



2021

# ANNUAL REPORT

**CHILD NEUROLOGY  
FOUNDATION**

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[www.childneurologyfoundation.org](http://www.childneurologyfoundation.org)



Dear Child Neurology Community,

It's hard to believe that 2021 is already in the rear-view mirror. This year flew by for us at the Child Neurology Foundation ... as I know it has for many of you, too. The continued pivots with COVID-19 and countless versions of "new normals" made it hard to avoid moments of uncertainty and exhaustion for all of us.



But 2021 has also been an incredible year of reflection, growth and success at the Child Neurology Foundation. We marched steady in our service to the community and held strong in our values of professionalism, integrity, collaboration and stewardship. We rose to meet the needs in our community where they are greatest – providing technology, wi-fi and training to families cut off by the digital divide, educating those in our community who support others, re-writing how advocacy and industry engage with each other, and celebrating the strength of our community in the first ever Child Neurology Awareness Day (and so many other initiatives outlined in this report!) #childneurostrong

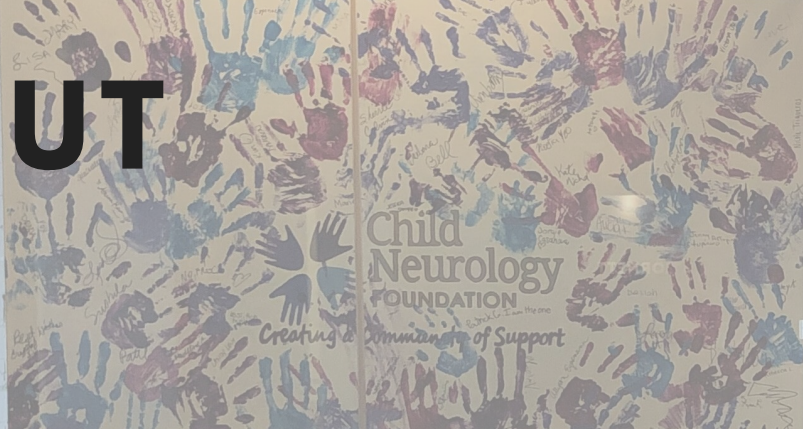
Above all, the real changes that we make together in the lives of our shared community's children and families are our most cherished accomplishments. And we don't do it alone. Rising tides truly do lift all boats. Thank you all for being a part of that rising tide and we look forward to our continued collaborative work in 2022.

In hope and with passion,

Amy E. Brin  
MSN, MA, PCNS-BC  
Executive Director/CEO, Child Neurology Foundation



# ABOUT CNF



## OUR VISION

A world in which all children affected by neurologic disorders reach their full potential.

## OUR MISSION

New addition  
to our mission  
in 2021!



To serve as a collaborative center of education, resources, and support for children and their families living with neurologic conditions, and **facilitate connection with medical professionals who care for them.**

## OUR CORE VALUES

- Professionalism
- Integrity
- Collaboration
- Stewardship

## OUR COMMITMENT TO DEI

As an organization, we are currently on a journey of self-reflection. We are working on:

- Cultivating an inclusive organization
- Providing culturally responsive and accessible resources
- Driving community collaboration

# BETTER TOGETHER FOR KIDS



## CONVENING TO WORK BETTER TOGETHER

This year, we brought together **16 different advocacy and industry leaders** to discuss the reality of these complex relationships, and how to make them more productive.

Participants engaged in 6 facilitated discussions which yielded **deeper insights and opportunities for applied change** between these stakeholder groups. Both groups share a true desire to have a more productive relationship, but exist within frameworks that can make it difficult to understand each other's roles, needs and priorities.

In fact, there was such energy to continue this conversation that CNF will continue it into 2022 with expanded participation!

**16**

**Patient advocates  
& industry  
leaders.**

“

It became abundantly clear that the shared passion advocacy and industry groups hold to find treatments for patients suffering from neurological disorders far outshone the differences.

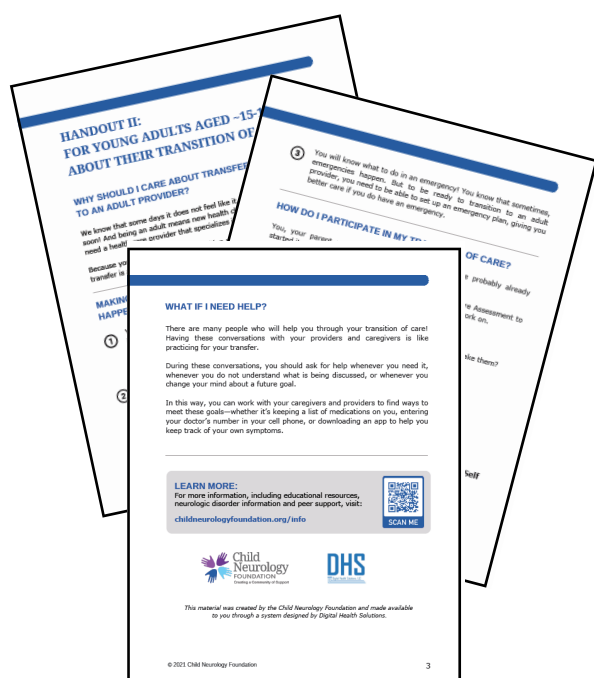
- Advocacy leader

”

Thank you for joining us in the inaugural convening of Better Together for Kids: Batten's Disease Research & Support Association, Biomarin, Dravet Syndrome Foundation, Eisai, FamilieSCN2A Foundation, Global Genes, Greenwich Biosciences, Hope for HIE, Neurelis, PTC Therapeutics, The Cute Syndrome Foundation, TSC Alliance, UCB, Upsher Smith Laboratories, VNS Therapy by Liva Nova.



# CLINICAL DECISION SUPPORT



25

Algorithms  
completed

All education is available in  
English and in Spanish!

CHICA-CN is ready for  
implementation at sites in 2022!

## CHILD HEALTH IMPROVEMENT THROUGH COMPUTER AUTOMATION SYSTEM – CHILD NEUROLOGY (CHICA-CN)

CHICA-CN is a clinical decision support system that presents an agenda to physicians based on a questionnaire filled out by the patient/caregiver in the waiting room.

### How does CHICA-CN help?

**Families:** The patient and caregiver are given a voice in the process.

**Physicians:** Using CHICA-CN is an efficient way to ask and prioritize responses to far more questions than can be asked during a short clinic visit.

**Healthcare Systems:** The improved process by using CHICA-CN saves time and money. Data can be used to maximize the patient experience.

# DIGITAL ACCESS



## BRIDGING THE DIGITAL DIVIDE BY GETTING FAMILIES ONLINE

For children and families living with neurologic conditions, access to digital resources is vital. Digital access is their avenue to telehealth and educational resources. It can truly be a lifeline.

For children living with neurologic conditions and their families, the COVID-19 pandemic has highlighted the need for equitable access to digital resources, as technology is needed to access online healthcare and schooling.

### Digital Access Means:

- Access to telehealth
- Access to community
- Access to online resources

# 100

**Families are now online.**

### Each family recieved:

- Brand new Chromebook
- Hotspot
- One year's worth of data

“You all have made my son happy happy. Thank you so much!”

# DISORDER DIRECTORY



50 +

Disorders added  
and updated

## Pages Include:

Description  
Signs and Symptoms  
Causes  
Diagnosis  
Treatment and Therapies  
Outlook  
Patient Resources  
Family Stories  
Clinical Trials  
Peer Support

## INFORMATION BUILT FOR THE PATIENT COMMUNITY

Families in the child neurology community are continuously in search of high-quality information. Whether they have just received a diagnosis or experienced a pivotal change on their journey with a disorder, they need accurate and credible information.

CNF's updated disorder directory includes new content and provides curated information written by child neurologists and edited professionally.

“ This is the most put-together and thorough, easy to understand explanation I have seen so far. This will be so valuable especially to parents hearing some of these words for the first time when pertaining to their child.

- Parent ”



# 2021 EDUCATION SERIES



## EDUCATION FOR THE ENTIRE COMMUNITY

Our original education series covers timely topics, bringing together experts from all areas - medical professionals, families, advocacy partners, and so many others - for relevant, trustworthy conversations answering questions and concerns we hear from our community.

**3200+**

Engage with our  
monthly education.

### Education Topics Included:

Palliative Care

Spasticity

Gene Therapy

Behavior  
Management

Newborn  
Screening

SUDEP

Siblings

Seizures  
& Diet

**And much more!**

“ Thank you for this discussion, incredibly powerful and helpful.  
- Webinar attendee ”

“ I loved how universally applicable the information shared was.  
-Webinar attendee ”



# NEXT 20

## CELEBRATING 20 YEARS AND PREPARING FOR THE NEXT 20

This year, we celebrated our 20th anniversary. We've accomplished a lot with the help of you, our child neurology community, over the years. **But there is still so much more to be done.**

We are doubling down our effort and tackling issues in our community head on with our new Next 20 Campaign,

# #CHILDNEUROSTRONG

## CHILD NEUROLOGY AWARENESS DAY



October 29, 2021 was the inaugural Child Neurology Awareness Day to increase understanding of childhood neurologic conditions, highlight the spectrum of support for families, and celebrate the strength of the collective community.

**Save the date for next year!**

# PEER SUPPORT



## EMOTIONAL AND PRACTICAL SUPPORT FOR ALL STAGES

For children with neurologic conditions to thrive, families and caregivers must receive support. CNF's Peer Support Program delivers resources and tools that empower caregivers to live healthier lives.

Everyone's situation is unique but being able to turn to someone who has faced similar challenges makes navigating the journey of disease diagnosis, treatment, and management less isolating.

### Peer Support Means:

- Community
- Encouragement
- Support finding resources
- Someone to listen
- Connection

“I just want to talk to someone who gets it.  
- Parent”



**57 diagnoses  
in 2021**

**21 countries  
in 2021**

“I would love for us to just have community.  
- Parent”



## PEER SUPPORT TRAINING

**SOLD OUT**

CNF Peer Support Training, offered for the first time this year, provides a standardized framework to support those in the child neurology community who assist other families and caregivers through the social and emotional challenges of diagnosis, treatment, and management.

The six-week online training included pre-recorded videos and interactive sessions with a Peer Support Trainer. Attendees received a certificate of completion. **Registration sold out within 48 hours.**

“ I sincerely appreciated the amount of detail and flexibility the training offered. - Participant ”

“ This was amazing. Thank you for including me and giving me the opportunity. - Participant ”

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## 2021 WORKSHOP: SETTING BOUNDARIES & MAINTAINING BALANCE

This was the most popular session from our Peer Support Training, so we made it **available at no cost to the entire child neurology community** in an online workshop!

“ It was just so reassuring to know that I am not alone. Having other people share was so incredibly beneficial. - Participant ”

# SHORTENING THE DIAGNOSTIC ODYSSEY



“

We were thrilled to get one [diagnosis]. We expected to strike out across the board. We consider this a huge success!  
– Genetic Counselor

”

## WHOLE GENOME SEQUENCING PROJECT

- Free whole genome sequencing provided for 25 children at five different medical sites.
- Each site that participated got at least one diagnosis.
- **Six families received a diagnosis!!**

## SYMPOSIUM AT CNS

- Opening event at Child Neurology Society Annual Meeting.
- Three hour **sold out symposium.**
- 200+ child neurologists attended the in-person symposium and 700+ viewed it online.

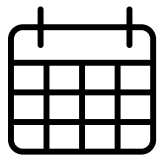


## FAMILY WEBINAR

**"Knowing the Name of a Gene Can End Your Diagnostic Odyssey and Begin the Search for Treatment"**

Our 2021 Education Initiative was supported by Neurogene (Believer Industry Partner); BioMarin, Genome Medical, Greenwich Biosciences, Illumina, Mallinckrodt Pharmaceuticals, PTC Therapeutics, REGENXBIO, Stoke Therapeutics, Taysha Gene Therapies, UCB, Ultragenyx Pharmaceutical, Zogenix (Industry Partners); TSC Alliance (Believe Partner); SynGap Research fund and NeurAbilities (Activist Partners); Dravet Syndrome Foundation, FamiliesSCN2A Foundation, GLUT1 Deficiency Foundation, Lennox-Gastaut Syndrome Foundation, and Phelan-McDermid Syndrome Foundation (Community Partners).

# TELEHEALTH



Families used to wait on average 9 weeks for their first visit with a neurologist.



With telehealth, almost half of patients had a neurology appointment within a week of their request.

## TELEHEALTH HAS REVOLUTIONIZED THE WAY CHILDREN RECEIVE NEUROLOGIC CARE

With telehealth, there isn't a one-size-fits-all solution.

How a family approaches telehealth, in-person medical appointments or a mix of both is a personal healthcare decision that depends on the child's needs and the doctor's goals.

CNF's telehealth resources, tools, and information help families and providers make the best decision for each child.

**Community  
Survey Results**

**Educational  
Videos**

**Advocacy  
Updates**

**Resource  
Hub**



# TRANSITION OF CARE



## TOC PATIENT SUMMIT

June 15-24, 2021

The inaugural CNF Transitions of Care Patient Advocacy Summit focused on ensuring that young adults living with a neurologic condition and those who support them have the knowledge, tools, and confidence to be able to make the process a success.

Each event of the summit featured a different topic related to the transitions process and give viewers the opportunity to dig deeper no matter where they are in the transition process.



**36**

Speakers

**10**

Topics

**500**

Families

# EXCELLENCE IN TRANSITION OF CARE AWARD

Dr. Madeline (Maddie) Kahan is a pediatric epilepsy fellow at Children's Hospital Los Angeles, and a graduate of the UCSF Child Neurology residency program.

She is the recipient of the inaugural 2021 Excellence In Transition Of Care Award.

Dr. Kahan's transitions work has included creating an EMR "transitions toolkit" for the UCSF Pediatric Epilepsy Center. She also conducted a cross-sectional survey of patients and families with complex epilepsy diagnoses to assess transitions readiness and determine demographic factors which may impact the transition process.



**Learn about Dr. Kahan's work in a  
video [interview here](#).**

# GRANTS AND SCHOLARSHIPS



## RISE FAMILY GRANTS

In 2021, we were able to offer **eleven \$1,000 grants to help families** cover food, housing, transportation, medical services, medications, schooling related expenses, and other needs.

Nine of those were for families with a child with infantile spasms thanks to the generosity of the Harnett family and Maverick Murthy, and two grants were for families with a child with any neurologic disorder. Families were selected in a randomized lottery-style process.

*"Thank you from the bottom of our hearts for starting something so big that touches so many families like mine." - Olivia's family*



*"We plan to use this grant for purchasing a bike trailer with special need inserts ... We truly appreciate this special gift and for helping us build unforgettable memories with our son." - Ellis' family*

*My youngest son is terminally ill ... That's when Elijah's Baby Bucket List was born! We take him on adventures and show him everything he should see before he goes. We try daily to make memories that they will never forget. - Elijah's family*





## **PEDIATRIC EPILEPSY RESEARCH FOUNDATION (PERF) ELTERMAN RESEARCH GRANT - \$100,000**

Autumn Ivy, MD, PhD is an Assistant Professor of Pediatrics, Neurology, and Anatomy/Neurobiology at the University of California, Irvine School of Medicine.

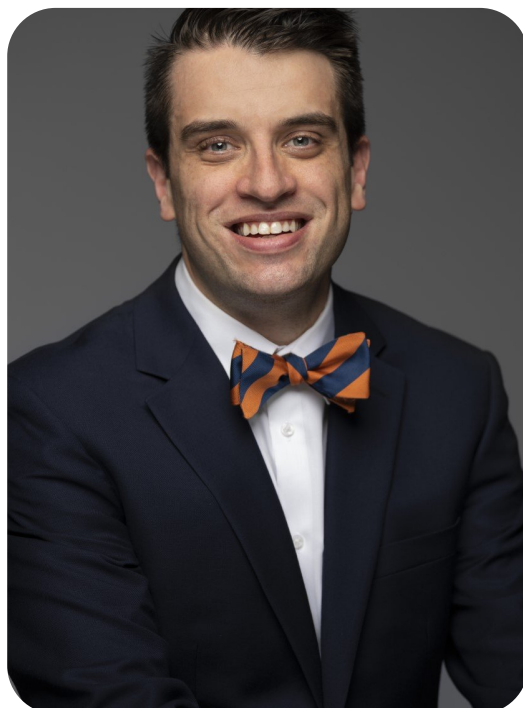
***Research topic: Targeting Epigenetic Mechanisms of Exercise to Preserve Cognitive Function After Early-Life Adversity.***



## **PEDIATRIC EPILEPSY RESEARCH FOUNDATION (PERF) ELTERMAN RESEARCH GRANT - \$100,000**

Nathan T. Cohen, MD, FAAP, is an Assistant Professor of Neurology and Pediatrics at The George Washington University School of Medicine and attending epileptologist and child neurologist at Children's National Hospital in Washington, DC.

***Research topic: Defining pharmacoresistant epileptic networks in pediatric focal cortical dysplasia***



## CNF NEURODEVELOPMENTAL DISABILITIES (NDD) SUMMER RESEARCH SCHOLARSHIP - \$3,500

Cole Deisseroth is a first-year medical student in the Medical Scientist Training Program of Baylor College of Medicine (BCM).

***Research topic: Study of Early B-Cell Factor 3 (EBF3)-related Hypotonia, Ataxia, and Delayed Development Syndrome (HADDs) to elucidate the genotype-phenotype spectrum and correlate developmental delays with variant type and location.***



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## DR. KENNETH F. SWAIMAN MEDICAL STUDENT SCHOLARSHIP - \$5,000

NEW

We are so thrilled and honored to announce the new Dr. Kenneth F. Swaiman Medical Student Scholarship.

Beginning in May 2022, three summer research scholarships will be given to U.S. and Canadian medical students each year to honor the legacy of our founder Dr. Kenneth Swaiman and his contribution to child neurology.

The establishment of the scholarship is thanks to the generous support of Dr. Swaiman's wife and pediatric neurologist Dr. Phyllis Sher.

# SOME IMPORTANT THANK YOUS



## CNF BOARD OF DIRECTORS

CNF's Board of Directors provide strategic oversight to our mission in action. Pediatric neurologists make up at least 51% of our Board Of Directors and join other Directors that include advocacy organization leaders and parents of children with neurologic disorders. We are grateful for the incredible professional expertise and new lived experiences they bring to our organization's leadership.

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**Executive Director/CEO,  
Child Neurology Foundation**



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**Roger Larson, CAE**  
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Child Neurology Society**



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Child Neurology Society**

# CNF CORPORATE ADVISORY BOARD

We value our partnership with each of our Corporate Advisory Board (CAB) members. In addition to financial support, members provide their unique expertise and perspectives on the issues and needs facing the child neurology community.










# THANK YOU FOR BEING PART OF OUR 2021

## JOIN US IN 2022!



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**GET INVOLVED OR DONATE:**

[www.childneurologyfoundation.org](http://www.childneurologyfoundation.org)

