

ACNN Currents



Winter Edition 2016



President's Message



Dear colleagues,

ACNN continues to grow. Over 80 child neurology nurses attended this year's annual meeting. I really enjoyed meeting many nurses whom I had known only through email contacts. I know we can all get bogged down in the often overwhelming amount of work we do. The meeting is a terrific opportunity to get reenergized, learn, and **CONNECT** with nurses who understand what you are all about.

Speaking of **CONNECT**, we can all now connect through the **CONNECT** function of the ACNN/CNS website. Any ACNN member can post a question, share a new resource, and reach out for support with a new challenge.

Please go to the CNS home page, www.childneurologysociety.org

Click on **View CNS Connect**; it's in the lower right of the photo at the top of the home page.

Then choose the Communities tab. Pick **My Communities** from the drop down tab.

Click on **ACNN** and then **ENTER**.

Now you are ready to post. I'm asking all ACNN members to take the time this month to post. I would especially appreciate hearing from you about what worked for you at the meeting and what needs improvement. If you didn't attend, what would entice you to attend next year?

My goal for the winter is that every ACNN member will send a post through **CONNECT**.

The first member to post gets a \$25 reduction in the registration fee for next year's meeting. Ready, set, post!

Hope to see you in Vancouver next year, October 26 through October 28, 2016.

Maureen Sheehan, CPNP

President ACNN

Meet the Board

Introducing your new Board Members:

Gretchen Heckel, RN

Position on Board: Director of Outreach, Development and Research

Where I Work: Children's Hospital of Wisconsin

Specialty: neuromuscular

Goal: To improve outreach to current members and new membership approval as well as increase awareness/communication regarding the research grants

Fun Fact: I have gone skydiving three times and I love to sew when I have time.



Nicole M. LaMarca, DNP, MSN, CPNP, PMHS

Position on Board: Treasurer

Where I Work: Columbia University

Specialty: neuromuscular disease

Goal: Manage and maintain the finances for ACNN

Fun Fact: I love going to Pinterest during my commute home from work!!!

Jo Ellen Lee, APRN

Position on Board: Secretary

Where I Work: Nationwide Children's Hospital, Section of Neurology

Specialty: Headaches and stroke

Goal: As Secretary my goal is to keep adequate records and help with the publication of the Currents. I plan to keep records up to date and disseminate appropriate information to membership

Fun Fact: I worked as a nurse in Yellowstone National Park

Maureen Sheehan, CPNP

Position on Board: President of the Association of Child Neurology Nurses

Where I Work: Packard Children's Hospital at Stanford

Specialty Clinics: Epilepsy, ketogenic diet, CBIT for tics

Goal: Through updating the website and using the Connect group conversation function, make ACNN the group to join for the latest in all things child neurology nursing.

Fun Fact: Prior to becoming a nurse in my 40's, I had many careers. Maybe the most unusual was the years I spent teaching sign language to Koko the gorilla. And yes, she really can sign!

Rhonda Roell Werner, MS, APNP, PCNS-BC

Position on Board: Liaison with the Awards and Clinical Practice Committees

Where I Work: Children's Hospital of Wisconsin

Specialty: Pediatric Neuroscience Center and Epilepsy Monitoring Unit

Goal: Child neurology nurses are the key team members that foster adaptation of a child and their family to their neurologic condition through support, education, care coordination, and research. My vision for child neurology nursing is a discipline that develops the standards of nursing care for children with neurologic conditions and their families. I would like to see ACNN grow as THE professional practice resource for nurses who work in pediatric neurology.

Fun Fact: I was the first baby delivered by the GP in our small town in Illinois. I was invited back for his retirement dinner a few years ago.

Sue Yudovin, RN, MN, CPNP

Position on Board: Director

Where I Work: UCLA

Specialty: Pediatric epilepsy surgery, concussion/TBI

Goal: My goal is to recruit new members in general, but specifically to the board.

Fun Fact: I love dogs!!!

The 2015 ACNN Claire Chee Nursing Excellence Awardee - Nancy Elling, RN

By Amy Vierhile,

Nancy Elling, RN is the recipient of the 2015 Association of Child Neurology Nurses Claire Chee Nursing Excellence Award. She is currently the clinical coordinator of the Neuroscience Program at Children's National Medical Centre in Washington, DC, where she has worked since 1999. her duties include coordinating outpatient services in a variety of neurology clinics including clinics for patients with tuberous sclerosis, new onset seizures, VNS devices, myelin disorders, and general neurologic diagnoses.

Ms. Elling was nominated for the award by Dr. Phillip Pearl who worked with her for over 20 years. Dr. Pearl describes Nancy as possessing a "caring optimism for each and every child neurology patient and family." She is touted as having "unlimited energy and empathy" and has both created and run numerous programs at Children's National over the past 16 years.

The first ketogenic diet program at Fairfax Hospital was established with Dr. Pearl and Ms. Elling. She also helped create the specialty clinics listed above. Dr. Pearl lists Nancy's primary focus as the Tuberous Sclerosis Clinic which she established at Walter Reed Army Medical Center and then Children's National. Nancy has been running quarterly Saturday morning clinics for years at no charge to families, and she has managed to gather the services of numerous specialists from multiple disciplines who coordinate services for every family. She has continued this clinic for over 20 years. In addition, Nancy has organized the Children's National site of the Tuberous Sclerosis Alliance National History Database Project in 2007. She has served on the Research Council of the National Tuberous Sclerosis Association, National Board of Directors and Professional Advisory

Board of the Tuberous Sclerosis Alliance, as well as on the Professional Advisory Board of the Epilepsy Foundation Association.

Nancy has numerous certifications: as a Certified Neuroscience Nurse, Certified Pediatric Nurse, Certification in INOVA Chemotherapy and in INOVA ECG. She is instrumental in the education of nurses and medical students and is currently a member of the Association of Neuroscience Nurses, the American Headache Society, ACNN, and the Tuberous Sclerosis Alliance. She also served as a member of the Tuberous Sclerosis National Clinic Committee in 2010. Nancy has acted as a Sub-investigator on numerous research studies on topics ranging from on-site and childhood headaches to the use of a medication to treat Subependymal Giant Cell Astrocytomas associated with Tuberous Sclerosis Complex. She has also co-authored several publications.

The Association of Child Neurology Nurses is proud to honour Nancy for her dedication to the care of children with neurologic disorders. She is truly deserving of the Nursing Excellence Award and exemplifies all of the ideal qualities exhibited by Claire Chee, the RN for whom the award is named.

The ACNN 2015 Nurse Practitioner Excellence Awardee - Regina Laine, CPNP

By Amy Vierhile



The Association of Child Neurology Nurses is pleased to honor Regina Laine with the 2015 Nurse Practitioner Excellence Award. Gina is a Paediatric Nurse Practitioner who has worked at Children's Hospital in Boston since 2007. She currently works in the Neurology Division in an urgent care clinic, and also has experience with procedures such as lumbar punctures, skin biopsies and baclofen pump refills.

Gina was nominated for the award by Dr. Maitreyi Mazumdar, a colleague at Boston Children's Hospital. Dr. Mazumdar describes Gina as "a remarkably gifted nurse who combines a caring approach with a skill she has fashioned in the art of the paediatric neurologic examination." Gina works diligently to expand her knowledge base and she worked closely with neurology administration to revamp the expedited access issue in child neurology. As a result of these changes, NPs are now performing lumbar punctures on sedated patients during MRIs and the process for managing those specimens following collection has been changed, which has resulted in reduced errors in handling and testing. Gina also played an active role in establishing the Brain Injury Center in 2011 and remains as a member of the steering committee. She has assisted in creating clinical algorithms for the concussion clinic which have resulted in shorter appointment wait times for patients and in the hiring of additional nurse practitioners to staff the concussion clinic.

As a result of her efforts, Child Neurology patients who need to be seen urgently but not emergently are triaged by Gina and seen in an urgent care clinic. She sees each patient and works under the supervision of the attending physician on the consult service. Providing this service to the division has resulted in increased satisfaction on the part of both patients and Child Neurology physicians.

She has assisted in the training of nine nurse practitioners in Child Neurology and has ensured that all of them are fully trained in neurology. Gina seeks out educational opportunities whenever they arise and has been instrumental in planning and presenting educational offerings on caring for patients with traumatic brain injury. Gina has precepted numerous nurse practitioner students over the past five years. She is the recipient of the Allen Cohen and Scott Pomeroy Neuroscience Nursing Award 2015 and received the Neurology "Round of Applause" in 2010.

Dr. Mazundar noted that Gina's proficiency and skill in examination and treatment has led even the most skeptical of physicians to recognize the importance of the nurse practitioner role in Child Neurology. It is clear from Gina's dedication to her patients and institution that she is a role model for nurse practitioners and is very deserving of the ACNN 2015 Nurse Practitioner Excellence Award.

ACNN Conference Clips

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 Hutchison, MSN, RN, CPNP, PPCNP-BC

Take Away Message: Although the statistics don't knock us over with staggering numbers, drug related hair loss (alopecia) in our patients can be emotionally unsettling for both patients and families. While research among the pediatric population is lacking, research in adult epilepsy patients finds that adults with epilepsy are willing to sacrifice some degree of seizure control in exchange for a reduction in hair loss or other cosmetic effects. (Lloyd, McIntosh & Price, 2005). Would we expect fewer concerns among our adolescent population? Do families of neurologically impaired children have fewer concerns? We won't know unless we ask. Thinking of recommending a supplement for hair loss? Supplements can have many interactions. If you are not well versed in their use, or have a medically complicated patient, please consider a nutritional consultation.

References:

Chen, B., et al. (2015). Cosmetic side effects of antiepileptic drugs in adults with epilepsy. *Epilepsy & Behavior*, 42:129-137.

Lloyd, A., McIntosh, E., & Price, M. (2005). The Importance of Drug Adverse Effects Compared with Seizure Control for People with Epilepsy A Discrete Choice Experiment. *Pharmacoeconomics*, 23(11): 1167-1181.

Patel, M., Harrison, S., & Sinclair, R. (2013). Drugs and Hair Loss. *Dermatology Clinics*, 31:67–73.

Resources:

https://www.nlm.nih.gov/medlineplus/druginfo/herb_All.html

<https://ods.od.nih.gov/factsheets/list-all/>

I Feel Dizzy; A Clinical Approach to Evaluation

Mona Jacobson, MSN, CPNP-PC

Take Away Message: It is important to determine what is meant by “feeling dizzy” when this is the chief presenting complaint. Once determination of what “dizziness” means to the child then an algorithm can be followed to help determine a diagnosis. The 3 main areas of diagnosis for dizziness are: syncope, vertigo and ill defined dizziness. The most common etiology of vertigo in children is migraine headache and benign paroxysmal vertigo of childhood. Postural orthostatic tachycardia syndrome is associated with ill defined dizziness.

Recommended References:

Syed, M.I., Rutka, J.A., Sharma, A., & Cushing, S.L. (2014). The ‘dizzy child’: a 12-minute consultation. *Clinical Otolaryngology* 39,228-234.

Jahn, K., Langhagen, T., & Heinen, F. (2015). Vertigo and dizziness in children. *Current Opinion in Neurology*, 28,78-82.

Resources:

<https://pedclerk.bsd.uchicago.edu/page/vertigo>

ESES/CSWS (Electrical Status Epilepticus of Slow Wave Sleep): Beyond Landau-Kleffner Syndrome

Rhonda Roell Werner, MS, APNP, PCNS-BC

Take Away Message:

- ESES/CSWS is likely a spectrum of epileptic encephalopathies
- Consider ESES in a patient who has a decline in any area of language, learning, behavior or attention.
- May be prudent to consider steroid therapy earlier in management of ESES.

Recommended References:

Fortini, S, Corredera, L, Pastrana, AL, Reyes, G, Fasulo, L, & Caraballo, RH. (2013).

Encephalopathy with hemi-status epilepticus during sleep or hem-continuous spikes and waves during slow sleep syndrome: A study of 21 patients. *Seizure*, 22, 565-571.

Hughes, JR. (2011). A review of the relationships between Landau-Kleffner syndrome, electrical status epilepticus during sleep, and continuous spike-waves during sleep. *Epilepsy & Behavior*, 20, 247-253.

Van den Munckhof, B, van Dee, V, Sagi, L, Caraballo, RH, Veggiotti, P, Liukkonen, E, Loddenkemper, T, Fernandez, IS, Buzatu, M, Bulteau, C, Braun, KPJ, & Jansen, FE. (2015).

Treatment of electrical status epilepticus in sleep: A pooled analysis of 575 cases. *Epilepsia*. doi: 10.1111/epi.13128

Concussion in the Pediatric Patient: An Update

Elaine Phillipson, MS, PPCNP-BC

Take Away Message: Research is being done only on concussion in sport and care for children with concussions of all types is being extrapolated from that. There is not much strong evidence-based data to support care given. Providers caring for children with concussions should be very aware of the particular vulnerabilities that children, especially teens, have to serious complications of concussion and plan care and recommendations around these vulnerabilities using the best evidence available to date

References:

Harmon, et al. American medical society for sports medicine position statement; concussion in sport. *Br J Sports Med* 2013, 47, 15-26

Giza, et al., Summary of evidence-based guideline update: evaluation and management of concussion in sports: Report of the guideline development subcommittee of the American Academy of Neurology. *Neurology* 2013, 80, 2250-2257

Resources:

McCrary, et al. Consensus statement on concussion in sport – the 4th international conference on concussion in sport held in Zurich, November 2012. *Br J Sports Med* 2013, 47, 250- 258

http://www.cdc.gov/traumaticbraininjury/get_the_facts.html

Understanding the Ketogenic Diet

Elaine Phillipson, MS, PPCNP-BC

Take Away Message: The ketogenic diets offer another hopeful treatment option for families with children struggling with epilepsy. Though not easy, the different ketogenic diets can use the body's metabolism to create a metabolic environment less conducive to seizure propagation. Nurses provide essential support for these families and need to understand how the diet works to provide

this support accurately. A good understanding of normal and ketogenic metabolism is instrumental in providing complete epilepsy care in a child neurology practice.

References:

Freeman, JM, Kossoff, EH, Rubenstein, JE & Turner, Z. *Ketogenic Diets: Treatments for epilepsy and other disorders, 5th edition*. Demos Medical Publishing: New York, 2011

Zupec-Kania, B Professional's Guide to the Ketogenic Diet. *Protocols for the initiation and management of the ketogenic diet*, 2008.

Resources:

www.charlifoundation.org

Up in Smoke: Cannabis for Pediatric Epilepsy

Maureen Sheehan, RN, MS, CPNP

Summation: There is a lack of evidence to support the use of cannabis for epilepsy. Trials are being attempted. As with all treatments, the individual family and child's risk:benefit ratio for that treatment is paramount.

Recommended References:

Friedman, D., & Devinsky, O. (2015). Cannabinoids in the Treatment of Epilepsy. *New England Journal of Medicine*, 373(11), 1048-1058.

Rosenberg, E. C., Tsien, R. W., Whalley, B. J., & Devinsky, O. (2015). Cannabinoids and Epilepsy. *Neurotherapeutics*, 1-22.

Resources:

www.westword.com/news/charlottes-web-untangling-one-of-colorados-biggest-cabbabis-suces-s-stories

www.aap.org American Academy of Pediatrics website: lots of up-to-date info on drugs, both legal and recreational, and drug trials

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

The fun run was a success this year. We raised \$500 for nursing research. We are excited to be able to support nursing growth through our Elizabeth F. Hobdell Nursing Research Grant. As grants are approved we will be updating you through the Currents newsletter. Thank you to all who donated and to all who joined us for the run/walk.



Research Grant

Research- Applications for the research grant will eventually be done on the website. At this time applications should be sent to Gretchen Heckel via email at gheckel@chw.org. Criteria that must be met are IRB approval, an itemized account of what the money being requested is going to be used for, and a summary of the research project and goals. Please see the application guidelines below.

GUIDELINES FOR FUNDING REQUESTS FOR ELIZABETH F. HOBDELL ACNN-CNF NURSING RESEARCH GRANT

1. Research funds will be allocated yearly for a 1 year award with final amount of award determined by ACNN and CNF. Reapplication will be necessary if the study exceeds 1 year.
2. Fundable projects will focus on pediatric neuroscience care issues within the scope of nursing practice for the country in which the study will be performed.
3. The primary investigator(s) must be a member in good standing in ACNN in the preceding and current year.
4. Research proposals must include:
 - A. Title of Proposal
 - B. Names and qualifications of the principal and co-investigators
 - C. Abstract of 250 words including significance of study
 - D. Purpose, hypothesis, questions of the project
 - E. Brief Background Literature review
 - F. Methodology including sample, procedures, data analysis
 - G. Evidence of Ethics/IRB approval
 - H. Budget and time frame
 - I. Amount requested
5. The completed research application form, a written letter of request, and research proposal should be submitted to the chairperson of the research committee.
6. The research committee will review the proposals and present qualified proposals to the ACNN Board of Directors for approval.
7. Grants are awarded throughout the year and recognized at the annual ACNN.
9. Progress reports must be submitted to the research committee in writing each quarter. A final report will be required for presentation at the annual Board of Directors meeting (at the annual conference). If the study is not completed within the 1st year of receiving the award, a progress report will be submitted to the Board of Directors. The final report must be presented to the Board of Directors within two years of receiving the award.
10. Results must be presented at the annual ACNN meeting within 2 years of completing the study.
11. Research should be submitted for publication within 2 years of the end of the project.

Membership Update

Membership application/renewal is all done online. Access <http://www.childneurologysociety.org/acnn> and click on the “click here to become a member” button. There are 3 types of membership categories: active, student, or associate member:

Active: registered nurse or nurse practitioner - \$ 75/year

Associate: LPN, LVN, PA, allied health professional - \$ 60/year

Students: \$ 25/year - NOTE: RNs who are undertaking nurse practitioner studies are considered active members

MEMBERSHIP BENEFITS

- Annual conference registration discount
- Access to online information including member contact information for networking (including participation in special interest groups such as ketogenic diet, headache, etc), quarterly newsletter, professional resources and annual conference presentation slides
- Regional meetings of ACNN members
- Eligibility to apply for a Child Neurology Society Education Travel Award for ACNN Members
- Eligibility to apply for the Elizabeth F. Hobdell Nursing Research Grant
- Eligibility for the Claire Chee Award for Excellence in Child Neurology Nursing
- Eligibility to apply for the Innovative Clinical Practice in Child Neurology Nursing Award
- Professional development through participation on committees that advance the goals of the organization

2016 Meetings of Interest

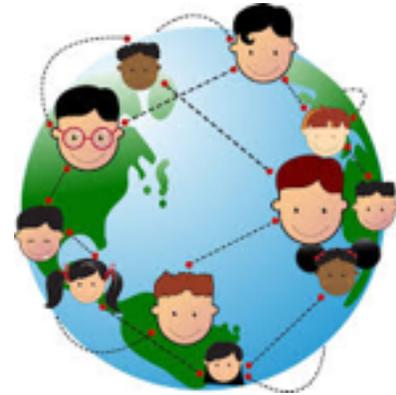
Pediatric Neuroscience Nursing Symposium

March 4, 2016

Nationwide Children's Hospital

Columbus, OH

<http://www.nationwidechildrens.org/Courses-Conferences>



Partners Against Mortality in Epilepsy Conference

June 23-26, 2016

The Westin Alexandria

Alexandria, VA

<http://pame.aesnet.org>

The Fetal Medicine Institute of Children's National presents

The Inaugural International Symposium on the Fetal Brain

September 15-16, 2016

The Fetal Medicine Institute at Children's National

Washington, DC

<http://childrenational.org/news-and-events/event-calenda/for-providers/international-symposium-on-the-fetal-brain>

Fifth Global Symposium for Ketogenic Dietary Therapies-Treating Epilepsy, Brain Cancer, Autism & Cognitive Disorders

September 20-24, 2016

Banff Springs Hotel

Banff, Alberta, Canada

www.ketoconnect.org

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 **Spring edition of ACNN Currents is March 15, 2016**. 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.