



Child  
Neurology  
FOUNDATION  
Creating a Community of Support



TOGETHER,  
WE ARE **ALL**  
child  
neurology

# 2019

A YEAR IN REVIEW





## DEAR CNF COMMUNITY,

As I enter my 6th year with CNF, I'm incredibly humbled to think of our journey. This is the longest in my career that I've stayed in one job, and that's probably because this isn't really a job - it's a passion. Looking back, and seeing how far we've come, I cannot believe that CNF was relaunched right from my dining-room table. It's been a steady climb ever since. This year, we experienced our most growth yet. Not just in our team, but in our voice and in our brand. In 2019, I loved walking into meetings, joining calls or receiving emails where patients, advocates, physicians, researchers or community leaders were like - "Oh, you are CNF! I've heard about you - you all are doing really big things." My absolute favorite was hearing someone say, "I've been in the child neurology community for decades, and I remember a time when I had never heard of CNF. And now people are talking about you everywhere I go!" There is a palpable buzz in the community about CNF, and we are committed to being its good steward. We also want to acknowledge that while the team here at CNF has worked hard to create programs and resources that warrant such buzz, the thing that is really at the center of all of this excitement is all of you! CNF's work centers on collaboration, and it is a direct reflection of the talent, empathy, passion, and drive of the entire child neurology community. Together, each and every one of us plays a vital role in child neurology, and elevating the quality of life for our kids.

As we kick off 2020, there will be no part of CNF that plays small. Look for big moves aimed at gigantic impact. We don't want to just improve care for children and families living with neurologic conditions; we want to change the whole dang game. Tomorrow's children need us to take courageous leaps today. As I told the team in early fall... better hit the gym now and get some rest, CNF is about to launch a running and passing game!

In the meantime, please join us in reflecting on our 2019 journey.

Sincerely,

**Amy E. Brin**  
CEO and Executive Director





# WE GREW

This year, we expanded the CNF staff team in a major way. Up until this year, believe it or not, the CNF team was made up of only a few staff members, and a network of contractors to fill in when needed. We still have a network of contractors to help out with things like website updates, but we also have a larger core team to help CNF create a bigger impact in our community, and to make sure that our programs and outreach directly connect with more families. With this larger core team, we've been able to attend more conferences, connect with more advocacy groups, collect more stories from our community, expand our resources, and convene more sensitive, but needed conversations in our community. Thank you for coming along with us on this journey as we work to serve the child neurology community. Together, we are all child neurology. And we couldn't do this work without you.





# WE CAME INTO OUR OWN

This year, along with our team growing physically, we also grew in so many other ways.

## We found our voice

This year, we began to build a culture of storytelling at CNF, and we started by telling our audience more about our organization, and bringing you into the process of growing our organization and programs. We also connected with so many of you about the ways that you'd like to share your own stories with our audience in the year ahead.

Our messaging shifted to include the whole child neurology community. We bring together voices from all different stakeholders and we wanted to reflect this in the way that we talk about CNF. Every voice in our community is important in providing the best care possible to children with neurologic conditions. The voices of families, physicians, parents, caregivers, teachers, nurses, researchers. And thus, our new tag line was born.

Together, we are ALL child neurology.

## We took a new direction with industry

Our relationship with industry became more intentional as we shifted our Corporate Advisory Board membership to be by invite only. In making this change, we are ensuring that all of our industry partners are strongly in line with our values.

Our CAB interactions have evolved into mutually-beneficial dialogues; exchanging insights from patient, healthcare provider and industry points of view.

## We solidified our values

In 2018, our Board of Directors began brainstorming a set of Core Values that truly capture the spirit of our organization, and everything that we hope to embody in our work. After a thoughtful discussion at our February 2019 Board Meeting, we finalized CNF's Core Values:



### PROFESSIONALISM

#### Professionalism


We treat others as they would want to be treated. We are collegial and respectful in our professional relationships. We are dedicated to expanding our knowledge, being innovative, and understanding the perspectives of others. We honor and respect difference and diversity in all its forms. We strive to exhibit excellence in our work.



### INTEGRITY

#### Integrity

We are accountable for our commitments and our actions. We are committed to ensuring the interests of the children and families we serve come first. We promote honesty and transparency in our relationships with each other and our collaborators.



### COLLABORATION

#### Collaboration

We work humbly, to identify and understand the urgencies and challenges facing our shared community; we know that they cannot be overcome alone. Whenever possible, we earnestly collaborate on the actions, programs, and initiatives we engage. We want to go farther, so we go together.



### STEWARDSHIP

#### Stewardship

We are committed to being good listeners and to act in responsive service to the needs of the child neurology community. We are respectful stewards of the relationships and stories shared with us. We are empathetic, compassionate, and positive.





# WE CONTINUED SOME GREAT INITIATIVES

Our programs continue to evolve to reach a larger audience, and more members of the child neurology community. We've heard from physicians and families to help improve our programs to serve you better.

## Transitions of Care

For children living with neurologic conditions, the transition to adulthood can be a challenging experience. In addition to grappling with every day questions that come along with growing up, there are additional things to consider: How will they make the transfer from a child neurologist to an adult neurologist? Will they be able to live independently? Will the same social supports be available once they are an adult? It's not just families asking these questions – neurologists want the best for their patients and families, too.

In 2019, we:

- Presented on Transitions of Care, our 8 Common Principles, and tool-kit to disease-specific communities.
- Hosted an event at the American Academy of Neurology Annual meeting to help facilitate conversations between adult and child neurologists.
- Convened the Transition Project Advisory Committee; with a special focus on the emerging educational trend of supportive decision-making within the context of transitions of care.

Thank-you to [Greenwich Biosciences](#), [Retrophin](#), [Sunovion Pharmaceuticals, Inc](#), [Ultragenyx Pharmaceutical Inc.](#), [Ipsen](#), and [Eisai](#) for your support.

## Growth in Partnerships

The Child Neurology Foundation is strongly grounded in collaboration, and the majority of our work is performed in partnerships. This year, we formalized our partnership process.

We get requests to partner all the time; sometimes these requests evolve into long-term collaborations, and other times they're a simple ask to share resources,

and promote each others' work in our different communities.

To facilitate these asks we created a partnerships page on our website, where other advocacy organizations can download resources, link to our calendar, request a conversation, or ask to share an announcement via CNF's social media channels.



## Family Support and Empowerment Program

Since the program began in 2017, FSEP has received inquiries, and helped to support families, from 71 countries and 50 states.

This year, we were able to share the lessons that we've learned with the larger child neurology community. At the 2019 American Epilepsy Society's Annual Meeting, we held a Peer Support Best Practices Workshop in collaboration with AES. There were over 50 attendees from advocacy groups across the country, and they learned about topics like volunteer recruitment, offering peer support, and growing a peer support program. Attendees reported that the opportunity to connect in person with their peers to affirm best practices and learn new skills will fundamentally improve their own efforts in peer support.



“ Peer support can change your life. And if you haven't found someone to lean on, take the effort to find someone. ”

-Wendy Fry, Dravet Syndrome Foundation



“ You don't need to look at life as a full staircase, you just need to take the first step. And I think the first step is to call and ask for help. ”

-Marsha Quinn, Parent to Parent

Thank-you to Ultragenyx Pharmaceutical Inc., Novartis, the American Epilepsy Society, Global Genes, The Brain Recovery Project, Ring14 USA, International Foundation for CDKL5 Research, Dravet Syndrome Foundation, TS Alliance, and Hemispherectomy Foundation for your support.



# WE BEGAN SOME NEW INITIATIVES

You asked and we listened. In 2019, we continued to build new initiatives that address the tough issues faced by the child neurology community.

## Facilitating Important Conversations Between Physicians and Families

In 2018, we conducted a pilot project to address Sudden Unexpected Death in Epilepsy (SUDEP). We partnered with Digital Health Solutions and Greenwich Biosciences to create a module on SUDEP for the Child Health Improvement through Computer Automation (CHICA) system. We tested this module in 5 centers, and saw incredible results. Physicians were previously talking to families about SUDEP 22% of the time, and the pilot increased this number to 50%. Starting this year, we're working to bring CHICA to the rest of child neurology.

We like to think of this project as the child neurology moonshot. Over the next three years, we'll be building CHICA modules to address current chasms in clinical care, as well as a repository of accessible, quality and health-literate patient centric materials.

Just watch where CHICA-Child Neurology takes us next!

Thank-you to our Founding Visionary Founders Greenwich Biosciences (Lead Visionary Partner), PTC Therapeutics and Avaxis.



## Shining a Light on Disruptive and Harmful Behavior

For this year's education in initiative, we took on harmful and disruptive behavior. This is an issue that affects so many families, but they are often at a loss for where to turn.

We sent out surveys to our community and received almost 2,000 responses from caregivers, and over 250 responses from child neurologists. Thank-you to everyone who reached out!

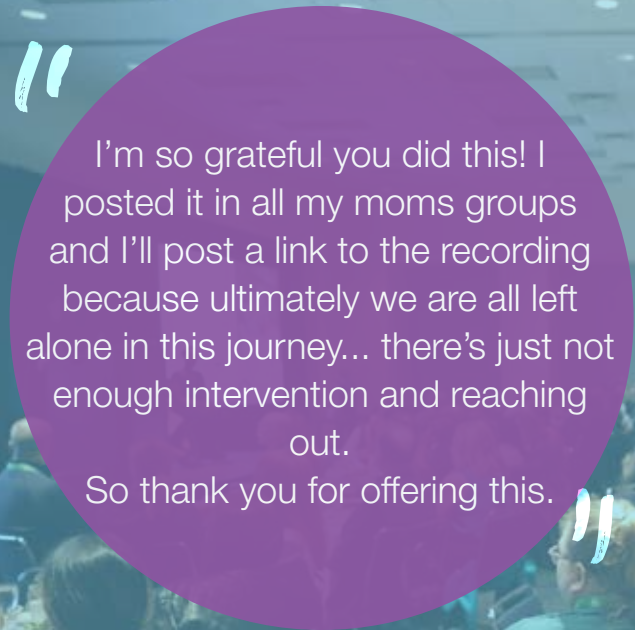
With this information, we hosted our 4th sold out symposium at the Child Neurology Society Annual meeting, where over 200 child neurologists received information on managing harmful and disruptive behavior. We also held a webinar for caregivers that had over 200 attendees and as of the end of 2019, had been viewed online almost 2,000 times in the first 90 days. This is just the beginning. We promise to continue our work to help families and physicians address this difficult topic and work together to move forward.

“

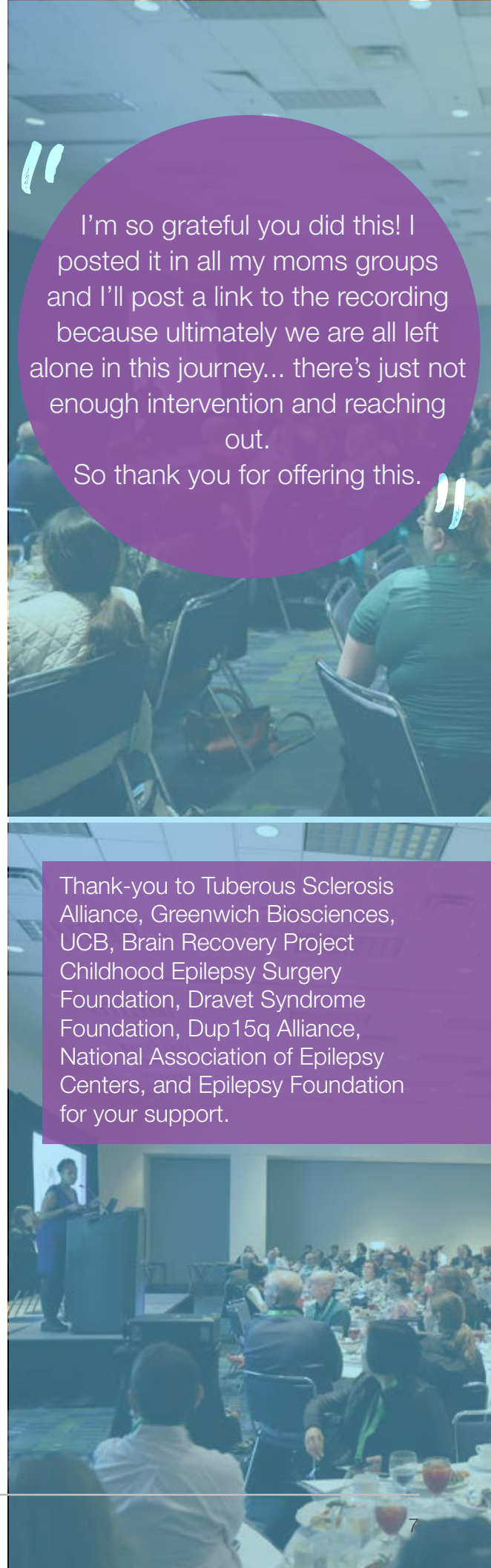
As a child neurology resident, I had to pave my own training plan to learn the field of behavioral child neurology.

This symposium made this sense of impostor syndrome lift from my shoulders to realize this is a common gap in our community. Thank you for the time and space to do so and thank you to the amazing parents who shared their stories.

”



Thank-you to Tuberous Sclerosis Alliance, Greenwich Biosciences, UCB, Brain Recovery Project Childhood Epilepsy Surgery Foundation, Dravet Syndrome Foundation, Dup15q Alliance, National Association of Epilepsy Centers, and Epilepsy Foundation for your support.



## Raising Epilepsy Awareness - 1:26 Art of Epilepsy

We partnered with the Hidden Truths Project and the Child Neurology Society to raise awareness about epilepsy and highlight artists impacted by epilepsy through our first 1:26 Art of Epilepsy Events. These events were held in Newport Beach and Minneapolis, and showcased over 30 artists from around the country, and around the world, who contributed more than 120 pieces of art. The art at these events is often very personal, sharing the journey of epilepsy with the viewer through different artistic mediums, from photography, to video, to paint, to embroidery. Through these events, we were able to talk about epilepsy awareness with over 300 guests, and raise over \$130K to benefit the Child Neurology Foundation's mission in action to improve the lives of children and youth living with neurologic conditions.

Epilepsy- along with a few other health conditions like diabetes and heart conditions-is one of the health concerns I worry most about with my students. The kids appear to be like any other kid, and unless everyone in the school who needs to know about the concern is informed, the student with epilepsy may have safety risks if they were to have seizures. For people who haven't been exposed to them, seizures are very upsetting and even "scary", and I would love for people to understand more about seizures and be prepared to jump in and provide first aid for seizures without hesitation. At the same time, I would love for my students with seizures to feel confident and "normal" and for their classmates to be comfortable around them.

- 1:26 Art of Epilepsy Artist



In 2016, Noam suffered his first tonic-clonic seizure, and as we don't have a history of epilepsy, we did not know what was happening to our 4 year old. Following five random seizures that summer, he was diagnosed with idiopathic seizure disorder. Luckily, he responded to medication and for over two years has been seizure free. Nevertheless, the events profoundly changed our lives and I have been fighting for acknowledgment of his "invisible" disability.

We were turned away from summer camps and our anxiety over the unpredictability of the onset of his seizures was met often with disbelief as Noam is a gregarious, funny, and highly intelligent child without visible signs of neurological issues.

He has been drawing since he was two years old. We have submitted several of his pieces, so you could show the face of another young boy, who suffers with epilepsy. I hope that it can help other families in dealing with everything that entails such neurological issues.

- Parent of 1:26 Art of Epilepsy Artist

Thank you to our presenting sponsor Greenwich Biosciences, as well as the Minnesota Vikings, Eisai, CHOC Children's, Canopy by Hilton Minneapolis Mill District, Sunovion, the Jerome A. Fink Foundation, Upsher Smith, Epilepsy Foundation of Orange County, CA, The Allergan Foundation, the G. A. Fowler Family Foundation, Pioneer Management Consulting, Baker Party Rentals, Jays Catering, Jondo, Arts of Life, Erez Paz, Samsara Wine Company, Lovin Live Music and Davis & Associates.





# WE SUPPORTED OUR COMMUNITY

Sometimes everyone could use a little help. The Child Neurology Foundation was pleased to once again offer grants to young researchers and families in our community.

## Scholarships

CNF is committed to the interdependence of quality patient care and emerging science. To that end, we are proud of our history of funding nearly \$4 million in research grants to emerging scientists. Here are our 2019 recipients.



2019  
PERF Elterman  
Research Grant  
Recipient

Isaac Marin-Valencia, MD,  
The Rockefeller University

Mechanisms of cerebellar circuit  
formation in mitochondrial  
disease



2019  
PERF Shields  
Research Grant  
Recipient

Alexander Cohen, MD, PhD  
Boston Children's Hospital

Using clinical cohorts and  
functional connectivity to  
identify the neuroanatomical  
basis of atypical face  
processing in autism  
spectrum disorders



2019  
Neurodevelopmental  
Disorders Medical Student  
Summer Scholarship  
Recipient

Ms. Emily Isenstein MD,  
MD/PhD candidate  
University of Rochester

Investigating the Differentiation  
and Integration of Visual and  
Proprioceptive Information in  
Children with Autism Spectrum  
Disorder

Thanks to the Pediatric  
Epilepsy Research  
Foundation, and the  
Neurodevelopmental  
Special Interest Group  
for your support.

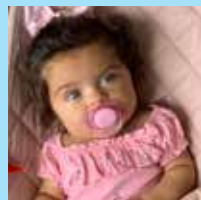
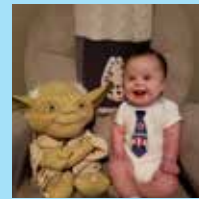
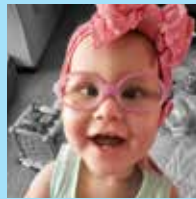
[www.childneurologyfoundation.org/providers-or-researchers/research-grant-opportunities/](http://www.childneurologyfoundation.org/providers-or-researchers/research-grant-opportunities/)

## Family Grants

Since 2014, we have partnered with the Harnett Family in commemorating Infantile Spasms Awareness Week from December 1-7 by offering a \$1,000 grant to a family impacted by infantile spasms. With our partners in the Infantile Spasms Action Network, we were also able to offer RISE grants to 20 families in 2019!

With these grants, families were able to obtain services or equipment that they identified would enhance the quality of life of their child. Items such as a supportive feeding chair or a new bath chair were purchased. Other families were able to bring in further services to their child's medical team like respite care or aqua therapy. CNF is committed to every child reaching his/her full potential, and we are honored to help them RISE up on their way to that bright future.

### Some of our 2019 Rise and Harnett Grant Awardees



# SOME IMPORTANT THANK-YOUS!

## CNF Board of Directors

CNF's Board of Directors provides strategic oversight to our mission in action. CNF was founded by physicians, and we're the only advocacy organization in the neurology space to be actively governed by physicians. Along with a group of some of the top child neurologists in the country, our Board also brings together multi-disciplinary leaders with broad-reaching expertise to inform our leadership as we move forward.

[www.childneurologyfoundation.org/who-we-are/](http://www.childneurologyfoundation.org/who-we-are/)





# CNF Corporate Advisory Board

CNF is proud of its 2019 Corporate Advisory Board (CAB)!

Our members share CNF's Core Values of Integrity, Collaboration, Stewardship and Integrity. We have the opportunity to meet with this group individually, and to convene the larger group to collaboratively work through issues facing the whole child neurology community. Our CAB provides CNF with their unique expertise and perspectives on the issues and needs facing the child neurology community from the industry perspective.





Child  
Neurology  
FOUNDATION  
Creating a Community of Support

TOGETHER,  
WE ARE **ALL**  
child  
neurology