



Child
Neurology
FOUNDATION
Creating a Community of Support

2022 Annual Report



We recognize that our impact extends beyond the realm of numbers and achievements. It lies in the connections we forge, the stories we share, and the empathy we embrace. It is the rising tide of compassion that lifts the spirits of every individual we touch, creating a ripple effect of hope and resilience throughout the child neurology community.

Amy Brin, *MSN, MA, PCNS-BC*
Executive Director & CEO
Child Neurology Foundation

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At the Child Neurology Foundation (CNF), our guiding principle is built upon empathy and the unwavering belief that every child, every family, and every caregiver affected by neurologic conditions deserves our unwavering support. We understand the challenges faced by those sailing through uncharted waters, and it is our collective mission to offer support, resources, and a clear direction.

We stand alongside children and families, extending a helping hand to ensure they are equipped with the tools, knowledge, and emotional support needed for their unique journey. Through our comprehensive support services, we provide a lifeline of understanding and empowerment to navigate the complex world of child neurology with confidence and hope. The CNF also embraces our role as navigators to promote progress and innovation in research, care, and education. We actively collaborate with esteemed partners, researchers, and medical professionals to drive advancements in pediatric neurology and seek to foster breakthrough discoveries that will transform lives and shape the future of care.

As we sail forward, we remain firmly dedicated to inclusivity, collaboration, and compassion. We recognize the value of every stakeholder's voice and know that together we can achieve remarkable progress. In the pages of our annual report, you will see the tangible outcomes of our collective efforts as well as the ripples we have nurtured. We invite you to immerse yourself in the CNF 2022 annual report and see what CNF is doing to help create a world where all children with a neurologic disorder reach their full potential!

Anup Patel, MD
President
Child Neurology Foundation

Amy Brin
Chief Executive Officer
Child Neurology Foundation



Our Story

The Child Neurology Foundation connects partners from all areas of the child neurology community so those navigating the journey of disease diagnosis, management, and care have the ongoing support from those dedicated to treatments and cures.

Our expanding network of patients and caregivers, volunteers and advocates, researchers and clinicians is committed to helping one another along the path that leads to the best quality of care — and the highest quality of life — for every child.

At Child Neurology Foundation, we are committed to helping children and their families living with a neurologic condition receive the best quality of care — and achieve their highest quality of life — by providing information, education, and one-on-one support when it's needed most.



1 *in* **5**

children will live
or are living with a
neurologic
condition.

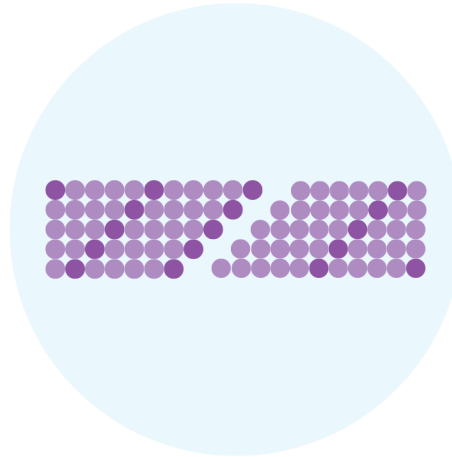




About CNF

Vision

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



Mission

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

CORE VALUES

Integrity

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.



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.



Collaboration

We work humbly, to identify and understand the urgencies and challenges facing our shared community; we know that they cannot be overcome alone.



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.

2022 Highlights

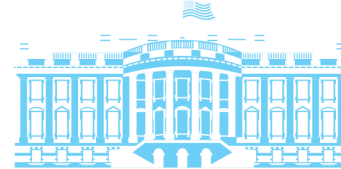


2022 was an exceptional year for CNF. Our staff and community partnered to make marked changes for the 20% of children and youth living with a neurologic condition in the United States.

The Child Neurology Foundation is a Healthy People 2030 Champion!



Recognized by the US Department of Health and Human Services, CNF is proud to be a Healthy People 2030 Champion. Healthy People Champions are a diverse array of public and private organizations that impact health outcomes at the state, tribal, and local level.



After responding to a request for information on digital health services, CNF was invited to a meeting with the White House Office of Science and Technology Policy to find ways to work toward mutual goals.

Participated in meetings with members of Congress, including Senate Minority Leaders McConnell (KY), Amy Klobuchar (MN) and Tina Smith (MN) as well as members of the House Energy and Commerce Committee's Health Subcommittee



Provided feedback to non-government organizations like The National Academies, The National Quality Forum on child neurology



200,000

unique visitors to CNF's Disorder Directory!



1,600

individuals participated in our Needs Assessment Survey



1,000

trained community members, including physicians, parents, caregivers, and family support specialists!

Child & Family Support

The Child Neurology Foundation offers free and confidential assistance to families facing child neurology disorders, ensuring they never feel isolated. Our program provides emotional and practical support, including access to disease-specific information, connections with other parents, guidance on transitioning to adult healthcare, digital resources, food assistance programs, insurance navigation, and preparation for medical appointments. We empower families to navigate their unique situations with strength and resilience.



34
organizations
joined the
Neurology Social
Services Network



*Average rating from Family
Support Training attendees*



45
disorders added
to the Disorder
Directory
200K+ page views!



100
Family Support Specialists trained, enabling
thousands of families to receive individualized
support and additional access to resources

When we have community, it is
the difference between hope
and despair.

-Peer Support
Training attendee

It was helpful to know
that there are stages of
grief that reoccur in my
life (as a caregiver).
There's nothing wrong
with me.

-Peer Support
Training attendee



I had to find this outside information and bring it in. It was through my own research that we were able to finally get to the bottom of what was going on with Mia.

Alyssa Kimball

Mother of Mia Kimball

CNF Digital Access Program

Digital Access Program Impact

Alyssa Kimball faced significant difficulties in finding the right care and resources for her daughter Mia's neurologic disorder. The challenge was compounded by their rural location, which made it both expensive and time-consuming to access medical care. The Kimballs would have to drive for three hours each way for doctor's appointments, making it extremely challenging to find the right care for Mia. That's where the Child Neurology Foundation came in through the Digital Access Program.

Through the program, Mia's family was able to access telehealth and connect with other families.



The Digital Access Program has been life-changing for us. It has given us access to care that we wouldn't have been able to access otherwise, and it's given us a community of support that we desperately needed.



CNF

Alyssa Kimball
mia's mother

Education

Through our Education Support Services, we aim to provide families and medical professionals with the necessary knowledge and resources to navigate the complexities of child neurology disorders successfully.



277 *attendees*

Child Neurology Society Symposium

4.6 out of 5 rating and
83 emails submitted requesting additional information and follow up materials.



Care Coordination Workshop
100% of registration target hit for first live, virtual CME event.



100 *registrants*
Transition of Care Workshops



250 *attendees*

American Epilepsy Society Symposium

4.8 out of 5 rating and
123 emails submitted requesting additional information and follow up materials.



I would **LOVE** to get access to the slides from all speakers as I found the talks very informative and helpful.

I learned a lot, would love to see this **topic continue next year!**



2022 Excellence Award Transition of Care Dianne Murrel



Diane Murrell **was nominated by three separate coworkers** for the 2022 Excellence Award — a level of enthusiasm we hadn't seen before!

As a social worker at Texas Children's, Diana supports physicians at the receiving institution in a way that facilitates a warm hand off and success for young adults with medical complexity. She is passionate about patient-centered care, and supports the rest of the care team in practicing this. A coworker in her application wrote: "Diane pours her entire heart and soul into helping our children in the neurology clinic, not just within the transition process...she goes above and beyond to help our patients, working long hours and gives her time, compassion, and effort so generously." Congratulations, Diane!



And so when we recognize the family's role, we have to respect whatever cultural diversity and strengths the family brings to the table. And that diversity can be educational, it can be social, can be spiritually, it can be economic. So then our understanding of the family and therefore the patient and their values should guide the plan of care that we develop.

Research & Care Advancement

Since 2001, we have awarded over **\$4.6 million dollars in research funding and scholarships** to child neurologists, medical students and researchers who are working on treatments and cures for pediatric neurologic diseases.

The importance of research and care advancement cannot be overstated in the field of healthcare. Through ongoing research efforts and the advancement of care practices, we are continually improving and enhancing the quality of care provided to patients.



2

Pediatric Epilepsy Research Foundation (PERF) Research Grants to support young investigator research \$150,000

Divakar Singh Mithal, MD, PhD

Ann & Robert H. Lurie Children's Hospital of Chicago
Mitochondrial Regulation of GABA Metabolism in Interneurons

Angela L. Hewitt, MD, PhD

University of Rochester Medical Center
Identifying Neurophysiological Biomarkers to Optimize Deep Brain Stimulation for Dystonia



4 Research Scholarships

Dr. Kenneth F. Swaiman Medical Student Scholarships

\$5,000 scholarship + \$1,000 travel stipend (each)

Daniel Connolly

MD/PhD candidate at University of Pennsylvania Perelman School of Medicine
Uncovering functional nodes of the Rett syndrome transcriptome

Geetanjali Rajamani

MD candidate at University of Minnesota Medical School
Characterizing Late-Stage Neurologic Dysfunction in a Cohort of Cockayne Syndrome Patients: A Retrospective Analysis

Alyssa Edwards, MPH

MD candidate at Case Western Reserve University, School of Medicine
Coordinate Network Mapping of Stimulant Use in Patients with Attention Deficit Hyperactivity Disorder

Neurodevelopmental Disabilities (NDD) Scholarship

\$3,500 scholarship

Dominic Julian

University of Arizona College of Medicine – Phoenix, MD/PhD candidate
Identifying novel autosomal recessive genetic mutations causing cerebral palsy through genomic analyses



Research & Care Advancement

Transition of Care is one of CNF's most important and comprehensive program areas. CNF describes transition of care as the multi-year preparation and eventual transfer from pediatric neurology to adult neurology. While there are many other aspects to a young person's growth to adulthood—like educational, vocational, and social changes—CNF provides resources for the medical transition because we believe it is foundational for achieving all the other goals a young person has for their adulthood.

Ann Tilton, MD kicking off the Transition of Care Workshop by talking about all the work CNF and partner orgs have done in TOC. The \$25K grants that funded this initiative are a big part of this work!



2 \$25,000
**Transition of Care
Grants**

David Bieber, MD and Stefanie McCormack, MSHC, CCRP

Ann & Robert H. Lurie Children's Hospital of Chicago

ADVANCE Collaborative at Lurie Children's Hospital and Northwestern Memorial Hospital

Sarah Spence, MD, PhD and Susan Shanske, MSW, LICSW

Boston Children's Hospital

Massachusetts Initiative to Improve Healthcare Transition for Individuals with Neurodevelopmental Disabilities

Policy & Advocacy Education

By providing education on policy issues and advocacy strategies, we empower individuals and communities to become active participants in shaping policies that affect their lives. Policy education equips individuals with the knowledge and understanding of key issues, legislative processes, and the impact of policies on various stakeholders. Advocacy education, on the other hand, teaches effective methods of influencing policymakers, raising awareness, and mobilizing support for important causes. By emphasizing policy and advocacy education, we empower individuals to be agents of change, fostering a society that is informed, engaged, and actively working towards creating positive and equitable policy outcomes.



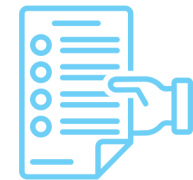
18



legislative sign-on letters

- telehealth access
- State-by-State seizure first aid in schools
- paid leave
- access to care

4



RFI's

(Request for Information)

4



comment letters

- Affordable Care Act comments to Internal Revenue Service
- Center for Medicaid and Medicare Services
- Medicaid Access

- White House Office of Science and Technology Policy regarding telehealth
- Agency for Healthcare Research and Quality, Whole Genome Sequencing and Telehealth for young people with IDD in WGS
- Health Equity at Center for Medicaid and Medicare Services

”

At CNF, we believe that there is both “Big A” and “little a” advocacy efforts. When we say “little a,” we mean advocacy parents and caregivers do daily—working with educators, physicians, and insurers to get the care and support their child needs. Many of our resources at CNF are designed to empower individuals to do exactly this. We think of “Big A” advocacy as our federal advocacy efforts. In 2022, we ramped up our activities in this area considerably. Working with a DC-based consultant group to help lead these efforts, CNF drafted a policy strategy, and began building connections with legislators, regulatory agencies, and other patient advocacy organizations.

-Jessica Nickrand, PhD



Financials

REVENUE	Operating Revenue	Restricted Revenue	Total
Contributions	\$645,981	\$548,630	\$ 1,194,611
Corporate Advisory Board	\$712,500		\$712,500
Other Revenue	\$17,965		\$17,965
Investment Income (Loss)	\$(34,011)	\$(16,454)	\$(50,465)
Net Assets Released from Restriction	\$2,490,063	\$(2,490,063)	-
TOTAL REVENUE	\$3,832,498	\$(1,957,887)	\$1,874,611

EXPENSES		
Program	\$2,130,758	\$2,130,758
Management & General	\$1,250,517	\$1,250,517
Fundraising	\$324,287	\$324,287
TOTAL EXPENSES	\$3,705,562	\$ -

ASSETS	Total
Cash & Cash Equivalents	\$1,233,982
Pledges Receivable, net	\$959,947
Prepaid Expenses	\$11,875
Right-of-use Asset	\$65,740
Property and equipment, net	\$25,987
Investments, Long-term	\$446,669
TOTAL ASSETS	\$2,744,200

LIABILITIES AND NET ASSETS

Liabilities	
Accounts Payable and Accrued Liabilities	\$290,630
Grants Payable, net	\$391,965
Lease Liability	\$70,485
Deferred Revenue	\$158,000
Note Payable	\$90,000
TOTAL LIABILITIES	\$1,001,080

Net Assets	
Without Donor Restrictions	\$575,013
With Donor Restrictions	\$1,168,107
TOTAL NET ASSETS	\$1,743,120
TOTAL LIABILITIES AND NET ASSETS	\$2,744,200

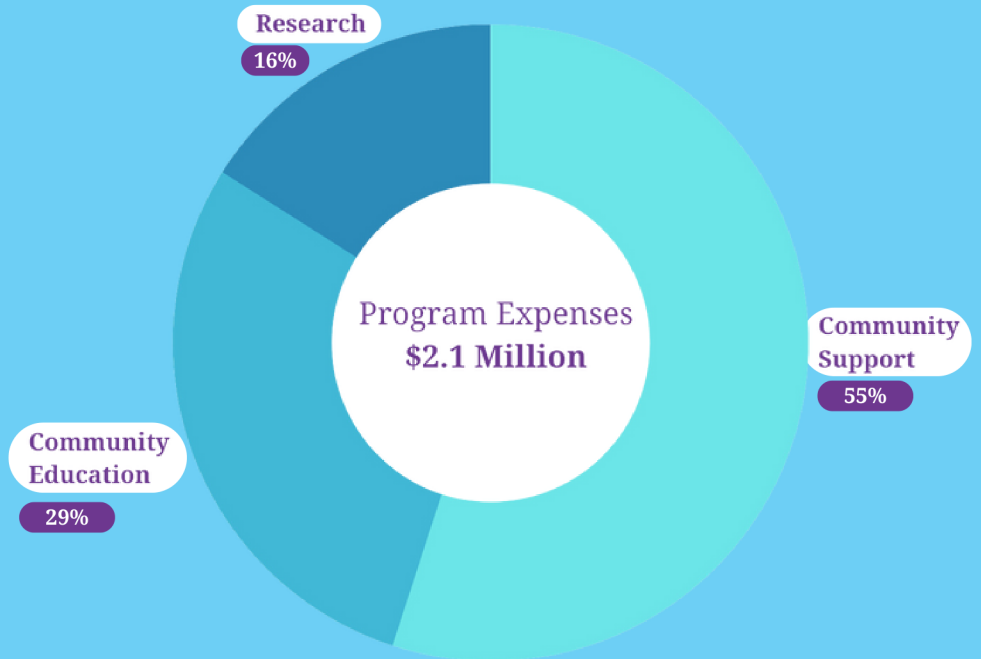
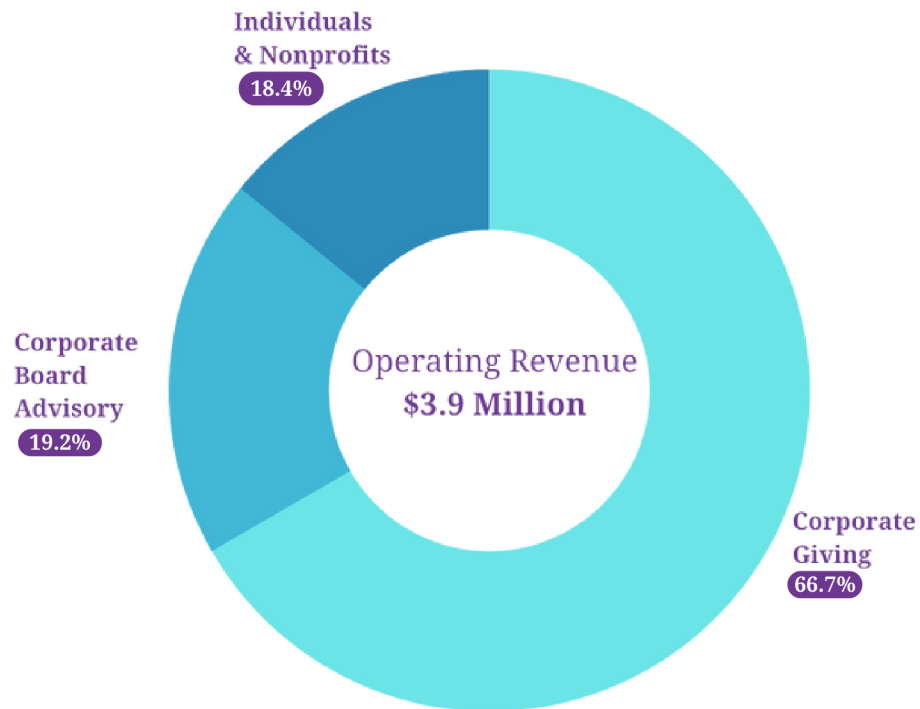


Our unwavering commitment to prudent stewardship and the generous support of our community have empowered the Child Neurology Foundation to pave the way for transformative advancements in pediatric neurological care.

-Stephen Peters, President, Melody West and CNF BOD President-Elect



Financials



CNF is proud to carry the Platinum Transparency badge into 2023.

Platinum
Transparency
2023

Candid.



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!

Honorary Directors

W. Donald Shields, MD
Honorary Director Chair

Ann Tilton, MD
Honorary Director of Strategic Partnerships

Mary Zupanc, MD
Honorary Director of Philanthropy

Officers



Anup Patel, MD
President



Stephen Peters
President-Elect



Scott Pomeroy, MD, PhD
Past President



Shaun Hussain, MD, MS
Secretary



Timothy Engel, CPA
Treasurer

Directors



Sonika Agarwal
MBBS, MD



Madeline Chadehumbe
MD



Amaris Sánchez-Larragoity
PsyD



John J. Millichap
MD



Donald Pearl



Scott Perry
MD



Rebecca J. Schultz
*Ph.D.,
APRN,
CPNP-PC,
FAES*

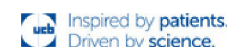


Corporate Advisory Board

We are so proud of our Corporate Advisory Board (CAB) and grateful for their support in 2022.

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!



Our leadership team recognizes that CNF is by far one of the most sophisticated and evolved organizations that we work with.

-2022 CNF CAB Member



—— Thank YOU for being part of our 2022! ——



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GET INVOLVED *or* DONATE!

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