In vivo codes will be identified and a codebook will be developed. Similar codes will be clustered. • Content validity will be assessed by initial focus group participants and also a group of multidisciplinary content experts **Conclusions:** Findings from this study will inform the development of educational resources and a decision-making support tool to facilitate shared decision making regarding disease modifying therapy in POMS. Patient-reported outcome measures will be used to evaluate the effectiveness of the decision support tool. Findings from this study can be generalizable to a variety of chronic conditions that would benefit from patient engagement in the decision making process.

**Learning Objectives:**

1. Discuss strategies to improve patient engagement in the decision making process.

**Impact Statements:**

1. Facilitating decision making among families of children with chronic neurological conditions.

**Presentation: X-linked Creatine Transporter Disorder-A Tale of 3 Brothers**

**Date: Wednesday, October 7**

**Time: 3:30 pm-4:15 pm**

**Presentation Title:** X-linked Creatine Transporter Disorder-A Tale of 3 Brothers

**Author with Credentials:** Carolyn Zook Lewis, RN, MSN, CPNP-DC, PMHS

**Abstract:**

Cerebral creatine transporter deficiency (CRTR-D) was first described in 2001 as an X-linked cause of intellectual disability characterized by deficiency of cerebral creatine. It is estimated that the prevalence of CRTR-D is up to 3.5% of males with intellectual disabilities. The clinical features can vary with the hallmark feature being intellectual developmental disability. Other features include expressive speech delay, behavior problems (hyperactivity and autistic features), seizures, extrapyramidal movement disorders, hypotonia, and gastrointestinal problems. I would like to present an overview of the 3 types of creatine deficiencies including clinical features, diagnosis, and potential treatments, with an emphasis on CRTR-D. I plan to present this information as a case study involving three brothers who have been diagnosed with CRTR-D. I have been following this family since 2008 and would like to present the story of each brother from initial presentation to present. I hope to increase awareness of this disorder, and encourage testing in all males with intellectual disability of unknown etiology.

**Learning Objectives:**

1. As a result of this educational activity, participants will be able to list the 3 types of creatine transporter deficiencies.
2. As a result of this educational activity, participants will be able to identify patients who should be tested for creatine transporter deficiency.
3. As a result of this educational activity, participants will be able to provide anticipatory guidance for families with children who have been diagnosed with x-linked creatine transporter deficiency.

**Impact Statements:**

1. This educational session helped me to identify changes I could make in my practice related to recognition of the clinical characteristics of creatine transporter deficiencies.
2. This educational session helped me to identify changes I could make in my practice related to testing of patients for creatine transporter deficiencies.

**Presentation: Febrile Seizures...to treat or not to treat, that is the question.**

**Date: Thursday, October 8**

**Time: 12:45 pm-1:15 pm**

**Presentation Title:** Febrile Seizures...to treat or not to treat, that is the question.

**Author with Credentials:** Lauren Siebrase, MSN, FNP-C

**Abstract:**

Febrile seizures are the most common type of childhood seizures. They occur in children under the age of 5 and during a febrile illness. Approximately 1 in 25 children will experience a febrile seizure and is commonly seen between 1 and 3 years of age, but no later than 5. The majority of children experience simple febrile seizures, which are characterized as

generalized seizures that last less than 10 minutes and have no recurrence within 24 hours of initial seizure. Despite reasonable parental concern and anxiety after a child has a febrile seizure, medical intervention and further diagnostic testing is typically not recommended. When a child has a prolonged febrile seizure (greater than 10 minutes), has focal onset, and or multiple seizures during the illness, the child now has complex febrile seizures and neurological evaluation is recommended. Besides the acute treatment for a prolonged febrile seizure, there is still much debate on initiation of treatment and which medication. If it is determined that treatment is needed than what kind; intermittent or daily prophylaxis? Prophylaxis treatment in febrile seizures can include the use of phenobarbital and valproic acid. Anti-pyretics may make the child feel better, but have no role in prevention of febrile seizures. Neurodiagnostic testing (MRI/EEG) for these children is determined case by case, but are not typically needed unless the child starts to have unprovoked seizures, focal onset, or presents as febrile seizure epilepticus. Whether a child has simple or complex febrile seizures, the single most important thing parents can do to help prevent recurrent seizures is to minimize the child's exposure to illness and having their children up to date on their immunizations. By having this knowledge, the nurse practitioner can assist in facilitating and expediting treatment along with enhancing parental understanding of their child's disorder.

**Learning Objectives:**

1. As a result of this educational session, participants will be able to differentiate between simple and complex febrile seizures.
2. As a result of this educational session, participants will be able to determine the most appropriate treatment and testing for patients with febrile seizures.
3. As a result of this educational session, participants will be able to educate families on febrile seizures.

**Impact Statements:**

1. This educational session helped me to identify changes I could make in my practice related to the management and treatment of febrile seizure.
2. This educational session helped me identify changes I could make in my practice related to educating patients, families, and colleagues on the treatment and management of febrile seizures.

**Presentation: You never told me she would GO BALD!" Addressing the anxieties and fears of parents, patients, and providers when encountering medication related hair thinning/hair loss with commonly used pediatric neurology drugs.**

**Date: Thursday, October 8**

**Time: 1:15 pm-1:45 pm**

**Presentation Title:** You never told me she would GO BALD!" Addressing the anxieties and fears of parents, patients, and providers when encountering medication related hair thinning/hair loss with commonly used pediatric neurology drugs.

**Author with Credentials:** Bethany C. Hutchinson, MSN, RN, CPNP, PPCNP-BC

**Abstract:**

One's hair plays a fundamental role in one's appearance and defining one's self-esteem. For those children with chronic illness, their sense of self-esteem is threatened by both the outward and inward manifestations of their illness. In these patients, facing unexpected thinning or loss of their hair can be emotionally devastating, as it is not something that anyone has typically prepared them for. Even in children with severe neurological impairment who may not possess a true sense of "self," the parent may view their child's hair as the one beautiful feature that seems untouched by their child's neurological condition. For both patient and parent, the child's thinning hair or hair loss can provoke extreme emotional responses. The provider may be unprepared for these extremely emotional reactions, and have little to offer the family in terms of options or remedies. This session will briefly review the developmental tasks associated with various stages of child development as it pertains to the topic. The speaker will identify medications prescribed in routine pediatric neurological disorders that may commonly be associated with hair thinning or hair loss. An approach to the preliminary evaluation of a patient presenting with hair loss will be discussed, along with options for management.

**Learning Objectives:**

1. As a result of this educational session, participants will be able to integrate their knowledge of child psychosocial development with the patient/family's concern of hair thinning/hair loss.
2. Identify medications utilized in routine pediatric neurological disorders that are commonly associated with hair thinning and/or hair loss.
3. Describe elements involved in the preliminary evaluation of a pediatric patient presenting with hair thinning and/or hair loss, who is receiving a drug commonly associated with hair thinning/hair loss.
4. Differentiate between treatment alternatives, identifying key contraindications for each.

**Impact Statements:**

1. Recognizing the emotional stressors experienced by patients and families who experience medication-related hair thinning/hair loss, and through validating their emotions/their experiences.
2. Educating my patients about hair thinning or hair loss as a potential side effect of medication(s) utilized in routine pediatric neurological disorders.
3. Increasing my sense of comfort with performing a preliminary clinical/laboratory evaluation of patients receiving commonly prescribed neurology medications, who present to my facility for evaluation of hair thinning/hair loss.
4. Providing me with a rationale for performing a preliminary clinical/laboratory evaluation for my patients receiving commonly prescribed neurology medications, who present to my facility for evaluation of hair thinning/hair loss.

5. Implementing a preliminary clinical evaluation for my pediatric patient(s) who currently receive one or more of these medications, who present to my facility with symptoms of hair thinning/hair loss.
6. Introducing a preliminary discussion with my pediatric patients and families regarding viable treatment options for medication-related hair thinning and/or hair loss.

**Presentation: Evaluation and Treatment Management of Childhood Epilepsy Syndromes****Date: Thursday, October 8****Time: 1:45 pm-2:15 pm****Presentation Title:** Evaluation and Treatment Management of Childhood Epilepsy Syndromes**Author with Credentials:** Lauren Siebrase, MSN, FNP-C  
Lai Brooks, DNP, FNP-BC**Abstract:**

Epilepsy is a medical condition that consists of recurrent seizures. Approximately 3 million Americans are affected with epilepsy, of that 300,000 are children. Most common childhood epilepsies are benign and the child's development and intellect are normal. However some seizure types are more serious and will require treatment into adulthood. Understanding the etiology and pathophysiology of these syndromes is critical during the evaluation, diagnosis and treatment management. Childhood epilepsy syndromes can be further categorized by seizure type and EEG findings (focal or generalized) and or by cause (idiopathic, genetic, or symptomatic) according to the International League Against Epilepsy (ILAE). Common localizing related (focal) epilepsies include: Benign infantile seizures, Benign childhood epilepsy with centrotemporal spikes, early onset childhood occipital epilepsy (Panayiotopoulos type) and late onset childhood occipital epilepsy (Gastaut type). Common generalized epilepsies include: myoclonic epilepsy in infancy, infantile spasms, childhood and juvenile absence epilepsy, juvenile myoclonic epilepsy, Idiopathic generalized tonic-clonic epilepsy, Lennox-Gastaut syndrome, Epilepsy with myoclonic-atonic (Doose syndrome), Eyelid myoclonia with absence seizures (Jeaven's syndrome). Severe myoclonic epilepsy in infancy (Dravet syndrome) has an unknown etiology and has recently been in the spotlight of national media attention. Knowledge of the child's underlying epilepsy syndrome will allow the provider to select the most appropriate treatment option (antiepileptic drug therapy, ketogenic diet, epilepsy surgery, and or medical device implantation) and facilitate further diagnostic testing and or resources (imaging, genetic testing, rehabilitation therapies, etc) for the child and family. As frontline providers and educators, this knowledge will allow the nurse practitioner to become a vital component in the evaluation, diagnosis, and treatment management of children with epilepsy while enhancing parental knowledge of their child's disorder.

**Learning Objectives:**

1. As a result of the this educational session, participants will be able to differentiate between common focal and generalize epilepsy syndromes
2. As a result of this educational session, participants will be able identify treatment options for common epilepsy syndromes.
3. As a result of this educational session, participants will be able to have the knowledge of common epilepsy syndromes to better educate patients and their families

**Impact Statements:**

1. This educational session helped me to identify changes I could make in my practice related to the initial treatment of childhood epilepsy syndromes.
2. This educational session helped me to identify changes I could make in my practice related to the evaluation and long-term outcomes in children with epilepsy syndromes.
3. This educational session helped me to identify changes I could make in my practice related to my knowledge to better facilitate parental understanding and education on their child's diagnosis

**Presentation: Up in Smoke: Cannabis for Pediatric Epilepsy****Date: Friday, October 9****Time: 12:45 pm-1:30 pm****Presentation Title:** Up in Smoke: Cannabis for Pediatric Epilepsy**Author with Credentials:** Maureen Sheehan, RN MS CPNP**Abstract:**

This talk will cover the following topics: History of cannabis use Basic science of the endocannabinoid system Epilepsy and the endocannabinoid system What is the evidence? Clinical trials Charlotte's Web What is the attraction? (Hoping for audience participation!)

**Learning Objectives:**

1. Name one reason why the endocannabinoid system can influence seizure control and one challenge to this regulation
2. Describe challenges facing clinical trials for use of cannabis for seizure control in children

**Impact Statements:**

1. Advising parents about the pros and cons of cannabis for seizure control
2. Making decisions including both quantitative and qualitative data

**Presentation: Fetal Surgery for Myelomeningocele: The UNC Experience****Date: Friday, October 9****Time: 1:30 pm-2:30 pm****Presentation Title:** Fetal Surgery for Myelomeningocele: The UNC Experience

**Author with Credentials:** Gretchen L. Delametter, RN, MSN, CPNP-AC, CNS

**Abstract:**

Spina Bifida is one of the most common central nervous system congenital anomalies. The most frequent form of spina bifida is myelomeningocele. These deformities are characterized as either open neural tube defects or closed neural tube defects. In addition to the spinal deformity, there are a constellation of other central nervous system deformities as well as the development of hydrocephalus. Postnatal closure of the spinal defect and ventriculoperitoneal shunt placement has long been the treatment. Prenatal repair of the spinal defect was studied for its benefits to reduce the need for shunting for hydrocephalus and is now an accepted treatment option. Our medical center participated in the pretrial study and three centers participated in the NIH study. Once the study was stopped for efficacy, our center was poised and ready to provide this as an option to parents faced with this congenital diagnosis. The development of our multidisciplinary team and our outcomes associated with this procedure highlight the success of our efforts.

**Learning Objectives:**

1. Discuss neurulation as it relates to myelomeningocele
2. Evaluate treatment options for fetuses with myelomeningocele based on the MOMS Trial
3. Describe fetal surgery for myelomeningocele and the UNC experience

**Impact Statements:**

1. Understanding embryologic process of the development of myelomeningocele
2. Discussing options for referral patterns to centers that provide all options for a diagnosis of fetus with myelomeningocele

## Conference Posters

**Gaylord National Resort & Convention Center  
National Harbor, MD/outside of Washington, DC  
October 6 - October 9, 2015  
Prince George Exhibit Hall A**

**Cardiac Neurodevelopment Clinic- A Good Fit for a Neurology APN**

*Carol Greene-Roethke, RN, MSN, CRNP-APN  
(Wilmington, DE)*

**Improving the Hospital Experience for Individuals with Intellectual Disabilities**

*Carole Atkinson, MS, PPCNP-BC, CNRN*

*Candice Marti, CPNP, CNRN*  
*Lora Pixley, CPNP, CNRN*  
*(Boston, MA)*

### **Initiative to Prevent EEG Lead-Related Pressure Ulcers**

*Carole Atkinson, MS, PPCNP-BC, CNRN*  
*Sandy Quigley, MSN, CWOCN, CPNP-PC*  
*Susan Hamilton, RN, MS, CCRN, CWOCN*  
*(Boston, MA)*

### **New Seizure Diagnosis: Educating the Caregivers**

*Carole Atkinson, MS, PPCNP-BC, CNRN*  
*Tara Kelly, BSN, EN, CNRN, CPHON*  
*Lisa Duffy, PhD, CPNP, CNRN, MSCN*  
*(Boston, MA)*

### **Comprehensive Care and Management of Leigh Syndrome at the UT Mitochondrial Center of Excellence**

*LaKeesha Minor, RN BSN*  
*Shamonica Williams, LVN*  
*Rahmat Adejumo, MBBS, MPH*  
*(Houston, TX)*

### **Patient Engagement in the Research Process**

*Lisa Duffy, PhD, RN, CPNP, CNRN, MSCN*  
*(Boston, MA)*

### **Glut 1 Transporter Deficiency Presenting as Alternating Hemiplegia of Childhood**

*Kelley L. Ward, RN, MSN, PNP-BC*  
*Davonna Ledet, RN, MBA, DNP, FNP-BC, CNRN*  
*Namrata Shah, MD, FRCPC*  
*(Memphis, TN)*

## **Conference Poster Presentation Abstracts**

### **160. Glut1 Transporter Deficiency presenting as Alternating Hemiplegia of Childhood**

*Ward K (Memphis, TN), Ledet D, Shah N*

GLUT1 is a rare metabolic disorder characterized by low cerebrospinal fluid (CSF) glucose level caused by decreased activity of the glucose transporter protein. The typical presentation is that of infantile-onset refractory epilepsy, movement disorder, developmental delay, and acquired microcephaly. This presentation highlights a case of Glut1 deficiency with recurrent transient hemiparesis and focal dystonia as the presenting symptoms.

A 3 year old male first presented at 27 months with transient hemiparesis and focal dystonia. He was born full term and had normal growth and development with mild expressive speech delay. At his initial presentation, differential diagnoses included transient ischemic attack and seizure with postictal weakness. Neuroimaging was normal (MRI and MRA); his EEG showed mild left posterior slowing. Over the next four months, he had three similar episodes of transient hemiparesis. Symptoms were at longest 2-3 hours and his exam was normal other than a mild ataxic gait. Investigations and genetic studies for AHC were sent including ATP1A2, SCN1A, CACNA1A2, plus SLC2A1, all of which were normal except a variant of SLC2A1. CSF studies revealed aglucose of 33 with a corresponding serum glucose of 74 (ratio 0.44). The diagnosis of Glut 1 transporter deficiency was confirmed and the ketogenic diet was started. He has not had any further episodes of hemiparesis or dystonia since being on the ketogenic diet and continues to have developmental progression.

**CONCLUSIONS:** GLUT1 deficiency is a unique, treatable metabolic encephalopathy with varied clinical presentations. High index of suspicion and CSF studies for glucose levels should be performed in children with alternating hemiplegia of childhood and focal dystonia. This case highlights the importance of early recognition, diagnosis, and treatment of this rare disorder in a child with recurrent hemiparesis and dystonia.

### 161. Patient Engagement in the Research Process

*Duffy L (Boston, MA)*

**OBJECTIVE:** The purpose of this study was to gain knowledge that can be applied to the development of a decision support tool to better aid families of children and adolescents with pediatric onset multiple sclerosis (POMS) in the decision-making process surrounding disease-modifying therapy. This study utilizes the approach supported by PCORI of engaging patients in each phase of the research process to help improve patient outcomes. The specific aim of this study was to describe the experience of decision making related to the use of disease-modifying therapy in patients with POMS and their parents.

**METHODS:** Focus groups were conducted with four populations; 1) young adolescents ages 12 to 15 years with POMS, 2) adolescents ages 16 to 18 years with POMS, 3) young adults ages 19 to 24 years with POMS, and 4) parents of children ages 12 to 24 years who have a diagnosis of POMS. Participants were recruited from a pediatric MS clinic at an urban quaternary academic medical center.

**RESULTS:** Data collection is currently ongoing. Analysis of the data obtained from the focus groups will include: Field notes about the environment, and participant observation, context, and tone will be added, In vivo codes will be identified and a codebook will be developed. Similar codes will be clustered, content validity will be assessed by initial focus group participants and also a group of multidisciplinary content experts

**CONCLUSIONS:** Findings from this study will inform the development of educational resources and a decision-making support tool to facilitate shared decision making regarding disease modifying therapy in POMS. Patient-reported outcome measures will be used to

evaluate the effectiveness of the decision support tool. Findings from this study can be generalizable to a variety of chronic conditions that would benefit from patient engagement in the decision making process.

### **162. New Seizure Diagnosis: Educating the Caregivers**

*Atkinson C (Boston, MA), Kelly T, Duffy L*

**OBJECTIVE:** To develop a process of providing consistent, relevant information to caregivers of children with seizures. To initiate routine interventions using skills and teach-back to assure caregivers understand the diagnosis, seizure first aide, and medication administration and potential side effects prior to discharge.

**BACKGROUND/SIGNIFICANCE:** A new multidisciplinary approach to Quality Assurance/Performance Improvement (QAPI) was undertaken several years ago. A leadership triad of physician, nurse and MPH support specialist met with representative clinical stakeholders in inpatient and outpatient settings. The goal was to identify one area of clinical care we could improve to benefit our patients and families.

**FINDINGS:** Patient education provided at the time of new seizure diagnosis was chosen because of its high volume and increased risk for calls to outpatient before first followup visit, return to the emergency department, readmission and medication side effect. The educational materials currently used were reviewed, edited and supplemented with additional materials. A dynamic checklist tool "Ticket Home" was utilized to track the completion of each aspect of the education provided.

**IMPLICATIONS/NEXT STEPS:** The result is an educational packet of consistent materials, supplemented by unique materials such as medication information sheets, provided to all families of children with diagnosis of new onset seizure. At time of follow-up visit, a RedCap survey was administered to measure retained knowledge and query regarding the usefulness of materials distributed. Based on the response, the materials were again modified and edited and the second cycle of review is underway. One topic, SUDEP, originally omitted is now included at the physician's discretion. This educational packet has now been available in the outpatient Epilepsy and Neurology settings for both new and established patients and in the inpatient setting for established families requesting a refresher.

### **163. Initiative to Prevent EEG Lead-Related Pressure Ulcers**

*Atkinson C (Boston, MA), Quigley S, Hamilton S*

**OBJECTIVE:** To develop a process for prevention of skin breakdown in patients undergoing continuous EEG monitoring. To initiate routine interventions in the management of patients on continuous EEG monitoring.

**BACKGROUND/SIGNIFICANCE:** Availability of medical technology to support clinical care can lead to increase usage and in some cases extending the duration of continuous electroencephalogram monitoring. In some instances monitoring is interrupted

for testing, such as MRI, and resumed thereafter. Adverse effects of prolonged testing and the removal and reapplication of leads, are pressure ulcers and other skin-related issues.

**FINDINGS:** In response to a pressure ulcer event, a multidisciplinary team, now referred to as the “EEG Skin Task Force”, convened to review prior adverse event reports and current practice. The group determined the guideline for managing patients on EEG monitoring could be revised to include more specific steps the technologist, nurse and physician could institute to prevent skin injury while maintaining the quality of studies. A policy and procedure was adopted and hospital- wide education was rolled out with the support of the Skin SME and EEG Skin Task Force. Communication has improved through the use of a Power Form tool in the patients’ electronic medical record.

**IMPLICATIONS/NEXT STEPS:** The change in practice has improved awareness in the clinical providers of the vulnerability of patients on continuous monitoring. The number of EEG lead skin- related events has decreased. A 100% review of all continuous EEG monitoring is done weekly for adherence to the updated policy and shared with the staff. A risk cause analysis is done on all reports of EEG lead skin issues. The technologists continue to explore available products and setup techniques. And as a team, thoughtful review of extended studies is discussed. The EEG Skin Task force will continue to meet quarterly.

#### **164. Improving the Hospital Experience for Individuals with Intellectual Disabilities**

*Atkinson C (Boston, MA), Marti C, Pixley L*

**OBJECTIVE:** Development of a process to proactively prepare not only the care team, but the patient and family for the medical experience. Initiate a preadmission screening for patients identified by the provider as aggressive or possibly behavioral. Formulate and institute an individualized plan of care.

**BACKGROUND/SIGNIFICANCE:** An increasing number of cognitively challenged and impaired children, including children on the autism spectrum, are elective admissions to our Inpatient Neuroscience and Epilepsy Monitoring Unit to facilitate diagnostic evaluation. Our response to behavioral issues was crisis intervention mode.

**METHODS:** The admission coordinator who activates the request notifies the outpatient clinical team and a chart review is completed. The information obtained at this phase is shared with a core inpatient clinical team and triaged for a telephone interview by either the behavioral response team (BRT) or child life specialist (CLS). This contact establishes a relationship with the caregivers and a mutually developed behavioral plan, as well as a crisis management plan for the duration of the hospitalization is prepared and entered into the EMR.

**FINDINGS:** Understanding unique triggers and de-escalation techniques for the individual has improved the patient experience in the medical environment. Although the intensity of resources and additional preparation and training to care for this patient population was identified by the care team of nurses (RN), technologists and CLS, our success rate accomplishing the goals for admission have improved substantially.

**IMPLICATIONS/NEXT STEPS:** For the program, this quality improvement project developed a process to proactively prepare not only the care team, but patients with

intellectual disabilities and their family, for the medical experience. The process has improved patient and staff safety, improved the overall hospital experience and resulted in staff and family satisfaction.

### **165. Comprehensive Care and Management of Leigh Syndrome at the UT Mitochondrial Center of Excellence**

*Minor L (Houston, TX), Williams S, Adejumo R*

**OBJECTIVE:** To review the clinical presentation, neuroimaging findings and management of patients with genetically confirmed Leigh syndrome at a comprehensive Leigh Syndrome clinic.

**FINDINGS:** We reviewed the clinical presentations, imaging findings and management of 15 genetically confirmed Leigh syndrome patients followed at the University of Texas Mitochondrial Center of Excellence Leigh clinic. Of our 15 patients, 9 were male and 6 were female. The age of first symptom onset was birth in 6 (40%), less than two years in 4 (26%), and more than three years in 5 (33%). The most frequent presenting symptoms were hypotonia (n=11, 73%), developmental regression (n=11, 73%), hypertonia (n=4, 26%), and ataxia (n=4, 26%). Genetic studies showed mitochondrial DNA mutations in 11 and nuclear mutations in 4. MR findings included lesions in the brainstem in 7 patients (46%), basal ganglia in 12 (80%), thalami in 3 (20%), cerebellar white matter in 2 (13%), and global atrophy in 2 (13%). Medical life-saving interventions were needed for 7 patients (47%). Gastrostomy tubes were placed in 7 (47%) and 5 out of 15 (33%) required supplemental oxygen with 2 (40%) of these involving mechanical ventilation. Each of these cases required substantial nursing intervention and coordination.

**CONCLUSIONS:** Leigh syndrome is a devastating neurodegenerative disorder with multi-system involvement requiring comprehensive nursing management. Historically it is described as presenting in infancy with death by 2 years. Diverging from the classic descriptions, we found a significant proportion of patients presenting after the third year of life (33%). Nursing coordination increased dramatically in those surviving beyond the previously described life expectancy. As expected by their presentation, the majority of patients with Leigh syndrome and diagnosed and managed in a pediatric neurology setting making it imperative that neurology nurses are familiar with the management of this condition.

### **166. Cardiac Neurodevelopment - Good Fit for a Neurology APN Clinic**

*Greene-Roethke C (Wilmington, DE)*

With medical and surgical advances, babies with congenital heart disorders are now living well in to adulthood, meaning that the focus of care needs to shift from survival to quality of life. Recent investigations have highlighted the many potential neurologic complications that may accompany congenital heart disease and their impact on childhood development. I partnered with the Developmental Psychologist who performs assessments for research within our cardiac surgery program to launch a neurodevelopmental program that was

instituted in our hospital two years ago. The program combines neurology assessments at the bedside and outpatient, family support and education that begin in the perioperative stage, and ongoing neurodevelopmental evaluations with a team that includes Therapists and Dieticians. Anecdotally, parents report greater satisfaction and professionally we feel we are contributing positively to the body of knowledge in this area.



## 8th Annual Research Fund 5K Run/3K Walk



Dear ACNN Conference Attendees, Members and Friends:

Please join your colleagues for some fun and exercise and support an important ACNN initiative, the **Elizabeth F. Hobdell Nursing Research Grant**.

Run or walk 3K or 5K (3 miles). The minimum entry fee is \$20. Donate this money yourself and/or obtain sponsorship pledges. If you are unable to participate in this event, you can sponsor a colleague. Donations/pledges/entry fees are tax deductible through the Child Neurology Foundation.

You and your sponsors can donate online or by check or cash at the ACNN/CNS meeting. Completed pledge forms and money/checks can be brought with you on the day of the run/walk. Please make checks out to "CNF/ACNN nursing research grant".

To continue to offer the nursing research grant on an annual basis we need to contribute to the fund. Thanks for your support!

**Who:** Anyone who is willing and able to participate

**What:** 3K/5K run/walk

**When:** Thursday, October 8, 2015 at 4:30pm

**Where:** Meet the route leaders and get a map in the lobby of the Gaylord National Resort & Convention Center

**Why:** Raise funds for the CNF/ACNN Nursing Research Grant

**Requirements:** All participants must bring a \$20 minimum donation, be physically fit and able to safely participate, sign a waiver prior to participation and wear appropriate shoes and clothing for a 5K run or 3K walk.

Gretchen Heckel, RN  
Director, ACNN Research Committee  
Children's Hospital of Wisconsin  
gheckel@chw.org

## Keeping Connected Upcoming Conferences

### 6th Oxford Neurology Course

July 6 - 8, 2015

Oxford, United Kingdom

### 9th Baltic Sea Summer School on Epilepsy 2015

August 2 - 7, 2015

Sigulda, Latvia

### Mayo Clinic Headache Symposium 2015

August 7-9, 2015

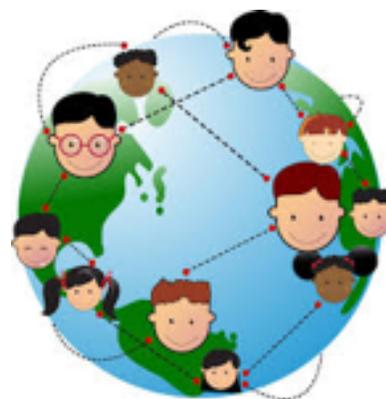
San Francisco, CA, United States

### 2015 Neurology Update - A Comprehensive Review for the Clinician

August 7 - 9, 2015

Washington, DC, United States

### 12th World Congress in Inflammation 2015



August 8 - 12, 2015  
Boston, MA, United States

**2nd World Congress on NeuroTherapeutics (DDDn), Dilemmas, Debates, Discussion**

September 3 - 6, 2015  
Prague, Czech Republic

**Epilepsy Congress Istanbul 2015**

September 5 - 9, 2015  
Harblye, Turkey

**44th Annual Child Neurology Society Conference**

October 7-9, 2015  
Washington, DC, United States

**69th American Epilepsy Society Annual Meeting**

December 4-8, 2015  
Philadelphia, PA, United States

# Christopher Ward Neuroscience Nursing Conference



The Christopher Ward Neuroscience Nursing Conference will be held August 6-7, 2015 by the Children's Hospital Colorado. Video conference sites:

Children's Hospital of Wisconsin and Casper, Wyoming

To register for either Colorado or one of the video conference sites please go to:

<http://www.childrenscolorado.org/events-community/events/christopher-ward-neuroscience-nursing-conference>

# Save the Date - Neuroscience Nursing Conference - Hot Topics in Paediatric Neuroscience

Save the Date: March 4, 2016 for the Neuroscience Nursing Conference – Hot Topics in Pediatric Neuroscience. To be held at Nationwide Children’s Hospital in Columbus OH. More information in the next issue of Currents.



## Newsletter Submissions

Staying connected with our community of paediatric neurology nursing colleagues is one of the primary reasons we joined ACNN. The annual conference is one way to us to gather and network. The website provides some updates and information on awards, research grants and a listing of members. The newsletter is a quarterly modern of communication that offers us the opportunity to share our experiences, accomplishments, and to teach others.



The deadline for the **Fall edition of ACNN Currents is September 10, 2015.** It is my hope as the Chairperson of the

Communications Committee and editor of this newsletter, that you submit something to ACNN Currents to share and showcase. It up to you to make ACNN a stronger, better organization. Play your part, submit. All submissions can be sent to [maria.zak@sickkids.ca](mailto:maria.zak@sickkids.ca).

