



TOP 8 of 2018

CONTRIBUTIONS

Cementing its **IMPACT**
in the child neurology community



In the past few years, CNF has made great strides to create new resources, reach more families, and offer the best support to the child neurology community. For 2018, we thought that we'd finish off the year by sharing some of our biggest contributions.

Thank you all for being a part of the CNF community.

We're excited for the year ahead, and can't wait for you to join us for everything we have planned.

Without further ado, here's our Top 8 of 2018!

Thank you

—Amy Brin Miller, MSN, MA, PCNS-BC
Executive Director/CEO

1

Connecting the child neurology community in 50 states and 58 countries!



CNF's Family Support & Empowerment Program (FSEP) offers a direct connection with experienced, compassionate peers who help families navigate life with a neurologic condition.

CNF partnered with Global Genes to offer a pre-session to the RARE Patient Advocacy Summit. **Peer Support Bootcamp** was held on October 2, 2018 in Irvine, CA. It brought together people who were already engaged in some level of providing peer support to families/caregivers in their disease communities, and were interested in elevating the provision of that support.

www.childneurologyfoundation.org/fsep/

From Bootcamp Participants:

"This was a wonderful and informative session."

"Great meeting!"

"The speakers were excellent. This was more of an experience (journey) than a workshop!"

2

Valuing relationships



In 2018, CNF began hosting intimate events throughout the country to make new friends and reconnect with old!

Our June FRIENDRaiser event in Minneapolis provided a forum to meet-and-greet with local leaders, philanthropists, clinicians and families. CNF showcased their programs and how they enrich the child neurology community.



3

Advancing the patient & caregiver voice in physician education



Transitions was the focus of this year's CNF annual symposium – **Not Your Typical Transitions Symposium: How to Integrate Transition into Your Practice and Successfully Transfer Your Patients to Adult Providers**, at the CNS Annual Meeting on October 18th in Chicago. In addition to receiving tools and resources, participants heard what neurologists and families/caregivers are saying about transition needs, learned coding and payment strategies for transition-related services, and matched real-life case studies to current CNF resources. The symposium was a great success with much engagement from the 160-person audience.

www.childneurologyfoundation.org/transitions/

“CNF’s symposiums at the CNS annual meeting continue to impress! The integration of the patient perspective provides a whole new experience than the typical CME format.”

4

Tackling complex and divisive issues: Access to Critical Therapies Summit



Along with Global Genes, CNF convened over 200 stakeholders from the advocacy, provider, industry, and payer communities on Friday, October 5th to discuss the value of therapies within the rare pediatric population. This first-of-its-kind summit provided level-setting qualitative data from stakeholder interviews, as well as cost-effectiveness modeling on therapies. Working sessions for stakeholders to discuss strategies for solutions were facilitated, and data was captured and shared with invitees post meeting with the intention of fueling subsequent, balanced, and comprehensive conversations amongst stakeholders.



5

Supporting all members of the child neurology community

Each year, CNF awards research grants, medical student scholarships, advocacy awareness community grants and family grants to empower all stakeholders in our shared community! In 2018, CNF awarded over \$230,000 in grants and scholarships!

www.childneurologyfoundation.org/providers-or-researchers/research-grant-opportunities/

This year, we were lucky enough to have...



2018
PERF Elterman
Research Grant Recipient

Hsiao-Tuan Chao, MD, PhD
Baylor College of Medicine
Deciphering the
Regulatory Landscape
of Inhibitory Signaling in
Neurodevelopmental Disorders



2018
PERF Shields Research
Grant Recipient

April Levin, MD
Boston Children's Hospital
Electrophysiological
Markers of Neural Network
Timing in Autism



2018
Neurodevelopmental
Disorders Medical Student
Summer Scholarship
Recipient

Ms. Brittany Charsar, MD,
PhD candidate
Thomas Jefferson University
Classification of Mutations in
TUBB4A: A New Spectrum
of Disease

2018
Rise Grant
Awardees



2018 Disease Awareness Building Grant Recipients



6

Sharing knowledge and connections

CNF's clinical expertise and commitment to collaboration, fuels our provision of innovative patient & family resources!

Peer Support Collaborative Workgroup

- Conducted literature review and qualitative needs assessment to better inform the child neurology community on the effective intervention of peer support
- Distributed Workgroup's recommendations for the child neurology community
- Promoted the importance of healthy, accessible peer support

www.childneurologyfoundation.org/fsep/cpswg/

SUDEP Resources

We worked together with the larger child neurology community to develop a set of resources to help families learn about the risks of SUDEP and manage their child's seizures with an actionable plan.



* Forms are available downloadable and fillable, as well as in Spanish

www.childneurologyfoundation.org/programs/sudep/

7

Effectively interfacing with industry partners

CNF is proud of its 2018 Corporate Advisory Board (CAB)! Our members provide their unique expertise and perspectives on the issues and needs facing the child neurology community. CNF's 2018 CAB boasted several innovative examples of balanced partnership between an advocacy organization and industry, such as a Transition Project Advisory Committee, Infantile Spasms Action Network and our pilot project in the SUDEP space!

A huge thank you to our 2018 CAB!



8

Leading by example

CNF's Board of Directors provide strategic oversight to our mission in action! We are proud of its multi-disciplinary nature, and the robust expertise they integrate into our leadership.

www.childneurologyfoundation.org/who-we-are/



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And a #9 in 2019...

You!

Join us in 2019! In the new year, we'll have more opportunities to share stories, get involved, and support CNF's great programs. Keep your eyes on our O&A Newsletter for updates throughout the year, and head over to our website to make a donation today.

www.donatenow.networkforgood.org/childneurologyfoundation



**Child
Neurology
FOUNDATION**
Creating a Community of Support