

# CNS CONNECTIONS



Bringing CNS Members Together to Make Children's Lives Better



**“The Gold Standard”**  
Humility, Compassion, and Grace

Looking Back on KC, Looking Ahead to ‘The Big C’—Chicago 2018

# CHILD NEUROLOGY SOCIETY

## From the President



Jonathan Mink, MD, PhD  
President, CNS

### ***My Top Priorities:***

*...Increase diversity  
in CNS leadership*

*...Strengthen alliances  
with other  
organizations in  
our field*

*...Expand programming  
for Junior Members*

## Seizing Opportunities, Setting Priorities

I wish everyone a Happy New Year. May you all have happiness and success in 2018. It is an exciting time for the field of child neurology. Disease-modifying therapeutics for rare and fatal neurodegenerative disease are now becoming reality with FDA approval in the past year of Brineura (cerliponase alfa) for CLN2 disease (late-infantile Batten Disease) and Spinraza (nusinersen) for spinal muscular atrophy; more are on the horizon. Despite a tight funding environment, research in child neurology and developmental neuroscience continues to provide important advances. The number of clinical child neurologists also continues to grow, providing improved access to high quality neurological care for children.

Plans are already underway for what promises to be an exciting 47th Annual Meeting in Chicago this year. By now, you have probably received a few notices that the meeting days will be different from our traditional Wednesday through Saturday. This year's meeting will start Monday October 15 and run through Thursday October 18. Proposals for symposia and breakfast seminars have been received and will be reviewed by the Scientific Selection and Program Planning Committee over the next month. The abstract submission site will remain open until midnight, April 2.

As I assume the role of President, I want to state some of my priorities for the next two years.

The first is to increase the diversity of membership on the CNS committees and ultimately in the leadership of the Society. The membership of the CNS is currently about 50 percent men and 50 percent women, but 70 percent of current residents in child neurology are women. The number of historically under-represented minorities is also increasing among our members and trainees. As the path to leadership in professional societies usually starts with participation on a committee, this will be one focus of our efforts to increase

diversity. For any member who is interested in serving on a committee, please contact me (Jonathan\_Mink@urmc.rochester.edu) or Roger Larson (rblarson@childneurologysociety.org) to express your interest and which committee(s) would be most aligned with your interests. In addition, we will be launching a new effort to include junior member participation on the committees. An announcement regarding nominations will be forthcoming in the next couple of months.

Another priority is to increase our alliances with other organizations active in our field. These include the American Academy of Neurology, the American Academy of Pediatrics, the International Child Neurology Association, The Child Neurology Foundation, and others. I do believe that there is "safety in numbers". We must not relinquish our identity as child neurologists and must not allow the needs of child neurology to become secondary priorities to the needs of the larger fields of pediatrics and neurology. However, to have the greatest impact advocating for our profession we must work with these other organizations. Two years ago, a Child Neurology working group was formed that includes representatives from CNS, AAN, AAP, PCN, and CNF with a goal of coordinating our efforts to assure that the professional needs of child neurologists are supported.

A third priority is to expand programming at the Annual Meeting and between meetings for our junior members. They are the future of our profession. In my view, the Child Neurology Society has a responsibility to provide career-development support and mentoring in a broader context than is available at individual institutions. We will work to implement a "junior member track" with activities on each day of the Annual Meeting targeted at junior members.

I am excited about the Child Neurology Society and opportunities to continue and enhance our role as a professional society in advancing education, research, clinical care, and career satisfaction. I am proud to have been part of the CNS for over 25 years and look forward to working with all of you over the next two years.

# CONTENTS

WINTER 2018



Photos by Suzanne Shaff

## Connecting with Colleagues

- 4 In Memoriam: Arnold P. Gold, MD
- 6 Q&A with Erika Augustine, MD, PhD
- 21 2018 Abstract Submission Guidelines
- 22 CNS and Foundation Awards and Grants Guidelines
- 26 Focus On Young Researchers
- 28 Strategic Goals of the CNS: 2018 Committees and Charges

## Connecting with the Past

- 8 Looking Back on the 45th CNS Annual Meeting in Kansas City
- 10 Thank You CNS Annual Meeting Presenters
- 11 Thank You to Our Sponsors
- 14 Legacy Reception
- 15 Child Neurology Society Awards
- 16 Scientific Sessions
- 17 Exhibits & Poster Review
- 18 Networking

## Connecting to the Future

- 12 Child Neurology Career Development Program (CNCDP-K12)
- 13 2nd Annual CNS John M. "Jack" Pellock Resident Seminar on Epilepsy

## Connecting with Colleagues Globally

- 23 2018 Bernard D'Souza International Fellowship Award Guidelines
- 24 ICNC 2018 in Mumbai

## Connecting with Partners

- 33 Professors of Child Neurology
- 34 Association of Child Neurology Nurses

## DEPARTMENT

- 2 FROM THE PRESIDENT
- 36 PERSONNEL REGISTRY



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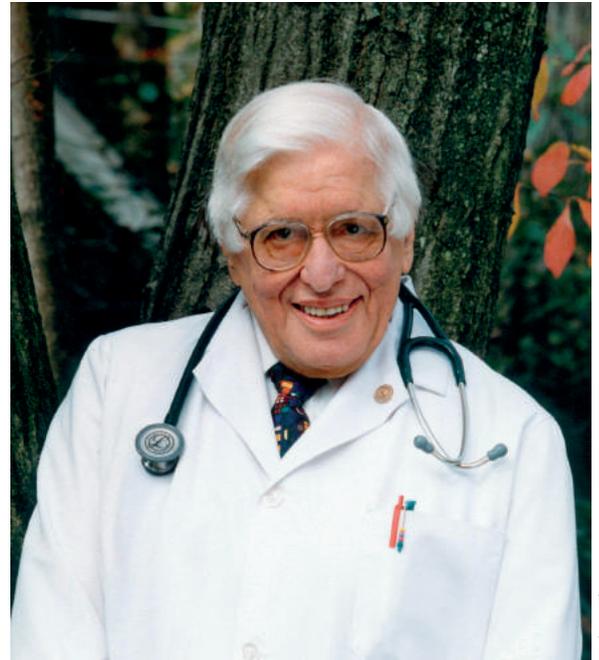
# CONNECTING WITH COLLEAGUES

## In Memoriam: Arnold P. Gold, MD (1925-2018)

By Nigel S. Bamford, MD and Darryl C. De Vivo, MD

### Education and Training:

- University of Texas, (1943-1947) B.A.
- University of Florida, (1947-1949) M.S.
- University of Lausanne, (1950-1954) M.D.
- Charity Hospital of Louisiana, New Orleans, (1954-1955) Rotating Internship
- Children's Hospital, Cincinnati, Ohio, (1955-1958) Residency in Pediatrics
- Columbia-Presbyterian Medical Center, (1958-1961) Fellow in Pediatric Neurology



**D**r. Arnold P. Gold, one of the true giants in child neurology and American medicine, passed away on Tuesday, January 23, 2018 at the age of 92. Gold was a founder of modern child neurology and a longtime colleague, collaborator and mentor of many who worked and trained at the Columbia University Medical Center and the Neurological Institute of New York. Much has changed in medicine since Dr. Gold began his career, but his ideals and teachings have not, and now live on in many, if not all, practicing child neurologists.

While a resident in pediatrics at Cincinnati, Gold developed an interest in endocrinopathies, published a few papers on the subject and planned a fellowship in endocrinology at Johns Hopkins. These plans changed after spending a one month rotation with Sidney Carter at the Neurological Institute of New York. Carter, a founding father of modern American child neurology, had established one of the country's first training programs and Gold considered Sid "a very special person: a friend, mentor and role model; the ultimate of what a physician should be." During his fellowship, Gold viewed Carter as an astute diagnostician and a compassionate clinician who cared about every child and their suffering family members and conveyed these admirable qualities to all of his trainees.

At the end of Gold's training, Carter offered him a faculty position at the Neurological Institute and he joined the

growing divisional ranks with Abe Chutorian, Niels Low, Jim Hammill and Richard Koenigsberger. These colleagues also would make their own marks and become giants in the nascent field of child neurology. Gold rose from assistant to full professor over fifteen years. During this rise in academia, he would distinguish himself as an outstanding teacher and able clinician. He enjoyed seeing patients with a broad array of neurological diseases and published widely in many diverse areas of pediatric neurology. He developed a special interest in the areas of vascular neurology and neurocutaneous diseases which led to chairmanships of the NIH Child Study Group for Stroke and the Medical Advisory Board of the National Tuberous Sclerosis Association. He served as a member on the American Heart Association Stroke Council and the Committee on Drugs of the American Academy of Pediatrics. His diverse interests in child neurology also contributed to our basic understanding of epilepsy, migraine, cerebral palsies, collagen vascular diseases, attention/hyperactivity disorders, movement disorders, infectious and inflammatory disorders, developmental neurology, neuromuscular disease, and learning disabilities. His presence was always felt on the wards at Babies Hospital in New York, where compassion for the sick children and their families was constant—a continuing measure of the Carter/Gold legacy. Dr. Gold was indefatigable as he sought out new ways to help the children and their families under his care, and he later explored philanthropy to improve clinical care and the hospital infrastructure.

Gold received numerous awards and visiting professorships for his contributions to medicine and child neurology. He was the recipient of the National Brennerman Award in Pediatrics, Lifetime Community Service Award from the Autism Society of America, an Honorary Doctorate from the University of Medicine and Dentistry of New Jersey, an Honorary Doctorate of Humane Letters from Sacred Heart University, and awards for Humanitarian Excellence from various institutions, including the New Jersey Council for the Humanities.

Gold was a beloved teacher and mentor for the many pediatricians who trained at Babies Hospital and the pediatric neurologists who trained at the Neurological Institute. Undoubtedly an inborn tendency, Gold elevated the thoughtful manner of his mentors and colleagues to promote care for the families of his patients; one often heard the words “care for the family, not just the patient.” Gold would often extend his clinical visits with the child to spend quality time with the child’s parents and other family members. The net result often was a comprehensive plan that would ultimately embrace the family and improve each child’s long term quality of life—the true signature of a caring, compassionate child neurologist.

A charter member of the Child Neurology Society and recipient in 2005 of the Society’s Lifetime Achievement Award, Gold is perhaps best known for founding, in 1988 along with his wife, Dr. Sandra Gold, the Arnold P. Gold Foundation, dedicated to fostering humanism in medicine. With a grant from the Robert Wood Johnson Foundation, he gathered fifty medical school deans together to discuss ways to offset the diminishing emphasis on the humane aspects of medicine. He proposed mechanisms that would inculcate these humanistic behaviors in medical students at the beginning of their careers; behaviors that he regarded as fundamental to the practice of medicine. One outcome was the White Coat Ceremony that medical and dental students participate in at the beginning of their training. The first ceremony was in 1993 at the Columbia University College of Physicians and Surgeons; it has since spread to nearly every medical and dental school in the United States and more than a dozen countries overseas. The white

coat is a symbol that emphasizes the ethical, moral and humane imperatives that medical students accept upon matriculation.

In creating the Arnold P. Gold Foundation, the Gold’s institutionalized their vision of compassionate healthcare through sponsored programs which promote humanism in medicine, along with student and resident recognitions for individuals who exemplify Gold’s values, including integrity, compassion, empathy, cultural sensitivity, effective communication, trust and confidence, respect, service and deep appreciation for the emotional concerns of patients and family members.

***Humility, compassion and grace characterize “the Gold Standard” in the practice of child neurology, and are the essential traits that Dr. Arnold P. Gold personified throughout his long and distinguished career.***

Gold encouraged programs to evaluate problems in medicine that resulted from the de-emphasis of humanity in medicine. He believed that a constant awareness of suffering and the capacity to alleviate it by maintaining competency would prevent physician “burnout”. The first Arnold P. Gold Foundation Humanism in Medicine Award was presented to Dr. Ruth Nass at the Child Neurology Society Annual Meeting in 2010. Nass was one of Gold’s former trainees who had promoted humanism in pediatric neurology throughout the New York tri-state area. Since that time, the Foundation has supported seven additional CNS awardees that exemplify the Gold example, and a biennial Humanism in Medicine Forum at the CNS meeting. By honoring those clinicians who actively promote humanism in medicine, and by continuing dialogue about the factors that contribute to physician burnout, Dr. Gold felt that the nobility of medicine would be preserved and elevated. Those trainees who have followed and who did not have the privilege of interacting directly with Dr. Gold will benefit indirectly from the ongoing work of the Foundation and will be viewed as his “grandchildren”. These fundamental principles of humanism will allow the profession to serve our children humanely and to thrive well into the future. Humility, compassion and grace characterize “the Gold Standard” in the practice of child neurology, and are the essential traits that Dr. Arnold P. Gold personified throughout his long and distinguished career.

Dr. Gold is survived by his wife, Sandra; his children and 13 grandchildren.

# CONNECTING WITH COLLEAGUES

## Q&A

### Toward Treatments and Cures for Rare Diseases: Perspective of Dr. Erika Augustine

By Daniel J. Bonthius, MD, PhD | CNS Connections Editor



Erika Augustine, MD, PhD

**QUESTION** | *Let's start by talking about the development of therapeutics for rare diseases. How did you become interested in this topic?*

One of the great aspects of clinical child neurology is the opportunity to care for patients with a broad spectrum of disorders, from common to rare. The unique expertise of a child neurologist regarding the interactions of each organ system with the brain and the diagnostic challenges of complex metabolic and genetic conditions drew me to the field. Even as a medical student, it was clear to me that the field of Child Neurology would change during the course of my career as new scientific knowledge led to novel therapeutics. The need for effective therapies is especially high in these rare, complex diseases that initially sparked my interest in child neurology and subsequently became my focus.

**QUESTION** | *What are the special challenges that researchers face when they are dealing with rare diseases?*

The key is in that word 'rare'. By definition, these are disorders that affect small numbers of people, which, in turn, impacts every aspect of care and research—garnering interest in the area, access to expertise, small numbers of researchers, limited dedicated research funding, and challenges with developing clinical studies of sufficient size to enable rigorous research.

**QUESTION** | *Do clinical trials need to be organized differently or have different goals when they are addressing a rare disease, in comparison to more common diseases?*

The same principles underlying high quality scientific research and rigorous evidence apply in rare diseases, even with the challenge of small samples. This is critical for generating robust knowledge regarding the safety and efficacy of new treatments. The infrastructure for trials targeted to rare disorders may necessarily be multi-center or even multi-national, in order to garner sufficient patient numbers. In addition, patient partnership in the development and execution of trials is especially important.

**QUESTION** | *Do the funding agencies in the US give enough priority to rare diseases?*

There are a number of efforts to support rare disease research from federal agencies, including the Food and Drug Administration (FDA) Office of Orphan Products. The 21st Century Cures Act, passed in late 2016, includes several provisions related to rare diseases, including reauthorization of the FDA Rare Disease Priority Review voucher program and updates to the FDA Orphan Drug grant program. There are, however, more than 7,000 rare diseases, the majority of which lack disease-modifying treatments. There is certainly a continued need for greater priority and support.

**QUESTION** | *Are there challenges in motivating pharmaceutical companies to pursue development of treatments for rare diseases?*

The Orphan Drug Act of 1983 was developed to address this specific issue. It provides financial incentives to motivate development of new treatments for rare diseases. Based on the annual number of treatments approved by the FDA for rare conditions, the Act has been quite successful.

**QUESTION** | *Are there certain rare diseases of pediatric neurology about which you have particular optimism for a new treatment in the near future?*

We are seeing new therapeutics emerge with great impact. A particularly exciting aspect of recently approved technologies is the potential for use in many diseases. As gene transfer, RNA-based approaches, and CNS-directed enzyme replacement therapies expand in application, there is the potential for huge impact on rare diseases, many of which are genetically based, and consequently for the entire field of child neurology.

**QUESTION** | *Let's change the subject a bit and talk about your experiences with the Emerging Leadership Program. How about if you start by explaining what the ELF program is?*

The Emerging Leaders Program (formerly Emerging Leaders Forum, ELF) is a leadership initiative of the American Academy of Neurology and is part of its growing portfolio of leadership programs. The Emerging Leaders Program is a 6-month leadership training program targeted to individuals in the early career phase, within 10 years of completion of residency.

**Editor's Note:** Dr. Erika Augustine is an Associate Professor of Neurology and Pediatrics at the University of Rochester Medical Center where she serves as Assistant Program Director for the NINDS-funded Experimental Therapeutics training program. She is a member of the NIH Taskforce on Childhood Motor Disorders and is a consultant to the FDA Neurological Devices Panel.

**QUESTION** | *What was your personal experience with ELF?*

ELF was a fantastic experience and I recommend it highly. We spend close to a decade in medical school and residency (or more with fellowship) preparing for the practice of child neurology, building our medical knowledge and our ability to work with patients to provide high quality, compassionate care. Yet, much of what we do involves leadership—leading a clinical team, building a research program, directing a course, clerkship, or residency/fellowship are just a few examples. Dedicated opportunities to develop those critical leadership skills and structured ways to build professional networks early in one's career can be invaluable. During my participation in ELF, Dr. Ann Tilton (President of the Child Neurology Foundation) was a phenomenal mentor and resource. I am delighted that my relationship with the Emerging Leaders Program continues today, now as a mentor to another Child Neurology Society member, Dr. Mathula Thangarajh of the Children's National Health System.



*Changing of the Guard: 2018-19 Scientific Program Chair, Erika Augustine, exchanges intel with 2016-17 Program Chair, Marc Patterson in Kansas City.*

Dr. Augustine's research interests include methodology of clinical research and experimental therapeutics in rare pediatric neurological disorders. She also currently serves as the Diversity Officer for the NIH-funded Child Neurology Career Development Project (CNCDP-K12; see page 12) and chairs the Scientific Program Committee for the 2018 and 2019 CNS Annual Meeting.

## From DC to BC to KC to “The Big C”—Chicago

The last three CNS Annual Meetings (2015 in Washington DC, 2016 in Vancouver BC, and last year in Kansas City) all surpassed previous attendance records, setting a new “threshold” of 1000+ attendees and 275-300 exhibitors gathered for what is, hands down, **THE** meeting of choice for professionals active in the field of child neurology. This year’s meeting in Chicago will shatter those records, lured by the easy access to a full menu of flight options and the meeting hotel’s unbeatable proximity to the river, the Magnificent Mile, Millenium Park and world-class museums.

### Kansas City 2017 — Largest-ever Gathering in the United States

Last year’s meeting in KC didn’t quite eclipse Vancouver for attendance, but it did stake a serious claim to being the largest-ever gathering of child neurologists in the United States to date (again, Chicago is a lock to set a new record). And people didn’t come just in time for the traditional Wednesday evening Welcome Reception or leave immediately after the Saturday morning Hower Award Lecture and final scientific symposium. They gathered on “the shoulders” as well, for special interest meetings before and after the main CNS meeting:

- The NIH-funded Child Neurology Career Development Program (CNCDP) staged its second annual retreat on the front end of the CNS Annual Meeting, with nearly 30 young physician-scientists presenting their research and/or interviewing for available slots in future years.
- CNS and CNF Boards both logged long hours before any general sessions were held.
- Nine faculty members and 58 PGY5 residents gathered on Tuesday evening and all-day Wednesday for the 2nd Annual CNS John M. “Jack” Pellock Residents Seminar on Epilepsy.
- Bernie Maria’s all-day Wednesday Neurobiology of Diseases in Children Symposium on Leukodystrophies drew over 300 attendees.
- The Association of Child Neurology Nurses met for their traditional all-day Wednesday educational program, then added special interest group meetings to their usual follow-up fare of mid-day Thursday and Friday lunch seminars.
- The International Pediatric Stroke Study Investigators (30+) gathered for their 15th pre-CNS meeting since

the multicenter study group was launched at the 2002 CNS Annual Meeting in Washington, DC.

- More than 80 PCN members and an additional 25 members of the Program Coordinators of Child Neurology met on Wednesday afternoon, incorporating for the first time, an audience response system providing immediate feedback to questions from the podium.

That all took place before the first wine bottle was uncorked and the first appetizer served on the Exhibit Floor at the Wednesday evening Welcome Reception, sponsored by Children’s Mercy Hospital. And it didn’t end on Saturday at noon. More than 125 attendees stayed on to attend the 3rd Annual Child Neurology Foundation Symposium; this year’s meeting brought neurologists, nurses, parent and advocacy groups together to focus on SUDEP. Nearby, the 2nd Annual Biomedical Writing Workshop attracted early career academic-researchers eager to be “schooled” by seasoned editors Jon Mink, Marc Patterson, Scott Pomeroy and Steve Roach.

And the traditional annual meeting time block in between? Lots of networking, a little bit of rain (OK—a lot), an impressive line-up of continuing medical education, including six breakfast seminars, four symposia, four SIG-organized CME sessions, two platform sessions, four satellite programs, three award lectures, scientific posters and a record-shattering 100 exhibit booths. Toss in a half-dozen SIG meetings, Wednesday’s first ever Legacy Reception honoring Drs. Abe Chutorian, Don Shields, David Coulter and Kenneth Swaiman, the Friday evening Gala Receptions, numerous smaller receptions, and you have a great meeting, setting the table for what will be a truly memorable meeting this year in Chicago, if...if...if...if...

**IF...** you remember to mark your calendars, make your reservations, and book your flights to arrive on Sunday night or Monday, **NOT** your traditional Tuesday/Wednesday grand entrance. This year's meeting (and this year's meeting only) will run from Monday thru Thursday.

In addition to marking your calendars for a Sunday/Monday arrival, please note the following:

- The line-up of seminars and symposia selected from member-submitted proposals will be announced in early March.
- Abstracts will be accepted for review from February 1 to April 2, with acceptance letters slated to go out in May.
- A call for SIG-designed educational fare will be announced in April.
- Meeting registration and hotel reservations will be available on-line beginning mid-June.



## Thank You CNS Annual Meeting Presenters



Expertise is great and the CNS is no different than any other major medical association in showcasing and offering it to members at its annual meeting. What sets the CNS apart from many organizations is the generosity its members consistently demonstrate by offering their expertise *pro bono*. Fifty CNS members served as faculty on one or more of the seminars and symposia offered at the 2017 CNS Annual Meeting. Their willingness to present *pro bono* continued a long and honorable tradition of CNS members making common cause with their colleagues to ensure high level CME without commensurately high level registration and course fees by foregoing honoraria, per diems, waived registration fees, and other perks. So, before taking a backward glance at last fall's meeting in the eight pages to follow, let's pause to offer a special thanks to CNS members for their generous gift of time and talent in Kansas City.

### **JOHN M. "JACK" PELLOCK RESIDENCY SEMINAR ON EPILEPSY**

Organizers: Phillip Pearl, MD  
Renée Shellhaas, MD  
Elaine Wirrell, MD

Faculty: Carol Camfield, MD  
Peter Camfield, MD  
Kevin Chapman, MD  
Bill Gaillard, MD  
Nancy McNamara, MD  
Katherine Nickels, MD  
Heather Olson, MD  
Carl Stafstrom, MD, PhD  
Syndi Seinfeld, DO

### **BIOMEDICAL WRITING WORKSHOP**

E. Steve Roach, MD, Organizer  
Marc Patterson, MD  
Jonathan Mink, MD, PhD  
Scott Pomeroy, MD, PhD

### **SYMPOSIUM I: NEUROBIOLOGY OF DISEASE IN CHILDREN (LEUKODYSTROPHIES)**

Bernard Maria, MD, MBA  
Joshua Bonkowsky, MD, PhD  
Florian Eichler, MD  
Ali Fatemi, MD  
Sakkubai Naidu MD  
Adeline Vanderver, MD  
Keith VanHaren, MD

### **SYMPOSIUM II: PRESIDENTIAL SYMPOSIUM: PRACTICE ISSUES IN CHILD NEUROLOGY**

Kenneth Mack, MD, PhD, Organizer  
Jeffrey Buchhalter, MD, PhD  
Bruce Cohen, MD  
Sidney Gospe, Jr., MD, PhD

### **SYMPOSIUM III: GLOBAL HEALTH**

Jorge Vidaurre, MD, Organizer  
Harry Chugani, MD  
Dave Clarke, MBBS  
Solomon L. Moshé, MD

### **SYMPOSIUM IV: CONVERSION DISORDERS AND PSYCHOGENIC NON-EPILEPTIC SEIZURES**

Steven Leber, MD, PhD, Organizer  
Leon Dure, MD  
Jonathan Mink, MD, PhD

### **SYMPOSIUM V: PEDIATRIC NEURO-ONCOLOGY**

Sonia Partap, MD, MS  
Yasmin Khakoo, MD  
Nicole Ullrich, MD, PhD

### **SYMPOSIUM VI: CHILD NEUROLOGY FOUNDATION SYMPOSIUM: SUDEP**

William Trescher, MD, Organizer  
Jeffrey Buchhalter, MD, PhD  
Elizabeth Donner, MD

*All CNS Annual Meeting photos in this issue by Suzanne Shaff.*

### SEMINAR 1: UPDATE ON PAROXYSMAL MOVEMENT DISORDERS

Harvey Singer, MD, Organizer  
Donald Gilbert, MD  
Toni Pearson, MD

### SEMINAR 2: SEX: WHY THIS BIOLOGICAL VARIABLE IS RELEVANT TO THE CHILD NEUROLOGIST

Mary Zupanc, MD, Organizer  
Tallie Z. Baram, MD, PhD  
Bradley Schlaggar, MD, PhD

### SEMINAR 3: HOW TO GET STARTED IN CHILD NEUROLOGY RESEARCH AT ANY POINT IN YOUR CAREER

Adam Hartmann, MD, Organizer  
Mustafa Sahin, MD, PhD  
Courtney Wusthoff, MD, PhD

### SEMINAR 4: NEWBORN SCREENING CONSIDERATION FOR SPINAL MUSCULAR ATROPHY

Han Phan, MD, Organizer

### SEMINAR 5: THE COMPREHENSIVE EVALUATION OF MITOCHONDRIAL MYOPATHIES

Zarazuela Zolkipli, MBChB, MRCP, Organizer  
Shana McCormack, MD

### SEMINAR 6: DIAGNOSING DRAVET SYNDROME—WHAT'S THE RUSH?

Kelly Knupp, MD, Organizer  
Sookyong Koh, MD, PhD  
Elaine Wirrell, MD

## Thank You to Our Sponsors

#### LEADER LEVEL (\$100,000+)



##### Eisai, Inc.

- Child Neuro News Wrap
- Hotel key cards
- Meeting app



##### Mallinckrodt

- Charging Stations

#### PARTNER LEVEL (\$50,000+)



##### Biogen

- Child Neuro News Forum (Thursday poster review)
- Satellite Symposium



##### Greenwich Biosciences

- Satellite Symposium
- Unrestricted Educational Grant
- Wall-to-Wall Wifi



##### Jazz Pharmaceuticals

- Satellite Symposium



##### Sunovion Pharmaceuticals

- Connections Corridor

#### SUPPORTER LEVEL (\$20,000+)



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- Unrestricted Grant



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##### Bluebird bio

- Unrestricted Grant



##### Child Neurology Foundation

- Unrestricted Educational Grant



##### Children's Mercy Kansas City

- Wednesday Welcome Reception, Host Institution



##### PTC Therapeutics

- Unrestricted Grant



##### Sarepta Therapeutics

- Meeting tote bags

### Thanks to the following for their continued support of awards presented at the CNS Annual Meeting



##### Akron Children's Hospital

- Hower Award Lecture



##### Arnold P. Gold Foundation

- Humanism in Medicine Award & Luncheon



##### Blue Bird Circle

- CNS/PCN Training Director Award

### Child Neurologist Career Development Program (CNCDP-K12) Funded by NIH-NINDS

The NIH Child Neurologist Career Development Program held its second annual retreat just prior to the CNS Annual Meeting in Kansas City. The retreat brought together key program directors from the NINDS, division chiefs representing more than a dozen child neurology training programs, and more than three dozen child neurology residents and fellows. CNCDP PI and Director, Dr. Michael Johnston outlined the program in a piece published last year in *CNS Connections*, noting that it was “the brainchild” of Dr. Stephen Korn, Director of Training at NINDS, who envisioned “an open selection process whereby child neurology residents completing their clinical training at any institution in the country would receive three years of critically important funding and focused mentorship that would lead, over time, to increased number of child neurologists actively pursuing NIH-funded research careers.” The first cohort, selected at the retreat in Vancouver in 2016 and presenting their work for critique at the 2017 retreat included Hsaio-Tuan Chao, MD, PhD, Baylor University; Aaron Boes, MD, PhD, University of Iowa; Christa Habela, MD, PhD, Johns Hopkins; Mai Dang, MD,

PhD, UPenn; and Autumn Ivy, MD, PhD, Stanford. Dr. Chao also presented a paper at one of the Friday morning platform sessions, for which she received one of four CNS Outstanding Junior Member Awards (photo on page 15). Dr. Boes is the subject of this issue’s Research Focus (see page 26).



## 2nd Annual CNS John M. “Jack” Pellock Resident Seminar on Epilepsy

Meanwhile, in another section of the Sheraton Crown Center, a select cohort of 58 PGY5 residents participated in the 2nd Annual CNS John M. “Jack” Pellock Resident Seminar on Epilepsy, organized by Drs. Phillip Pearl, Renée Shellhaas and Elaine Wirrell. One of the primary objectives of the seminar, in addition to providing a significant opportunity for the next generation of child neurologists to meet peers from around the country and launch the kind of lifelong, career-enhancing friendships and collaborations driving the Child Neurology Society’s mission and success, is to cultivate an ethos of “dual citizenship” typified by Jack Pellock. To that end, the CNS, AES, and CNF launched a three-year pilot program in 2017, funded by Upsher-Smith, that will select and recognize two residents from each Pellock Seminar cohort as “Pellock Fellows”. The fellows will receive both CNS and AES membership dues and annual meeting fee waivers, and follow up their participation in the Pellock Seminar with active participation in a leadership development program at the following year’s AES Annual Meeting. The first two CNS Pellock Fellows selected in 2017 were Dr. Thomas Foutz, from Seattle Children’s Hospital, and Dr. Lila Worden, from Massachusetts General Hospital.



Faculty pictured left. Front Row (l-r): Drs. Syndi Seinfeld (who was trained by and practiced with Jack Pellock), Carl Stafstrom, Karen Nickels, Carol Camfield, Elaine Wirrell, Heather Olsen. Back Row (l-r): Drs. William Gaillard, Phillip Pearl, Kevin Chapman. Not Pictured: Drs. Nancy McNamara, Renée Shellhaas.

## Legacy Reception

In a conference devoted to sharing insights and information about the developing brain, one doesn't hear much talk about the heart. Even less about the soul. But if one were to search for the vital center of the Child Neurology Society, that place where the heart and mind and soul are most radiantly and resonantly present and alive, one need look no further than the Legacy Reception in Kansas City on the opening night of the 2017 CNS Annual Meeting. To listen to friends and colleagues of Ken Swaiman recall the animating vision and relentless drive he and a supporting cast, now largely gone, summoned in service to the founding of the CNS, PCN, CNF and the journal *Pediatric Neurology*; to hear Chris Giza tell tales about his

mentor, Don Shields, and Leonardo Garcia introduce his old friend, Abe Chutorian, each recipients of the 2017 Roger and Mary Brumbach Lifetime Achievement Awards; to link the memories Dr. Mary Cerreto shared introducing her husband, David Coulter, to the Arnold P. Gold Foundation Award for Humanism in Medicine Award he was about to receive; and then to hear each of these honored men speak with wisdom and humor and humility—and even a little poetry—was to learn or re-learn more, perhaps, about how and why you came to be here in Kansas City with 1000 other child neurologists on this night, at this Legacy Reception, than you might have ever thought possible. It was a night to remember.



# Child Neurology Society Awards



CNS/PCN Blue Bird Circle Training Director Award recipient, Sidney M. Gospe, Jr, MD, PhD stands alongside the traditional award profile board.



CNS President, Kenneth Mack and Philip R. Dodge Young Investigator Awardee, Audrey Brumback, MD, PhD.



Melissa A. Walker, MD, PhD, from Massachusetts General Hospital, received the Shields Research Grant. Pictured (L-R): Dr. Roy Elterman, President, Pediatric Epilepsy Research Foundation (PERF); Dr. Walker; W. Donald Shields, MD.



Hower Award Lecturer, Nina Schor (center) was introduced by her twin sons, Jonathan (L) and Stanford (R), flanked here by CNS Executive Director, Roger Larson (L) and her husband, Robert Schor (R).



Lauren Singer, recipient of the CNS Bhuwan Garg High School Neuroscience Award.

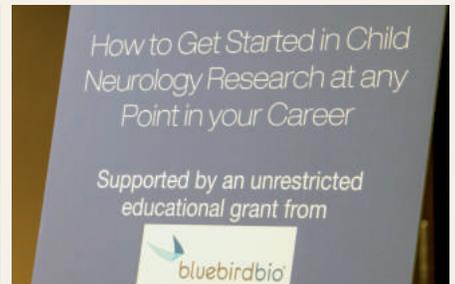


CNS Outstanding Junior Member Award recipients: (L-R) Carla Watson, MD, Children's Hospital of Michigan; Rachel Goldstein Hirschberger, MD, MPH, Boston Children's Hospital; Hsiao-Tuan Chao, MD, PhD, Baylor College of Medicine, Ka Ye Clara Chan, MD, Loma Linda University Medical Center.



2017 Sachs Award Lecturer, Solomon Moshé, MD (center) with his wife, colleagues, and past trainees.

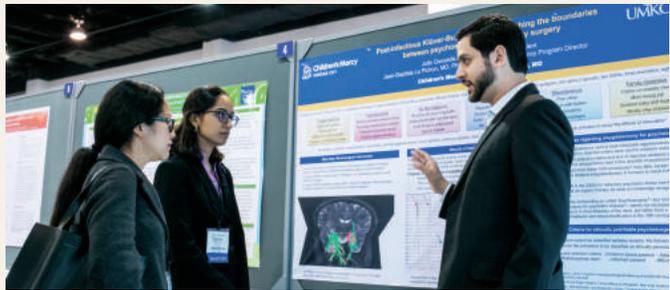
# Scientific Sessions



# Exhibits



# Poster Review



# Networking







Forty-Seventh

# CNS

ANNUAL MEETING

October 15-18, 2018  
CHICAGO, ILLINOIS

**This year's meeting  
(and this year's meeting only)  
will run from  
Monday thru Thursday.**



October

2018

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	<b>15</b>	<b>16</b>	<b>17</b>	<b>18</b>	19	20
21	22	23	24	25	26	27
28	29	30	31			

**Remember to mark your calendars, make your reservations, and book your flights to arrive on Sunday night or Monday, NOT your traditional Tuesday/Wednesday grand entrance.**

# CONNECTING WITH THE FUTURE

**Deadline**  
**April 2, 2018**

## 2018 Abstract Submission Guidelines

### Submissions

(Deadline: April 2, 2018; 11:59 pm PDT)

1. CNS Membership not required for abstract submission or presentation.
2. First Author listed will be required to verify work submitted is their own.
3. Multiple submissions allowed. Multiple authors allowed. (Max. 3 submissions)
4. Word Count: 250 (does not include title, authors, or text embedded in graphs or graphics) (Maximum of 2 graphics)
5. Work presented at other meeting(s) and or recently published will be reviewed; author must identify previous presentation venues and verify work was presented before a substantially different audience in space provided.
6. Abstracts should be broken into four-header format: Objective, Methods, Results, Conclusions.
7. **SAVE & FINALIZE** when submission is completed. Once your submission is completed. Submitter is required to click "Publish" and the submitter will receive a confirmation email to verify completed submission has been received.

### Review & Presentation

1. Abstracts will be reviewed by minimum five members of the CNS Scientific Selection and Program Planning Committee as assigned by the committee chair.
2. Anonymous review; author ID is not available to reviewers prior to final selection of abstracts.
3. Notification of acceptance and guidelines for presentation will be emailed to first author on or before May 7, 2018.
4. Notification of non-acceptance will be emailed to first author on or after May 25, 2018.
5. Authors presenting papers in platform/plenary session(s) will be required to adhere to ACCME financial disclosure/conflict of interest guidelines as defined by the meeting Joint CME Sponsor, MN Medical Association.

6. Abstracts accepted for presentation will be published in an Annals of Neurology supplement. Submitting authors assume all responsibility for accuracy of information submitted and printed.
7. Authors of abstracts accepted for presentation are required to register for the 47th Annual CNS Meeting. A registered proxy listed as contributing author may present for author unable to attend.
8. Authors are responsible for all expenses related to attending and presenting at the meeting. No honoraria will be awarded for poster or platform/plenary presentations.

### Junior Member Awards & Registration Fee Waivers

Notification of acceptance for presentation will be emailed to contact author listed on or before May 7; notice of non-acceptance will be emailed on or before May 25. Junior Members of the CNS may qualify for the following awards:

#### Outstanding Junior Member Awards (4)

Presented to four qualifying first/primary author of abstracts submitted by CNS Junior Members. Includes hotel/air/registration fee waiver, plaque.

#### M. Richard Koenigsberger Scholarship

Presented to best abstract submitted by CNS Junior Member in following subject areas: neonatal neurology, genetics diseases, HIV, metabolic disorders. Includes \$300 scholarship and registration fee waiver.

#### AAP Section on Neurology Trainee Travel Award

Criteria for selection will include the significance of the question addressed, methodological rigor, and broad relevance to child health. All eligible submitted abstracts will automatically be considered.

### Future Leaders Program

(Grant pending; awarded only if outside funding is secured.)

Registration fee waiver for CNS Junior Members presenting as first/ primary author. To qualify, author must be:

- Primary/first author enrolled in child neurology or neurodevelopmental disabilities training program as of April 2, 2018
- CNS Junior Member (or have application for Junior Membership completed and pending approval as of May 15, 2018).

### Questions? Contact...

[nationaloffice@childneurologysociety.org](mailto:nationaloffice@childneurologysociety.org)

### Please Note:

- The Abstract Submission site is independent of the CNS.
  - You will be required to create a username and password before beginning a submission.
  - You may use the same username/ password as you have for the CNS, however, you will be required to create this independently on the Abstract website.
  - All auto generated emails will appear as they are coming from Emily McConnell ([ermcconnell@childneurologysociety.org](mailto:ermcconnell@childneurologysociety.org)).
- Some auto generated emails show up in your spam folder. Please be sure to check your spam mail if you do not receive an email after completing a submission.
- Please begin a submission only after
    1. Completely reading guidelines and
    2. When final abstract is ready to upload/submit

### Abstract Submission Link:

<https://catalyst.omnipress.com/#collection/302/submission>

# CONNECTING WITH COLLEAGUES

## Focus on Young Investigators

### Child Neurology Society and Foundation Awards and Grants

**Deadline**  
**April 1, 2018**

Dr. Kenneth Swaiman was honored at the 2017 CNS Annual Meeting Legacy Reception for his seminal role in founding the Child Neurology Society in 1972 and the Child Neurology Foundation in 2001. While the Society is the professional organization for the nation's pediatric neurologists, the Foundation is committed to serving as a connective center of education and support for children and their families living with neurologic conditions. Together, the CNS and CNF have developed a joint committee, chaired by Dr. Nigel Bamford, to review applications and work submitted by young members of the CNS for the following Awards and Grants:

**The Philip R. Dodge Young Investigator Award** is an award for basic science or clinical research by promising young investigators who are members of the Child Neurology Society. Applications will be judged on the basis of originality, scientific merit, succinctness and relevance. The recipient of the Dodge award will receive a \$30,000 grant-in-aid and will be invited to present their work at the Annual Meeting of the Child Neurology Society immediately prior to the CNS Bernard Sachs Award Lecture, signaling a line of succession between established and emerging researchers in the field of child neurology.

#### Eligibility Criteria

1. The applicant completed a pediatric neurology residency on or after June 30, 2013 or a neurodevelopmental disability residency on or after June 30, 2014, and graduated medical school on or after May 2008, or after May 2007 if the applicant completed a 3-year pediatric residency.
2. The scientific work is mainly the result of the applicant's efforts.
3. The applicant is a Junior or Active member of the Child Neurology Society.
4. Candidates are NOT disqualified if they have received NIH funding.
5. Candidates should consider applying before their final year of eligibility.

**The Child Neurology Shields Research Grant** supports translational or clinical research by a child neurologist or developmental pediatrician early in his/her academic career. The selected investigator will receive a \$100,000 grant of \$50,000 per year for two years. The Shields Grant is supported by the Winokur Family Foundation and the Pediatric Epilepsy Research Foundation (PERF).

#### Eligibility Criteria

1. The applicant must be a junior faculty member who has developed clinical research skills and has a plan for further development of that research or has basic science research skills related to child neurology and who has a plan to translate the new knowledge into clinical care for children with neurologic diseases.
2. The Shields Grant must have a clinical research/patient care component.
3. The applicant is a legal resident of the United States or Canada.
4. The applicant is a Junior or Active member of the Child Neurology Society.
5. Candidates are NOT disqualified if they have received NIH funding.
6. A pre-application is no longer required.

**Pediatric Epilepsy Research Foundation (PERF) Scientific Research Grant** supports clinical or basic science research by a child neurologist or developmental pediatrician early in his/her academic career. The selected investigator will receive a \$100,000 grant of \$50,000 per year for two years. The PERF Grant is supported fully by PERF.

#### Eligibility Criteria

1. The applicant completed training in child neurology or neurodevelopment disabilities in an ACGME-approved program no more than seven years prior to application.
2. The applicant is a legal resident of the United States or Canada.
3. The applicant is a Junior or Active member of the Child Neurology Society.
4. Applicants with current or approved pending NIH funding will be excluded. No NIH grant is allowed, other than an institutional (i.e. K12, T32) or training grant (i.e. NRSA).

**APPLICATIONS FOR THESE AWARDS ARE DUE APRIL 1. APPLICANTS WILL BE INFORMED OF THE COMMITTEE'S DECISION BY MAY 10.**

*To access full criteria and application, go to CNS website.*

# CONNECTING WITH COLLEAGUES GLOBALLY

## 2018 Bernard D'Souza International Fellowship Award

The Child Neurology Society is now accepting applications for the 2018 Bernard D'Souza International Fellowship Award, which will sponsor two child neurologists from developing countries to attend the 47th Annual Meeting of the Child Neurology Society to be held in Chicago, Illinois (October 15-18, 2018). Following the meeting, D'Souza fellows will spend one week visiting a selected training program in North America before returning home. The purpose of the award is to promote child neurology in developing countries.

A link will be published on the CNS 2018 Annual Meeting page March 1 for applications to be submitted on-line thru May 1, 2018. Applicants will be required to upload a CV and up to three letters of recommendation.

### Requirements

- Applicant trained in a developing country.
- Applicant is practicing child neurology in an academic environment in a developing country.
- Applicant should be prepared to present a scientific paper in English.
- Preference will be shown to applicants less than age 45 years.

**Deadline  
May 1, 2018**



### Expenses Covered

- CNS Annual Meeting registration fee waiver
- Round-trip coach fare originating and ending in home country with in-between flights to/from Chicago, IL and a single host training program (strong preference for child neurology programs within 250 mile radius of Chicago, IL). Travel must be arranged through CNS designated travel agent.
- Hotel room nights at CNS Annual Meeting and up to one-week at host training program in a CNS-designated hotel.
- Standard per diem payment for up to five days in Chicago and seven days in host training program city (including transportation to and from airport).
- Award recipient will be responsible for all other expenses.



CNS International Affairs Committee Chair, Dr. Jorge Vidaurre is pictured here with the two 2018 Bernard D'Souza International Fellowship Awardees: (Above): Dr. Charles Hammond, from Kumasi, Ghana. (Below): Dr. Aye Mya Min Aye, from Yangon, Myanmar.



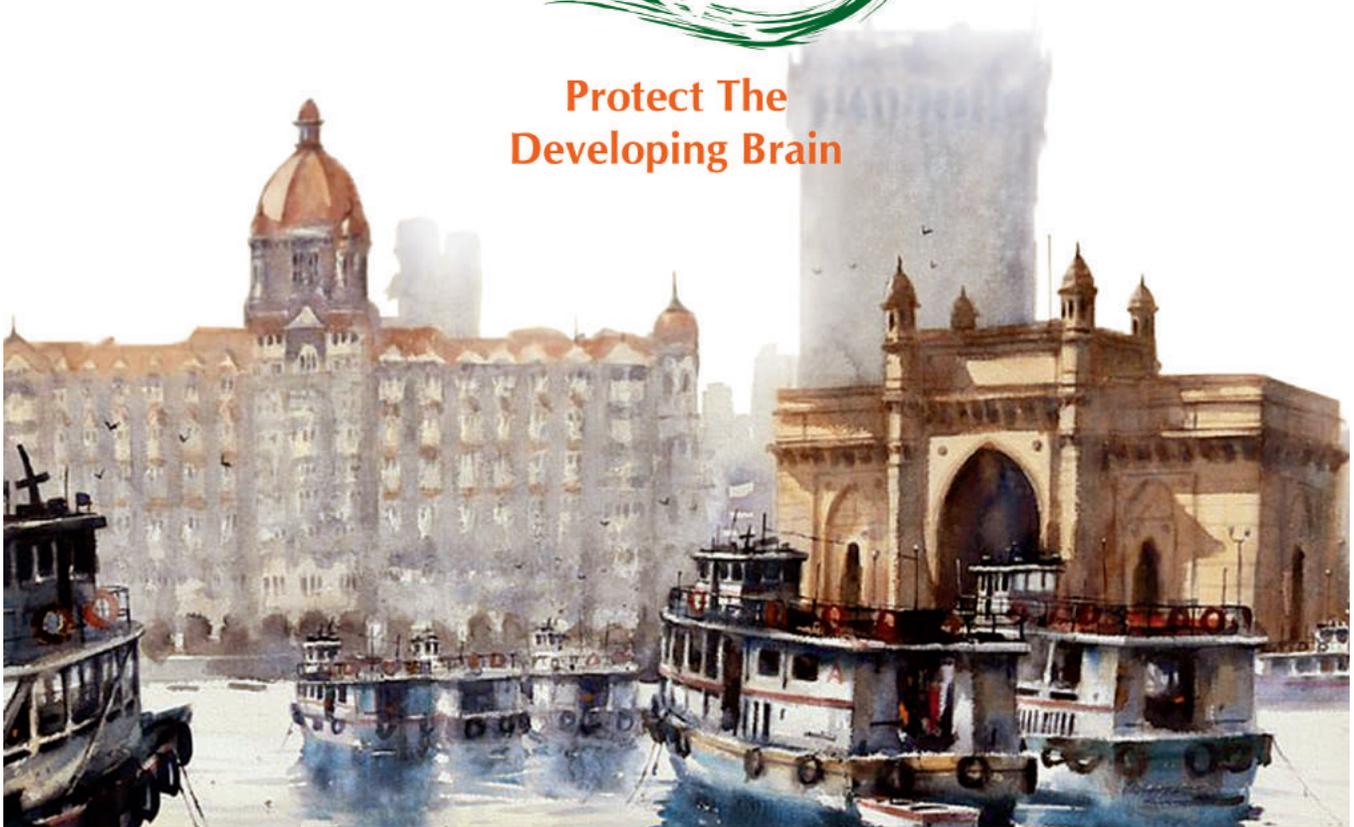


# International Child Neurology Congress

15 - 18 November, 2018 | Hotel Grand Hyatt, Kalina, Mumbai



Protect The  
Developing Brain



[www.icnc2018mumbai.com](http://www.icnc2018mumbai.com)

## INTERNATIONAL DELEGATE REGISTRATION

### REGISTRATION PACKAGES

Membership	ICNA Member	Non ICNA Member	Accomp. Person	ICNA Member	Non ICNA Member	Accomp. Person	ICNA Member	Non ICNA Member	Accomp. Person
Dates:	Early Bird Registration 30th June 2018			Regular Registration October 31st 2018			Late Registration November 1st 2018		
A. High Income Countries	750	800	300	800	850	300	950	1000	300
B. Middle High Income Countries	450	500	300	500	550	300	650	700	300
C. Middle Low Income Countries & Low Income Countries	175	225	200	225	275	200	375	425	200
D. Students, Nurses and Paramedical Specialists	100	150	200	150	200	200	300	350	200

### INCLUSIONS

- Registration to the Conference includes Access to all sessions (Including Breakfast Courses). Masterclass & Workshops are not a part of your inclusions.
- Access to the Exhibition, Conference Materials Coffee Breaks, Lunches, Welcome Reception and Banquet\*
- Taxes included

### NOTE:

- Membership to ICNA is free. Please register yourself as a member of ICNA prior to registering for this meeting to avail of the special rate for ICNA members.
- All delegates registering under Category D must submit the necessary supporting documents to establish either country of work or category of occupation.

### CONFERENCE HIGHLIGHTS :

- Illustrious International and National faculty
- Scientific topics like Epilepsy, Sleep Disorders, Autoimmune Disorders, Demyelinating Syndromes, Zika Virus Infection, Perinatal brain Injury, Autism Spectrum Disorders, Genetics in Child neurology, Movement disorders, The leukodystrophies, Pediatric Stroke, Neurological Critical Care & many more ...
- 6 Workshops on practical based neurological topics
- Interactive Masterclass Sessions
- Orations and invited lectures
- Stimulating programs like plenary sessions and symposium

### PAYMENT:

- To pay online via credit/debit card log on to " www.icnc2018mumbai.com. "
- Cheque/ DD, payable to "ICNC 2018 Mumbai"
- Add Rs. 100 for outstation cheques (not required for at par cheques).

**Early Bird Registrations till 30<sup>th</sup> June 2018**

Office No. 4, Ground Floor, Anmol Co. Op. Housing Society, Sakharam Keer Road, Shivaji Park, Mumbai - 400 016. Tel. No. 022 2438 3498/ 99 Email - vamahospitality@hotmail.com/icnc2018mumbai@gmail.com

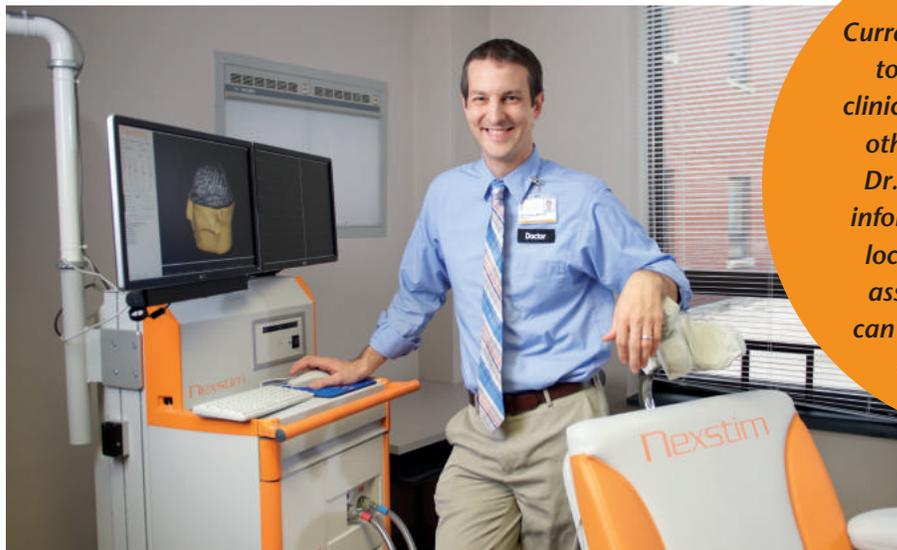
[www.icnc2018mumbai.com](http://www.icnc2018mumbai.com)

# CONNECTING WITH COLLEAGUES

## Focus on Young Researchers

### Thinking Outside the Lesion: Lesion Network Mapping

By Daniel J. Bonthius, MD, PhD | *CNS Connections* Editor



Aaron Boes, MD, PhD

*Currently, neurologists' ability to accurately predict the clinical outcome of stroke and other focal lesions is poor. Dr. Boes hypothesizes that information regarding lesion location and the networks associated with the lesion can improve the accuracy of outcome predictions.*

Important advances in neurology often begin with an intellectually curious physician observing an interesting patient. Such was the case that led Dr. Aaron Boes to the discovery of *lesion network mapping*.

Aaron was a resident in child neurology at Massachusetts General Hospital when he encountered an unusual teenager. The patient was a previously-healthy 17-year-old girl, who had the sudden onset of visual hallucinations. She was previously a straight-A student and captain of her soccer team, but she was suddenly impaired by the presence of vivid visual symptoms, including the perception of objects coming in and out of focus “like a zoom lens” and of the scenery around her being drawn in by crayon. A toxicology screen and head CT scan were negative, but an MRI scan of the brain revealed a small stroke in the thalamus.

Aaron realized that the MRI results could explain the *etiology* of the patient’s symptoms, but could not adequately explain their mechanism. Why would a

small stroke in the non-visual region of the thalamus induce visual hallucinations? Aaron hypothesized that this condition—peduncular hallucinosis—is due to brain dysfunction not restricted to the lesion site itself, but to neuronal networks connected to the lesion.

With the help of his colleagues, Aaron investigated the lesions of 23 patients with peduncular hallucinosis. He utilized the 3D volume of each lesion in a large normative database of functional connectivity MRI to examine the networks associated with each lesion location. In this way, he was able to infer the remote sites impacted by the lesions.

Dr. Boes found that there was much more overlap in the *networks* associated with the lesions than in the lesion locations themselves. He further found that 22 of the 23 studied lesions in peduncular hallucinosis fell along a single network with connectivity to the ventral extrastriate visual cortex, a brain region long-hypothesized to be involved in the generation of hallucinations.

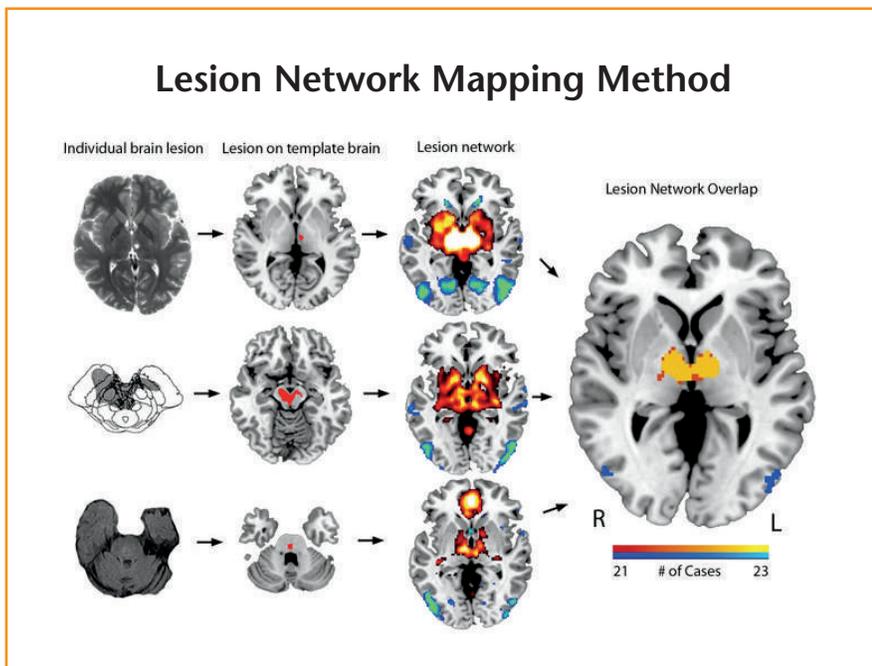
To conduct these studies, Dr. Boes developed a novel method to assess the effects of cerebral lesions on remote brain regions and networks. The technique involves mapping a brain lesion from a clinical scan onto a reference brain, then using the lesion volume as a seed region of interest for a resting state functional connectivity MRI analysis that uses normative data from a large representative cohort (see figure). Aaron named this technique lesion network mapping and published his findings in *Brain* (138: 3061-3075).

Now an Assistant Professor of Pediatrics at the University of Iowa, Dr. Boes utilizes lesion network mapping in several exciting projects. In one project, he is examining the neural basis for posterior fossa syndrome (PFS). Following surgery of the cerebellum, many pediatric patients develop dramatic neuropsychiatric symptoms, including mutism and other behavioral problems. With the use of lesion network mapping, Dr. Boes is examining the neuroanatomical and neural network basis for this syndrome. Elucidation of the involved structures could guide neurosurgical approaches to avoid PFS. In addition, knowledge of the lesion-associated networks could augment rehabilitation for those who develop PFS.

In a second project, Dr. Boes is attempting to improve the accuracy of prognosis following the onset of focal brain lesions. Currently, neurologists' ability to accurately predict the clinical outcome of stroke and other focal lesions is poor. Dr. Boes hypothesizes that information regarding lesion location and the networks associated with the lesion can improve the accuracy of outcome predictions.

In a third set of projects, Dr. Boes is studying TMS. He is working with neurosurgical colleagues, who implant intracranial electrodes, to examine the remote effects of TMS on network dynamics and to identify the basic mechanisms through which TMS improves outcome in some patients with depression. He hopes that understanding the basic mechanisms of TMS will expand its clinical indications.

Dr. Boes' research idea—utilizing network localization to explain symptoms—originated from a single patient with visual hallucinations. The technique is proving versatile and durable, as it is now being used in a wide range of applications, and may, someday, become a standard tool in neurology.



**Figure Legends:** Lesion network mapping involves two steps. First, a brain lesion from a clinical scan is mapped onto a reference brain (columns 1 & 2). Second, the lesion volume is used as a seed region of interest for a resting state functional connectivity MRI analysis that uses normative data (column 3). The lesion-associated networks derived from the latter step can be used for research or clinical applications, providing more information than is available from the lesion location alone.

Dr. Boes directs the Noninvasive Brain Stimulation Clinical Program at the University of Iowa and the Iowa Neuroimaging and Noninvasive Brain Stimulation Laboratory.

# CONNECTING WITH COLLEAGUES

## Committee Rosters

### Strategic Goals of the Child Neurology Society



2018 CNS Executive Committee: Front (L-R): Peter Kang, Mary Zupanc, Gary Clark. Back (L-R): Bruce Cohen, Kenneth Mack, Jonathan Mink, Donald Gilbert, Michael Shevell.

1. Provide current, relevant, and engaging mechanisms for life-long learning among child neurologists  
*Archives, Awards, Electronic communication, Ethics, International affairs, Practice, Research Scientific Program*
2. Establish for the CNS stable and consistent funding sources for specific, longitudinal, targeted initiatives  
*Finance*
3. Achieve awareness among the public and national policy makers of the importance and cost-effectiveness of child neurologist workforce  
*Archives, Awards, Electronic communication, Legislative affairs*
4. Achieve awareness among the public and national policy makers of general health needs and challenges for individuals with chronic neurological conditions of childhood origin  
*Electronic communication, Legislative affairs*
5. Engage and encourage the child neurology workforce of the future  
*Archives, Awards, Electronic communication, International affairs, Membership*
6. Provide a robust infrastructure and consistent direction for the CNS  
*Bylaws, Finance, Long-range planning, Membership, Nominating, Administrative liaison*

#### Archives

**Co-Chairs: E. Steve Roach and Robert Rust**

**Liaison: Michael Shevell**

**Staff Liaison: Roger Larson**

1. Collect and categorize materials of historic significance to the CNS. These materials might include videos or other information about prominent members, information about the founding of the Society, or materials about the development of significant concepts in the field of child neurology.
2. Create displays for the annual meeting that illustrate the career of the Society's award winners or the history of the Society.
3. Pursue and create innovative uses, showcasing, and publicizing of materials created that serve to educate the public and national policy makers about the contributions of child neurology and child neurologists to healthy communities and cost-effective, high-quality health care.

#### Proximate Goal and Deliverable:

The 50th anniversary of the CNS will occur in 2021-2022, beginning with the 50th Annual Meeting of the CNS. The Archives Committee is charged with organizing and presenting historical documents/displays for presentation on-site at the 50th Anniversary Meeting in Boston in October 2021, and on-line before, during and after.

#### Archives Committee Members

Dara Albert (2019)  
Stephen Ashwal (2020)  
James Bale (2021)  
Audrey Brumback (2019)  
Pat Crumrine (2019)  
Francis DiMario (2019)  
Claudio de Gusmao (2019)  
John Mytinger (2019)  
Farooq Osman (2019)  
Phillip Pearl (2021)  
Thomas Reynolds (2018)  
Robert Safier (2019)  
Nina Schor (2021)

#### Awards

**Chair: Nigel Bamford**

**Emeritus: Dean Timmons**

**Liaison: Don Gilbert**

**Staff Liaison: Roger Larson**

1. Solicit nominations and select recipients: Hower and Sachs Lectureships, Roger and Mary Brumback Memorial Lifetime Achievement Awards, and the Arnold P. Gold Foundation Humanism in Medicine Award.
2. Solicit submission of proposals and select recipient: Philip R. Dodge Young Investigator Award.
3. Work with Finance Committee to secure sustainable funding for awards.
4. Work with Archives Committee to ensure publicity of award winners in lay and professional press and to awardees' respective U.S. governmental representatives.
5. Work with Child Neurology Foundation to review and select CNF Scientific Grant/Awards submissions.

### **Awards Committee Members**

John Bodensteiner (2021)  
Daniel Bonthius (2018)  
Harry Chugani (2020)  
Heather Fullerton (2021)  
Jimmy Holder, Jr. (2018)  
Laura Jansen (2019)  
Michael Johnston (2021)  
CJ Malanga (2019)  
Steven Miller (2019)  
Ann Neumeyer (2019)  
Richard Nordgren (2019)  
Colette Parker (2020)  
Mustafa Sahin (2019)  
Michael Shevell (2021)  
Faye Silverstein (2019)  
Alcy Torres (2020)

### **YIA Members**

Jimmy Holder (2018)  
Diana X. Bharucha-Goebel (2019)  
Audrey Brumback (2021)

### **Bylaws**

**Chair: Chaouki Khoury**  
**Liaison: Mary Zupanc**  
**Staff Liaison: Emily McConnell**

1. Ensure the currency and functionality of the bylaws of the CNS.
2. Recommend modifications of bylaws to the Executive Committee of the CNS as is warranted.

### **Bylaws Committee Members**

Mary Andriola (2019)  
Miya Asato (2021)  
Jennifer Hranilovich (2019)  
Lisa Nassif (2018)  
Ed Trevathan (2021)

### **Electronic Communications**

**Chair: David Hsieh**  
**Liaison: Mary Zupanc**  
**Staff Liaison: Roger Larson**

1. Maintain the engaging nature, user-friendliness, relevance, and currency of the CNS website to all potential viewers, including professional and lay community members.
2. Make recommendations to the Executive Committee regarding the implementation of a presence for the CNS on Facebook, Twitter, and other social media venues.
3. Work with the Training (MOC) Committee to provide to CNS members and others online tools for MOC.
4. Make recommendations to the Executive Committee regarding the use of electronic media to educate the public and national policy makers about child neurologists, their patients, and their impact on society at large.

### **Electronic Communications Committee Members**

Jeff Buchhalter (2020)  
Biju Hameed (2018)  
Mary Harbert (2018)  
Doug Larsen (2021)  
Steven Leber (2018)  
Jacki Martindale (2021)  
Mohamad Mikati (2019)  
Aaron Nelson (2018)  
Gary Nelson (2019)  
Julie Parson (2021)  
Sonia Partap (2021)  
Michael Segal (2018)  
Asim Shahid (2019)  
Yen Tran (2019)  
Jenny Wilson (2019)

### **Ethics**

**Chair: William Graf**  
**Liaison: Michael Shevell**  
**Staff Liaison: Emily McConnell**

1. Work with the AAN to provide the child neurology perspective to their discussions, presentations, and publications focused on advocacy and the interface between law and ethics.
2. Develop guidelines and statements to members regarding matters of ethical importance.
3. Publication of such guidelines is encouraged once they have been approved by the CNS Board.
4. Work with the Practice Committee to add the ethics perspective to the practice parameters they develop.
5. Develop seminar or symposium proposal for the Scientific Selection Committee to consider for presentation at each annual CNS meetings.

### **Ethics Committee Members**

Farida Abid (2018)  
Jennifer Armstrong-Wells (2019)  
Sheila Asghar (2019)  
Nancy Bass (2018)  
Meghan Candee (2019)  
Deepti Chrusciel (2019)  
Leon Epstein (2019)  
Shaun Hussain (2019)  
Sudha Kessler (2019)  
Monica Lemmon (2019)  
Donita Lightner (2018)  
Robert Nahouraii (2019)  
Renée Shellhaas (2018)  
Anu Venkat (2019)  
Courtney Wusthoff (2019)

# CONNECTING WITH COLLEAGUES

## 2018 Committees and Charges | continued

### Finance

**Chair: Cynthia Stack**  
**Liaison: Bruce Cohen**  
**Staff Liaison: Roger Larson**

1. Serve as the interface between BNY Mellon and the CNS in ensuring that BNY Mellon understands the strategic goals and targeted purposes of the CNS investments and that the CNS Executive Committee understands the recommendations of BNY Mellon.
2. In accordance with the strategic goals and targeted purposes of these investments, make quarterly recommendations to the Executive Board regarding the investments of the CNS.
3. Monitor current investments and investment strategies.
4. Review the annual CNS budget and monitor progress toward meeting the budget.
5. Work with the Long-range Planning Committee to identify and secure potential sources of sustainable funding (e.g., endowment funds, annual donations) for specific initiatives of the CNS.

### Finance Committee Members

Usha Dayal (2020)  
O'Neill D'Cruz (2019)  
Charles Gay (2018)  
Lori Jordan (2021)  
Soe Mar (2021)  
Migvis Monduy(2019)

### International Affairs

**Chair: Jorge Vidaurre**  
**Liaison: Ken Mack**  
**Staff Liaison: Emily McConnell**

1. Foster interactive and collaborative initiatives with ICNA.
2. Recommend 1-2 D'Souza awardees to the CNS Executive Committee. Upon approval, publicize this

extensively worldwide, especially in Asia and Africa, through instruments that are distributed to medical societies of these regions.

3. Work with the Scientific Selection Committee to plan and implement stimulating seminars for future CNS meetings on such topics as international medical graduates and global health care delivery and quality.
4. Work with ICNA to plan, budget and implement joint educational outreach projects in developing countries
5. Provide key input and interface for planning, publicizing, and staging of 2020 Joint CNS-ICNA meeting in San Diego, CA.

### International Affairs Committee Members

Marie Acosta (2018)  
Sonika Agarwal (2019)  
Aniklumar Arayaparambil (2019)  
Tonya Balmakund (2018)  
Sonal Bhatia (2019)  
Harry Chugani (2019)  
David Clarke (2019)  
Jason Coryell (2019)  
Jay Desai (2019)  
Terence Edgar (2019)  
Erin Fedak-Romanowski (2019)  
Satyanarayana Gedela (2019)  
Debrata Ghosh (2019)  
Sailaja Golla (2019)  
Ajay Gupta (2018)  
Himali Jayakody (2018)  
Agustin Legido (2020)  
Mirjana Maletic-Savatic (2019)  
Dana Marafie (2018)  
Mubeen Rafay (2019)  
Rosario Riel-Romero (2019)  
Mary Spiciarich (2019)  
Edwin Trevathan (2019)  
Pedro Weisleder (2018)

### Legislative Affairs

**Chair: Bennett Lavenstein**  
**Liaison: Jon Mink**  
**Staff Liaison: Roger Larson**

1. Work with the Practice, Research, and Long-range Planning Committees to develop materials, marketing/ PR strategies, and interactions with other organizations and governmental agencies that promote and publicize the importance of the child neurology workforce to enhancement of the quality of health care for, enhancement of the health and well-being of, and decrease in the cost of health care services for children and families.
2. Identify, create, and operationalize venues and events for interaction between governmental and organizational leaders with members and leaders of the CNS to promote advocacy for children with special healthcare needs, child neurology, and the child neurology workforce.
3. Identify for the CNS Executive Board those initiatives the CNS and CNF should undertake jointly with AAN, ANA, AAP, FASEB, SFN, COPS, FOPO, and/or APS-SPR and those the CNS and CNF should embark upon alone.
4. Propose to the Scientific Selection Committee seminars and/or symposia for future annual meetings on topics of relevance to legislative affairs and child neurology.
5. Proximate Goal and Deliverable: See this section under "Research Committee" and "Practice Committee".

### Legislative Affairs Committee Members

Miya Asato (2019)  
Timothy Feyma (2020)  
Hannah Glass (2020)  
John Ingram (2018)  
Michael Lopez (2019)  
Sohail Malek (2019)  
Mark Mintz (2019)

E. Brannon Morris (2020)  
Richard Nordgren (2019)  
Vinay Puri (2019)  
Karen Spencer (2019)  
Liu Thio (2019)

## **Maintenance of Certification**

**Chair: Yolanda Holler-Managan**

**Liaison: Don Gilbert**

**Staff Liaison: Emily McConnell**

1. Review evolving ABPN Maintenance of Certification and Lifelong Learning requirements pertaining to child neurology and work with National Office Staff to ensure CNS members are aware of MOC resources available to them through the CNS website
2. Continue to develop a "library" of self assessment exam questions to add one new exam every two-years
3. Work with ABPN and CNS Executive Committee on planning and implementation of ABPN Pilot Project exploring use of journal article-based assessment in lieu of proctored MOC Part III Examination.

## **Maintenance of Certification Committee Members**

Nancy Bass (2020)  
Paris Bhattarai (2019)  
Heidi Blume (2020)  
Stephen Deputy (2020)  
Carolyn Green (2020)  
Gina Jones (2019)  
Lenora Lehwald (2019)  
Carey Lockhart (2019)  
Louise Manganas (2018)  
Mark Mintz (2020)  
Erin Neil (2018)  
Diane Sieciechowicz (2018)  
Jan Wollack (2019)  
Ann Yeh (2020)

## **Membership**

**Chair: Francis Filloux**

**Liaison: Michael Shevell**

**Staff Liaison: Emily McConnell**

1. Review the credentials of applicants for membership in the CNS and provide recommendations to the Executive Board.
2. Explore mechanisms to expand the list of individuals (NPs, Psych, etc.) eligible to join the CNS and present recommendations to the Bylaws Committee.
3. Work with the Electronic Communications Committee to pursue mechanisms to enhance prevalence of membership in CNS among child neurologists, particularly in the U.S. and Canada.
4. Work to ensure that the membership of the CNS is, in its diversity, broadly representative both of the membership of the CNS and of the patients, families, and workforce for whom the CNS advocates.

## **Membership Committee Members**

Jhabali Balmakund (2018)  
Debra Byler (2018)  
Emily de los Reyes (2021)  
Susan Koh (2019)  
Jean Baptiste LePichon (2018)  
Mary Spiciarich (2019)  
Kaleb Yohay (2020)

## **Nominating**

**Chair: Ken Mack**

**Liaison: Jon Mink**

**Staff Liaison: Roger Larson**

1. Identify potential candidates to serve as officers of the CNS.
2. Recommend to the Executive Board at least two candidates and one alternate candidate for each office in time for review and approval by the Board prior to the general membership election.

3. Work to ensure that the membership of the Executive Board is, in its diversity, broadly representative both of the membership of the CNS and of the patients, families, and workforce for whom the CNS advocates.

## **Nominating Committee Members**

Amy Brooks-Kayal (2021)  
William Gaillard (2019)  
Andrea Gropman (2019)  
Kara Lewis (2021)

## **Practice**

**Chair: Jeffrey Buchhalter**

**Liaison: Bruce Cohen**

**Staff Liaison: Emily McConnell**

1. Work with the Legislative Affairs and Long-range Planning Committees to develop materials, marketing/ PR strategies, and interactions with other organizations and governmental agencies that promote and publicize the importance of the child neurology workforce to enhancement of the quality of health care for, enhancement of the health and well-being of, and decrease in the cost of health care services for children and families.
2. Develop and review evidence-based clinical practice guidelines alone and with other clinical societies and organizations for approval by the CNS Executive Committee.
3. Work with the Electronic Communications Committee to disseminate the materials developed above.
4. Work with the Scientific Selection Committee to plan and implement stimulating seminars for future CNS meetings on topics of relevance to clinical child neurology practice.
5. Work with AAN Practice Committee identifying and developing practice guidelines relevant to child neurology.

# CONNECTING WITH COLLEAGUES

## 2018 Committees and Charges | continued

### **Proximate Goal and Deliverable:**

The Practice Committee is charged with continuing to work toward an electronically distributed set of “talking points” for CNS members to use in their interactions with the lay press, governmental groups, and clinical practitioners in other disciplines as to the importance of the child neurology workforce to enhancement of the quality of health care for, enhancement of the health and well-being of, and decrease in the cost of health care services for children and families.

### **Practice Committee Members**

Cigden Akman (2019)  
Denis Altman (2021)  
Heidi Blume (2018)  
Michael Fayad (2018)  
Cary Fu (2021)  
Donald Gilbert (2019)  
Zachary Grinspan (2018)  
Vinita Knight (2018)  
Michael Kohrman (2019)  
Rebecca Lehman (2021)  
Deepa Menon (2019)  
Michael Noetzel (2019)  
Joseph Pinter (2020)  
Howard Schub (2019)  
Jeff Waugh (2020)  
Elizabeth Wells (2019)  
Lily Wong-Kiesel (2019)

### **Research**

**Chair: Barry Kosofsky**  
**Liaison: Jonathan Mink**  
**Staff Liaison: Emily McConnell**

1. Work with the NIH and the membership of the CNS to identify priorities for research funding in child neurology.
2. Work with the CNF and the Legislative Affairs and Electronic Communications Committees to develop and disseminate to lay and professional audiences written materials that promote and publicize the importance

of child neurology and developmental neurobiology research to enhancement of the quality of health care for, enhancement of the health and well-being of, and decrease in the cost of health care services for children and families.

3. Work with the Scientific Selection Committee to plan and implement stimulating seminars for future CNS meetings on topics of relevance to child neurology research and fostering of the careers of developmental neurology and neurobiology physician-scientists.
4. Liaison with NIH and Child Neurology Career Development Project in planning and staging of annual retreat.

### **Research Committee Members**

Mohammed Amuqbil (2019)  
Erika Augustine (2021)  
Joshua Bonkowsky (2018)  
Amy Brooks-Kayal (2021)  
Gabrielle deVeber (2020)  
Erika Finanger (2019)  
Heather Fullerton (2017)  
Adam Hartman (Ex Officio) (2021)  
Michael Johnston (2020)  
Steven Maricich (2018)  
Yu-tze Ng (2019)  
Scott Pomeroy (2020)  
Brenda Porter (2021)  
Deepa Rajan (2019)  
Jong Rho (2019)  
Brad Schlaggar (2021)  
Elliott Sherr (2018)  
Janet Soul (2021)  
Kevin Staley (2020)

### **Scientific Selection & Program Planning**

**Chair: Erika Augustine**  
**Liaison: Don Gilbert**  
**Staff Liaison: Emily McConnell**

1. Develop the scientific program for the annual meeting.
2. Review and select abstracts for presentations.

3. Create a program that ensures an appropriate balance between clinical and scientific topics. Explore and recommend to the Executive Board novel mechanisms of presentation such as poster symposia.
4. Work with the President of the CNS and the CNS National Office to coordinate satellite symposia at the annual meeting.
5. Work with the CNS staff to assess and formulate best response to the annual meeting evaluations.

### **Proximate Goal and Deliverable:**

Oversee integration of multiple co-temporal and regularly occurring symposia and forums that are not fully integrated administratively and programmatically into the CNS Annual Meeting at present.

### **Scientific Selection & Program Planning Committee Members**

Gyula Acsadi (2018)  
Nigel Bamford (2019)  
Brenda Banwell (2018)  
Joanna Blackburn (2021)  
Keith Coffmann (2020)  
Alex Cohen (2018)  
David Dredge (2019)  
Leon Dure (2021)  
Howard Goodkin (2020)  
Ajay Gupta (2019)  
Shafali Jeste (2019)  
Yasmin Khakoo (2018)  
Laura Lehman (2019)  
Warren Lo (2018)  
Ganesh Mochida (2019)  
Marc Patterson (2021)  
Toni Pearson (2020)  
Eugene Schnitzler (2019)  
Carl Stafstrom (2019)  
Liu Lin Thio (2021)  
Laura Tochen (2021)  
Keith Van Haren (2021)  
Yvonne Wu (2020)

# CONNECTING WITH PARTNERS

## Professors of Child Neurology



Gary Clark, MD  
President, PCN

### Dear Colleagues

This is a most remarkable time to be a child neurologist and a neurodevelopmental pediatrician. New treatments for heretofore untreatable and fatal neurological diseases have been championed, new genetic tests allow us to identify the cause of neurologic disease in ever increasing percentages of children, and the demand for clinical research to prove efficacy and safety of new, sometimes invasive, interventions and treatments is increasing. So how do we prepare our trainees and our training programs for the present and the future of a dramatically changing field?

I propose that we spend some time during the PCN Meeting in Chicago on October 15 talking about changes to programs that can help prepare for this future. In the past, the CNS has had a core curriculum that we have all been able to modify and utilize in our training programs. It is time for an update to that curriculum.

Our bylaws have not been modified since the inception of the PCN; it is time to update those

too. Proposed changes include formalizing the reality of online elections, recognition of neurodevelopmental pediatrics as part of our membership and charge, and the inclusion of program coordinators as non-voting associate members.

The proposed bylaw changes will be announced in the spring and subsequently voted upon on-line along with the election of a PCN President-elect. Two very capable program directors have been nominated to run for this office—Karen Keough and Tim Lotze—both of whom are currently serving as Councillors on the PCN Executive Committee.

So, please look for the announcement for this election and please participate in the election! Typically, only a minority of programs participate and therefore a minority determine the future of the PCN. Let's change that in this election cycle and prove that we all want a stake in the remarkable future of our profession.



Professors of Child Neurology Board Members: (L-R) Drs. Karen Keough, David Urion, Tim Lotze, Steve Leber, Gary Clark.



*Program Coordinators of Child Neurology*  
The PCCN met for the first time in 2015, following up in 2016 and 2017. A news update and agenda for the 2018 meeting will be posted in the Spring "CNS Connections".

# CONNECTING WITH PARTNERS

## Association of Child Neurology Nurses



Tara Pezzuto, APRN  
President, ACNN

### Dear Colleagues

By Tara Pezzuto, APRN | President, Association of Child Neurology Nurses

**W**e had a wonderful time in Kansas City where we had nurses from 29 states and Canada, and a fifty-fifty split between APRN and RN delegates. We had a record high 12.5 CEU's offered and some great conversations in our specialty interest groups. ACNN would love to continue these conversations and others through our newest communication opportunity on the *Connect* site of the CNS website (<http://connect.childneurologysociety.org/home>). We are actively planning for Chicago where our 2018 conference will be held at The Hyatt Regency on October 15-18. The meeting will run Monday thru Wednesday rather than the traditional Wednesday thru Friday.

ACNN has had exciting expansion in membership and resources for our members in the last few years. *The Child Neurology Encounter Guide* and the soon to be released *Caregiver Resource Guide* are outstanding examples of how we can enhance the opportunity for our members to provide excellent care to our communities. The presenters at our conferences have been increasingly impressive in the expansion of quality improvement and research to contribute to evidence based practice. ACNN will be happy to support further research and quality improvement projects through our Hobdel grant and travel grants to help support you in getting here to present your projects.

ACNN encourages all our members to join our committees and share your suggestions for improvement in the future. Please consider yourself and your colleagues as nominees for our innovative practice award, our nurse practitioner award and our Claire Chee nursing excellence award. We will be sending out email blasts to help remind you of deadlines for these awards and applications to 2018 presentations. Remember the annual 5K walk/run and gather your group to have fun in Chicago and raise money for future ACNN grants.

In the next few years we would like to take it further in providing the next generation of child neurology APRN providers and RNs with the resources necessary to transition to care. We look forward to hearing your suggestions for the process through our communication board on *Connect*. We will keep pressing forward to provide education and networking opportunities for all neurology nurses.

*The Child Neurology Encounter Guide and the soon to be released Caregiver Resource Guide are outstanding examples of how we can enhance the opportunity for our members to provide excellent care to our communities.*





ACNN President, Maureen Sheehan (R) presents the 2017 ACNN Nurse Practitioner Excellence Award to Rebecca Schultz.



Jennifer Boyd (C), the 2017 recipient of the Claire Chee Award for Nursing Excellence, is flanked by Claire Chee (L) and Maureen Sheehan (R).



Winner of the 2017 ACNN Innovative Clinical Practice in Child Neurology Nursing Award, Elizabeth Rende, is flanked by Amy Vierhile (L) and Maureen Sheehan (R).



ACNN Board Members (L-R): Maureen Sheehan, Rebecca Schultz, Mona Jacobson, Tara Pezzuto, Sue Yudovin, Jennifer Coffman.



## ACNN Award for Innovative Clinical Practice in Child Neurology Nursing Deadline is March 15, 2018

This award recognizes an ACNN Member who has demonstrated and implemented an innovation in Child Neurology clinical practice.

Do you work with a nurse who has discovered a creative way to help your practice meet the needs of your patients and their families? Last year's winner of this award, Elizabeth Rende, DNP, RN, CPNP-PC, from Duke University Medical Center, created the Migraine Action Plan (MAP) for the prevention and treatment of headaches in schools.

The recipient will receive a monetary award equal to the registration fee for the annual CNS/ACNN conference. The winner is expected to submit an abstract for presentation during the ACNN meeting. Please reach out to your nurse colleagues, recognize the work they do, and help them get to Chicago to share with all of us what they have learned.

<http://cns.nonprofitcms.org/a/Solicitations/Home/1150>



Child Neurology Society  
 1000 West Cty Rd. E, Suite 290  
 St. Paul, MN 55126

NON PROFIT ORG.  
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Forty-Seventh  
**CNS**  
 ANNUAL MEETING  
 October 15-18, 2018  
 CHICAGO, ILLINOIS

October 2018

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	<b>15</b>	<b>16</b>	<b>17</b>	<b>18</b>	19	20
21	22	23	24	25	26	27
28	29	30	31			



**This year's meeting  
 (and this year's meeting only)  
 will run from  
 Monday thru Thursday.**

**Remember to mark your calendars, make your reservations, and book your flights to arrive on Sunday night or Monday, NOT your traditional Tuesday/Wednesday grand entrance.**