

**CHILD  
NEUROLOGY  
FOUNDATION**

**2020 ANNUAL REPORT**





Dear Friends,

In the blink of an eye, a global pandemic changed our way of life. At the Child Neurology Foundation, we were fortunate to be able to respond quickly, aligning with our values and doubling down in our support for the child neurology community at a time when we were needed most.



Within weeks, we listened and pivoted, releasing our Covid-19 Response Action plan and boldly responding where needs emerged.

That meant shifting and delivering our educational programming and caregiver training virtually. It meant releasing \$250,000 in emergency relief funding to families and other non-profit organizations in the child neurology space when we heard of financial hardship. It meant launching all new educational programming to help families cut through the noise and make the best decision for their child's care.

Pets and children became a regular part of the backdrop. Zoom fatigue came and went.

Through it all, it is important to know that we could not have done this without you – thank you to the many partners, advocates, funders, physicians, lawyers, school administrators, nurses, therapists, and countless others who stepped up with us – you are a steadfast part of CNF's comrades in arms.

2020 will be defined as the year we illuminated the meaning of rising tides lift all boats. And we are not done. In 2021, we hope you'll join us as we continue to build a world in which all children affected by neurologic disorders can reach their full potential.

Onwards to 2021!

Warmly,

Amy E. Brin

MSN, MA, PCNS-BC Executive Director/ CEO



# OUR VISION, MISSION & VALUES

**At the Child Neurology Foundation, we live our vision,  
mission and values in all that we do.**

## **Our Vision**

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

## **Our Mission**

To serve as a collaborative center of education and support for children and their families living with neurologic conditions.

## **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**

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.

## **Stewardship**

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

## **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.



# 2020: THE HIGHLIGHTS

2020 was a year of rapid growth and change at the Child Neurology Foundation. The Covid-19 pandemic forced us to be nimble, pivoting into educational programming and financial support for families, while all the while delivering our core programming virtually.

Take a journey with us through our major highlights and key moments of 2020.





# IN MEMORIAM: DR. KENNETH SWAIMAN



*November 19, 1931 -  
September 18, 2020*

Our founder and the first president of Child Neurology Foundation, Kenneth Swaiman, MD, passed away this year.

Dr. Swaiman was an engaged, visionary leader who played a pivotal role in establishing the field of pediatric neurology and improving the lives of tens of thousands of children through his work with countless organizations, including the Child Neurology Foundation and the Child Neurology Society, and his pioneering editorial guidance on publications such as the journal *Pediatric Neurology* and the textbook *Pediatric Neurology: Principles and Practice*.

His legacy is unprecedented and universally recognized, and he is deeply missed.



# COVID-19 & OUR RESPONSE

## EDUCATIONAL CONTENT

The Child Neurology Foundation has always worked to respond to the greatest needs of the child neurology community. This year, the need for timely and relevant information was greater than ever during the Covid-19 pandemic.

In response to the need for education, we produced **more than 30 original educational pieces specific to navigating this new normal**. We worked with more than **45 different experts** from healthcare workers, psychologists, therapists, physicians, consultants, advocacy partners and parents for our COVID-19 and Back To School series.

**Curated videos    Blog posts    Interviews    Tips & Tricks**  
**Expert opinions    Online articles    Q&As    Storytelling**



*Just a few of our speakers who shared their expertise and stories.*







*Some of the children who received a RISE Family grant.*

## RISE FAMILY AND RISING TIDES GRANTS

We heard from the child neurology community that financial concerns were one of the most pressing impacts of COVID-19. Within weeks of COVID-19 being declared a global pandemic, with the incredibly generous support of our partners, we got money out the door to families and other non-profit advocacy organizations in need with emergency Rise Family and RISING TIDES grants.

In 2020, we distributed **\$250,000 directly into the child neurology community** across the United States.

**\$250,000**  
**150 families**  
**10 organizations**



*Our grants were distributed across the  
entire United States.*



# WHAT WE'RE HEARING FROM THE COMMUNITY



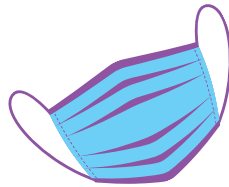
"My family and I are truly grateful that we were chosen [for a grant]. It just brought about **a sense of relief and true thankfulness** - a light so to speak - during such uncertain, and dark times that we've been facing."



"Thank you so much for doing **life-changing work** for these extra special people like [our son]."



"Thanks to the Child Neurology Foundation for this webinar on **such an important and timely topic** of teaching children to wear a mask."



"Thank you so much for this grant. You have brought **so much joy to our household!**"



"As a caregiver, it is critical we practice self-care so we can be there for our loved ones. Thank you to our partners at Child Neurology Foundation for providing this **critical content.**"

"**Excellent resource** from the Child Neurology Foundation for families that have been facing the loss of regular therapy services during the pandemic."



"We have no idea what we are going to do next, when the next job will come but **we are hopeful because of organizations like yours.**"



"Thanks Child Neurology Foundation for **supporting the community** in a time when it's needed most."





# WE LAUNCHED NEW PROGRAMMING

## SHORTENING THE DIAGNOSTIC ODYSSEY

In 2020, we focused on Shortening the Diagnostic Odyssey as our annual education initiative. Getting to a diagnosis, and making this journey as short and as error-free as possible, is especially important for children with a neurologic condition. In our first year of programming, we focused on educating both families and providers about genetic testing and how important it can be in making better decisions for children and their families.

### This year, CNF:

- Collected data about the journey through diagnosis from over 1,100 families and from over 300 pediatric neurologists.
- Held our first ever virtual educational symposium for clinicians at the Joint 16th International Child Neurology Congress & 49th Annual Child Neurology Society Meeting.
- Created family focused education to give information about genetic testing.

**100% of participants** on our family webinar reported having a better understanding of genetic testing after attending!



Click the image or visit  
[childneurologyfoundation.org/genetic-testing](https://childneurologyfoundation.org/genetic-testing)  
to download the PDF.

Shortening the Diagnostic Odyssey is such a crucial subject that our board decided to dedicate two years to it, and we will continue our work in this area throughout 2021.



# TELEHEALTH

2020 has been an especially difficult year for our community as parents and caregivers find ways to navigate the new normal with a medically complex child; including how they interact with their child's neurologist. Telehealth – medical care via a phone call or video call – became the primary way to “see” a child's physician almost overnight.

This new medium allowed for the provision of care to continue throughout the pandemic and now has the opportunity to now become the norm.

Due to CNF's belief that real, impactful, healthy change occurs when all stakeholder's perspectives are considered, we stepped up to listen to our community and learn more about what we can do to address the changing landscape.

**9 weeks:** Average wait time to access a child neurologist in the U.S.

**50 % of patients** surveyed received a telehealth appointment with a child neurologist **within one week** of their request.

**52 % of respondents** had five or more telehealth appointments in a 6 month period.

**34% of respondents** say they would not choose telehealth in the future, if given the choice.



**Click the image or visit [childneurologyfoundation.org/telehealth](https://childneurologyfoundation.org/telehealth) to get a copy.**

## In 2020, CNF:

- Distributed a survey that received nearly 200 responses about the family experience with telehealth and built a webpage to share the results with the community along with resources.
- Created multiple education pieces for both providers and caregivers about effective utilization of telehealth.
- Hosted a meeting with nearly 20 Key Opinion Leaders from around the healthcare world to identify needs of the child neurology community and identify paths forward.





# WE EXPANDED GREAT PROGRAMS

## BEHAVIOR MANAGEMENT

When the pandemic began in March 2020, CNF recognized immediately the impact shelter in place and distance learning would have on our community, particularly for children with challenging behavior. We released new education that helped families better manage harmful and disruptive behavior during COVID-19 and prevent challenging behaviors for minimally verbal children. Additionally, we worked to reach a broader audience on this topic by getting articles about behavior management in publications like NeurologyToday and Brain&Life.

We plan to continue to raise awareness about the challenges and importance of addressing disruptive and harmful behavior in children, as well as provide tools and education to help improve treatment and management of these behaviors. To ensure we focus on the most meaningful work, we interviewed behavior experts, including parents, to learn about common challenges and new opportunities in behavior management for children with neurological issues. We are excited to continue this important work in 2021.

## 400+ FAMILIES VIEWED OUR WEBINAR



***Want to watch a recording of the webinar? Find it on our YouTube channel or click on the image above.***

***"I now have basic tools to help [my child] navigate communication skills in an acceptable form. I will review the webinar again and again."***

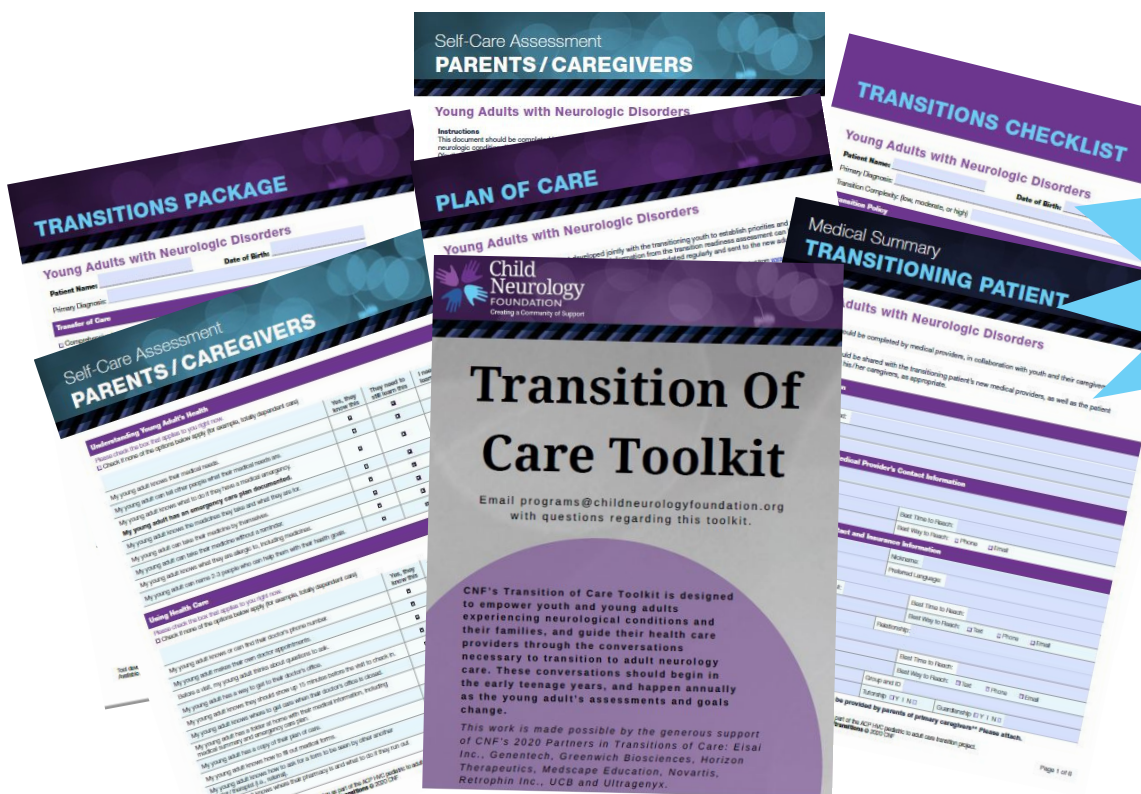


# TRANSITION OF CARE

Supporting young adults and their families' transition to adult care continues to be a flagship program area for the Child Neurology Foundation. Since our 2016 consensus statement was published on the topic, we have continued to develop resources and find new ways to support patients, families, and providers.

In 2020, we empowered our community in the following ways:

- Reimagined the Transition Project Advisory Committee (TPAC) to effect systems-level change in reimbursement, quality improvement, and federal advocacy to improve the landscape of transition of care in child neurology.
- Updated the CNF Transition of Care Toolkit and began working on an adult provider focused toolkit in partnership with AAP, AAN, and Got Transition.
- Continued to deliver education to families and providers through webinars, podcasts, and an article in partnership with *Neurology Today*.



Translated in Spanish, too!

Click the images or visit  
[childneurologyfoundation.org/transitions](https://childneurologyfoundation.org/transitions)  
to download our toolkit.





# PEER SUPPORT



CNF's Peer Support Program offers emotional support and resource navigation help to families from somebody who has lived through a similar experience and who is trained to offer support. Our peer support specialists – both parents of children with neurologic conditions with lived experience – are available virtually to listen, encourage, and help find resources for families from around the world. Our program also offers guidance and training to peer support leaders at other advocacy organizations to ensure our community receives the most effective support possible.

## **This year:**

- The Peer Support Program helped over 100 new families from 43 different disease states.
- CNF hosted our third annual Peer Support Workshop virtually, focusing on networking and the importance of self-care, the value of listening, being present, and how to better serve clients in a remote environment.
- We launched a quarterly newsletter specific to peer support, with a growing audience of families and peer support leaders.



**Kathy Leavens,**  
**CNF peer support specialist**

*"I asked myself one question over and over: 'Where is the person who has done this before me?'"*



**Brad Thompson,**  
**CNF peer support specialist**

*"We do everything we can to make sure that the information and the groups of people we are connecting you with are on the front-end of the battle as well. "*

# CHICA-CN

In 2020, CNF kicked off the first year of a three-year endeavor to build the Child Health Improvement through Computer Automation System – Child Neurology (CHICA-CN) in partnership with Digital Health Solutions (DHS).

CHICA-CN is a clinical decision support system that integrates with an Electronic Health Record (EHR) to help physicians make evidence-based clinical decisions in an office visit based on a questionnaire filled out by patients in the waiting room. This allows the patient or caregiver to have a voice in the process and will create an agenda for the physician prioritizing the patients' needs to help improve quality of care.

The first year of this pilot project was focused on building out the clinical content for the system and designing patient education that can be used in the office visit. The system will be ready to be implemented by mid-2021.

**We're on track to build CHICA-CN in 2021,  
with 25 topics coming!**

Infantile spasms  
Depression  
Maltreatment screening  
Migraines  
Genetic testing  
School/learning problems  
Epilepsy management  
SUDEP  
GI symptoms  
Tick disorder  
ADHD screening  
Muscular Dystrophy  
Obsessive Compulsive Disorder screening  
Tourette Syndrome  
Oppositional Defiant Disorder screening

**And many more!**





# RESEARCH GRANTS AND SCHOLARSHIPS

CNF is committed to the interdependence of quality patient care and emerging science. Every year, in partnership with the Child Neurology Society, we provide research grants to young scientists and researchers in the pediatric neurology field. Congratulations to our 2020 recipients.



## **2020 PERF ELTERMAN RESEARCH GRANT - \$100K**

**Juliet Knowles, MD, PhD**

Stanford University

Research topic: *Targeting Aberrant Activity-Dependent Myelination in Absence Epilepsy*

## **2020 PERF SHIELDS RESEARCH GRANT - \$100K**

**Youssef A. Kousa, MS, DO, PhD** Children's  
National Hospital

Research topic: *Identifying Genetic Risk Factors  
in Congenital Zika Syndrome*



## **2020 NEURODEVELOPMENTAL DISABILITIES (NDD) SUMMER RESEARCH SCHOLARSHIP - \$3,500**

**Camille Corre**

University of Rochester School of Medicine and Dentistry

Research topic: *Investigating Corical/Cerebral Visual  
Impairment and Visual Processing Deficits in Cerebral  
Andrenoleukodystrophy*



# SOME IMPORTANT THANK YOUS

## CNF BOARD OF DIRECTORS



CNF's Board of Directors provide 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.

Thank you for your expertise, generosity and oversight!



*Scott Pomeroy,  
MD, PhD*



*Anup Patel,  
MD*



*Ann Tilton,  
MD*



*Shaun Hussain,  
MD, MS*



*Stephen Peters*



*Sandra Cushner-  
Weinstein, PT,  
LICSW, LCSW-C*



*Timothy Engel,  
CPA*



*Julie Gilbert,  
MBA, CPA*



*Thomas Langan,  
MD*



*Donald Pearl*



*Phillip Pearl,  
MD*



*Scott Perry,  
MD*



*W. (Donald) Shields,  
MD*



*Sue Yudovin,  
RN, MN, CPNP*



*Mary Zupanc,  
MD*



*Bruce Cohen,  
MD, FAAN*



*Roger Larson*



*Amy Brin,  
MSN, MA, PCNS-BC*

# CNF CORPORATE ADVISORY BOARD



We are so proud of our Corporate Advisory Board (CAB)  
and grateful for their support in 2020.

Despite not being able to meet in person, our CAB was incredibly active and engaged this year with regular virtual meetings to convene and exchange insights from patient, healthcare provider and industry points of view.

Thank you for your commitment, authenticity and support!





# CNF PARTNERS AND DONORS

The programs and resources we develop for the child neurology community are possible thanks to the generous support from our partners and donors.

A big thank you to all of our industry partners, advocacy partners, community partners, supporters and donors for helping make change possible.

## COVID-19

Thank you to our 2020 COVID-19 partners - A Little Help Foundation, Amicus Therapeutics, Biogen, bluebird bio, Eisai, Illumina, Mallinckrodt Pharmaceuticals, Neurelis, Nick and Gardiner Lapham, Ovid Therapeutics, Retrophin, UCB, Ultragenyx, Upsher-Smith and the Winokur Family Foundation - for their support.

## DIAGNOSTIC ODYSSEY

Thank you to all of our partners including lead industry partners BioMarin, PTC Therapeutics and UCB, lead advocacy partners Epilepsy Foundation, Global Genes and NeurAbilities, believer industry partner Neurogene, activist partner Hope for Hypothalamic Hamartomas and community partner Dravet Syndrome Foundation.

## TRANSITION OF CARE

This work would be impossible without the generous support of Eisai, Genentech, Greenwich Biosciences, Horizon Therapeutics, Medscape Education, Novartis, Retrophin, UCB and Ultragenyx.

## TELEHEALTH

Thank you to our supporting sponsor Neurelis, and to UCB and Ultragenyx.

## RISE FAMILY AND RISING TIDES GRANTS

Special thanks goes to the Harnett family and to our COVID-19 partners - A Little Help Foundation, Amicus Therapeutics, Biogen, bluebird bio, Eisai, Illumina, Mallinckrodt Pharmaceuticals, Neurelis, Nick and Gardiner Lapham, Ovid Therapeutics, Retrophin, UCB, Ultragenyx, Upsher-Smith, the Winokur Family Foundation - and the Child Neurology Foundation Board of Directors.

## CHICA-CN

Thank you to our leading visionary sponsor Greenwich Biosciences, and our visionary sponsors PTC Therapeutics and Novartis.

## BEHAVIOR MANAGEMENT

Thank you to all our partners including lead industry sponsors Greenwich Biosciences and UCB, and lead advocacy partner Tuberous Sclerosis Alliance.

## PEER SUPPORT

Thank you to Greenwich Biosciences, UCB, Ultragenyx and the Winokur Family Foundation.



# THANK YOU FOR BEING PART OF OUR 2020

## JOIN US IN 2021



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**GET INVOLVED OR DONATE:**

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

