Get Caught in the Web
New ACNN Website Coming in 2014!

Submitted by Maureen Sheehan

As part of the new shared business management of the Association of Child Neurology Nurses and the Child Neurology Society, the website for ACNN will be rebuilt. Work has begun. Now we need your ideas. Dream big: in the perfect world what do you want to see on the ACNN website? Suggestions so far include CE content, list of all members, online interest groups like the ketogenic diet, and content for parents.

Please email your ideas to Maureen Sheehan, CPNP at Lucile Packard Children’s Hospital at Stanford, at msheehan@lpch.org

I would love to have some volunteers to be on a website committee with me! Apple users especially sought as I am a PC person.

Thanks!
Happy New Year! I am excited to begin my term as your ACNN President. I would like to thank all the Board Members, Committee Chairs and Committee Members who volunteered many hours in 2013 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 2014. We are now working with the Child Neurology Society who has taken over our management from Blue Chip Management.

You will see many changes in the coming months. The first major change is the renewal process. We will no longer be using Pay Pal for renewals and payments. CNS only uses credit cards and checks so we will make that change. Also the renewal period will be from January to December. Renewal packets will be going out shortly if not already by time you receive this. The next big change will be the website which is currently being upgraded which really needed a new facelift. You will 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 to help with the programs we do throughout the year. Please look at the renewal packet with the descriptions of each of the committee’s job descriptions.

There will be a regional meeting at Nationwide Children’s, Columbus, Ohio in the spring. I encourage other regions to have a meeting in their area to serve more nurses working with children with neurologic disorders that can not make it to the annual conference. ACNN has a small startup allowance to help with your conference.

I encourage everyone to take an active role in our organization. Think about submitting an abstract for this year’s meeting, or nominating a nurse for one of our many awards. Each of you has a gift to share with others. We also have some funding for small research projects that you may be thinking about doing. Don’t be afraid. Your Board of Directors and the committees are here to help you succeed.

I wish you a healthy and successful 2014 as you continue working with children and families living with neurologic disorders and helping them improve their lives.

Sincerely,
Kathy O’Hara
ACNN President
kohara@mcvh-vcu.edu
Hi ACNN members! We are in the full swing of winter, but it is amazing how fast the next ACNN conference will arrive. Our conference this year was in Austin, TX and was educational and fun. There was diversity in topics and each presenter brought their body of knowledge to share with us through their presentations.

The Janet Brucker Keynote address was delivered by Rebecca Schultz, PhD, RN, CPNP. Rebecca presented a topic that is common and complex to all of us. Her presentation was on transition of care from Pediatric to Adult Health care. Her presentation was very important especially in the climate of Health Care reform.

At our luncheon, Julie Sprague-McCrae presented data from a Pilot Survey Abstract on the ketogenic diet. This was very informative information for those who work with the ketogenic diet in their centers. Our SIG Group meetings were well attended and a variety of topics were discussed. I believe each of us gained some new piece of knowledge from one of our colleagues during this time.

Two of our members received awards for Excellence in Pediatric Neurology Care. Chelsey Stillman, PA-C was awarded the Innovative Practice Award for a program she developed called Seizure School-Simple but Significant. Cheryl Fischer, CPNP was awarded the Claire Chee Award for Excellence in Neurology Nursing. Congratulations to these two members for their contribution to Pediatric Neurology patients!

Our 5k Run/Walk was a success! Thanks to Maureen Sheehan for scouting out a route for us. Austin received several inches of rain the night before, but the sun came out the day of the run/walk. The monies raised from this event help fund research grants/awards.

If you were unable to attend this year’s conference, please consider attending the 2014 conference in Columbus, Ohio. It is a great time of networking and education. A call for abstracts will be going out soon. Please consider being a speaker and sharing your knowledge with your colleagues!
Squeeky Shoes and All...

2013 Fun Run A Success!

Despite a flash flood which washed out part of the trail the night before this year’s 3K/5K Fun Run/Walk in Austin, eight intrepid ACNN members persevered through muck and washed up flotsam and jetsam along the banks of Lady Bird Lake. We raised $510 for the ACNN Nursing Foundation. The Foundation supports travel grants for members attending the annual conference.

Thanks to the walkers and runners: Jennifer Boyd, Jayme Kagarice, JoEllen Lee, Mindy Mayer, Maureen Sheehan, Debbie Weaver, Courtney Wellman, and Jean Young.

Thanks also to those who pledged: Susan Caffey, Amy Harper, Patti Ogden, Kathy O’Hara, Ruth Shinnar, Adrienne Sinclair, Julie Sprague-McRae, and Ivanna Yau.

We are already planning the route for the 2014 Fun Run/Walk (emphasis on fun!) in Columbus, Ohio. See you there!
The recipient of the 2013 Association of Child Neurology Nurses Claire Chee Nursing Excellence Award is Cheryl Fischer, RN, MSN, CPNP. Ms. Fischer is currently a pediatric nurse practitioner at Memorial Sloan Kettering Cancer Center in the outpatient Child Neurology/Oncology Department. Cheryl began her career at Memorial Sloan Kettering Cancer Center on the inpatient unit in 2003 and after earning her Master’s Degree in 2006, she remained at the institution, moving into the outpatient clinic, seeing patients with a variety of pediatric Neuro-oncologic disorders. She has also recently joined the Neurofibromatosis clinic and has taken over the management of the Retinoblastoma clinic at her institution as well.

Cheryl was nominated by Dr. Yasmin Khakoo who describes her as “a true leader and a joy to work with, (her) clinical strengths include emergency neurologic care, end-of-life transitioning and education of patients and their families.” Other colleagues submitted testimonials describing Cheryl’s commitment to the care of children and her ability to individualize care and understand each child’s journey as a separate experience. She is praised for her calm and compassionate demeanor and her reassuring manner in dealing with families undergoing extraordinary stress. Cheryl’s knowledge in pediatric oncology allows her to independently function as a practitioner, delivering high quality care while incorporating the expertise of others into her daily practice. Several patients sent in recommendation letters as well. They describe Cheryl as meticulous and detail oriented with a drive to obtain the best care for her patients and their families. One mother stated that Cheryl treats her son “as if he is her only patient” and describes Cheryl as the “go to” person for any questions or concerns regarding her son’s neuro-oncology diagnosis.

In addition to her outstanding clinical care, Cheryl also finds time to act as a study coordinator for numerous clinical trials involving new treatments for childhood cancers and survivor revaccination. She has published several articles (one as first author) in peer-reviewed journals, presents posters and teaches classes, and Cheryl also precepts nurse practitioner students. Cheryl has even established a journal club for pediatric advanced practice nurses at her institution. She is a member of the Association of Child Neurology Nurses, NAPNAP and the Association of Pediatric Hematology Oncology Nurses.

It is apparent from the supportive letters submitted that Cheryl is an extremely valued member of the Child Neurology team at Memorial Sloan Kettering Cancer Center. Her colleagues were effusive in their praise of Cheryl and strongly recommended her for this award. It is with great honor that the Association of Child Neurology Nurses awards the 2013 Claire Chee Nursing Excellence Award to Cheryl Fischer.
Innovative Practice Award 2013
Chelsey Stillman, PA-C

Submitted by Amy Vierhile

The recipient of the Association of Child Neurology Nurses Innovative Practice Award was Chelsey Stillman, PA-C. Chelsey’s talk was entitled: Seizure Safety School- Simple but Significant. Her program involved teaching parents and children with newly diagnosed seizures about safety and helping to allay some of their fears. Chelsey is a Certified Physician’s Assistant at Children’s Hospital Colorado.

Share Your Innovative Practice
Innovative Practice Award 2014

The ACNN Award for Innovative Clinical Practice in Child Neurology Nursing was an award that was first granted in 2011. This award will recognize and honor annually an ACNN Member who has demonstrated and implemented an innovation in Child Neurology clinical practice. The recipient will receive a monetary award equal to the registration fee for the annual CNS/ACNN conference and be invited to submit a poster for display during the ACNN/CNS poster session.

The ACNN Award for Innovative Clinical Practice in Child Neurology Nursing is open to all current ACNN members in good standing, excluding Award Committee members and recipients of the award within the past three years. Applications for the Award for Innovative Clinical Practice in Child Neurology Nursing need to be submitted by an ACNN member who has been directly involved with the development and implementation of the innovation in Child Neurology clinical practice. Please go to www.acnn.org, enter the member’s only section and select the Awards tab for further details. Deadline for applications is March 14, 2014.
Tuberous Sclerosis Clinical Update

Submitted by Jo Ellen Lee


The 2012 International Tuberous Sclerosis Complex Consensus Group was comprised of 79 specialists from 14 countries. This group was further divided into subcommittees related to medical specialties. Each subcommittee was charged with reviewing prevalence and specificity of disease associated clinical findings and their impact on suspecting and confirming the diagnosis of tuberous sclerosis complex.

Tuberous Sclerosis complex (TSC) was described approximately 150 years ago by von Recklinghausen. TSC can be variable and affect multiple organ systems in the body with a variety of manifestations.

In this article the findings were reviewed. The clinical features of TSC continue to be the principle means of diagnosis. Key changes compared with 1998 criteria are the inclusion of genetic testing results and reducing diagnostic classes from three (possible, probable, and definite) to two (possible, definite). Additional changes were made for clarification and simplification.

These diagnostic criteria provide current, updated means using best available evidence to establish a diagnosis of tuberous sclerosis complex.
Bell Palsy
Clinical Update
Submitted by Jo Ellen Lee

Geller, T.J. (2013) Pediatric Bell Palsy: The Time is Ripe for a Clinical Trial
Journal of Child Neurology – Published online 16 December 2013
http://jcn.sagepub.com/content/early/2013/12/13/0883073813511860.

Recent reviews of Bell Palsy in the ENT and pediatric literature and a systematic
review published in 2010 suggested there might not be a difference for recovery
rate in treated and untreated pediatric populations with steroids, despite evidence
of effect in adults.
Dr. Geller is calling for a randomized controlled clinical trial to assess the utility of
using steroids for the treatment of Bell Palsy in the pediatric population. Data
concerning for severity of symptoms at onset, follow up and recurrence should be
included.

Children with Neuromuscular
Disorders
Quality of Life
Submitted by Jo Ellen Lee

Self-Report Quality of Life Questionnaire for Children with Neuromuscular
Disorders: Presentation of the Instrument, Rationale for Its Development and
Some Preliminary Results. Journal of Child Neurology –Published online 18 December
2013.
http://jcn.sagepub.com/content/early/2013/12/16/0883073813511859

This article reviews the development of the SOLE Questionnaire for neuromuscular
disorders (NMDs). The SOLE Questionnaire was utilized to assess the quality of life in
children aged 5-13 when compared to healthy children of similar ages. The SOLE
Questionnaire utilizes a visual and neutral approach. The authors report that it was “well
received, practical and rapid to administer and able to discriminate between patients and
controls.”
The most common NMD in the group was Duchene muscular dystrophy, followed by
Spinal muscular atrophy. The questionnaire took an average of 10 minutes to complete.
A comparison was made between the child’s perceptions of their quality of life and those
of their parents/guardians. There was poor agreement between the child and parent/
guardian in almost every item investigated.

This is a preliminary study for the presentation of the new questionnaire and the
rationale for creating it completed in Italy. The authors recommended further studies on
larger population cohorts to test the validity of the instrument. The SOLE Questionnaire
presents some new aspects for a quality of life scale for use in children.
Pretreatment cognitive deficits and treatment effects on attention in childhood absence epilepsy

Objective: To determine the neurocognitive deficits associated with newly diagnosed untreated childhood absence epilepsy (CAE), develop a model describing the factorial structure of items measuring academic achievement and 3 neuropsychological constructs, and determine short-term differential neuropsychological effects on attention among ethosuximide, valproic acid, and lamotrigine.

Methods: Subjects with newly diagnosed CAE entering a double-blind, randomized controlled clinical trial had neuropsychological testing including assessments of general intellectual functioning, attention, memory, executive function, and achievement. Attention was reassessed at the week 16–20 visit.

Results: At study entry, 36% of the cohort exhibited attention deficits despite otherwise intact neurocognitive functioning. Structural equation modeling of baseline neuropsychological data revealed a direct sequential effect among attention, memory, executive function, and academic achievement. At the week 16–20 visit, attention deficits persisted even if seizure freedom was attained. More subjects receiving valproic acid (49%) had attention deficits than subjects receiving ethosuximide (32%) or lamotrigine (24%) (p = 0.0006). Parental assessment did not reliably detect attention deficits before or after treatment (p < 0.0001).

Conclusions: Children with CAE have a high rate of pretreatment attentional deficits that persist despite seizure freedom. Rates are disproportionately higher for valproic acid treatment compared with ethosuximide or lamotrigine. Parents do not recognize these attentional deficits. These deficits present a threat to academic achievement. Vigilant cognitive and behavioral assessment of these children is warranted.

Classification of evidence: This study provides Class I evidence that valproic acid is associated with more significant attentional dysfunction than ethosuximide or lamotrigine in children with newly diagnosed CAE.
Michael J. Bresnan
Child Neurology Course
Submitted by Carole Atkinson, MS, PNP-BC, CNRN
The Boston Children’s Hospital, Department of Neurology’s, Michael J. Bresnan Child Neurology Course will be held in Boston Massachusetts from September 15-19, 2014. September 18 and 19 will have specific neurology nursing focused content with nursing contact hours. CME is awarded for the remainder of the course. The brochure will be available in the spring. In the interim, please email carole.atkinson@childrens.harvard.edu or lisa.duffy@childrens.harvard.edu if you have any questions.

Neuroscience Nursing Conference
Columbus, Ohio
Submitted by Jo Ellen Lee
Come join us for the 2014 Neuroscience Nursing Conference in Columbus OH on Friday, March 14, 2014. Supported by ACNN as one of the regional meetings. Our keynote speaker will be Linda Littlejohns, RN, MSN, CNRN, FAAN who is the immediate past president of the American Associate of Neuroscience Nurses. Topics will include: Neuroanatomy in clinical practice, advances in neuroradiology, advances in the management of hydrocephalus, update on newer anticonvulsants, postural orthostatic tachycardia syndrome (POTS) and psychogenic non-epileptic seizures. For more information call (614) 355-0676 or visit NationwideChildrens.org/Conferences.
Keeping Connected
Upcoming Meetings

British Paediatric Neurology Association Conference 2014
Jan 29 - Jan 31, 2014
Winchester, UK

India Association of Child Neurology 5th Annual Conference 2014
Feb 7 - Feb 9, 2014
Hyderabad, India

18th Annual Children’s Neuroscience Symposium 2014
Mar 9 - Mar 12, 2014
Phoenix, USA

ANN 66th Annual Meeting
April 26 - May 3, 2014
Philadelphia, PA

13th International Child Neurology Congress
May 4 - May 9, 2014
Iguazu Falls, Brazil

15th Annual Meeting of the Infantile Seizure Society 2014
June 23 - June 27, 2014
Nevsehir, Turkey

13th International Congress on Neuromuscular Diseases 2014
July 5 - July 10, 2014
Nice, France

Australia and New Zealand Child Neurology Society 3rd Annual Scientific Meeting
July 25 - July 27, 2014
Adelaide, Australia
Thank you to all ACNN members who made a submission to the Winter Edition of ACNN Currents. As members of ACNN, it is important for us to communicate with our peers. This is one of the benefits and obligations of membership. Let us know about your practice, innovation, an interesting case study, a mentor who has influenced you, your research, your publications, presentations, or a clinical practice change. Please send all submissions to maria.zak@sickkids.ca. The submission deadline for the Winter edition of ACNN Currents is March 7, 2014.

Nominating Committee Seeks Chairperson

Submitted by Ruth Shinnar, RN, MSN

This is a great time to step up and volunteer to contribute to your organization. The nominating chairperson assists the Board of Directors in forming the nominating committee and soliciting for open board positions for the coming year. It is an important position in that those nominated will be making decisions that affect all of us. The committee work begins in April with canvassing the membership for appropriate candidates and then reviewing applications for those positions posted. Voting is done in July/August. As board liaison to that committee I will be available to assist with protocol and procedure. Please consider volunteering. I can be reached at codell@sprynet.com or call Ruth Shinnar at 718 920 7756. Thank you.