



Child
Neurology
FOUNDATION

Creating a Community of Support

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2017 - 2021 Strategic Plan



Our Mission

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

Our Vision

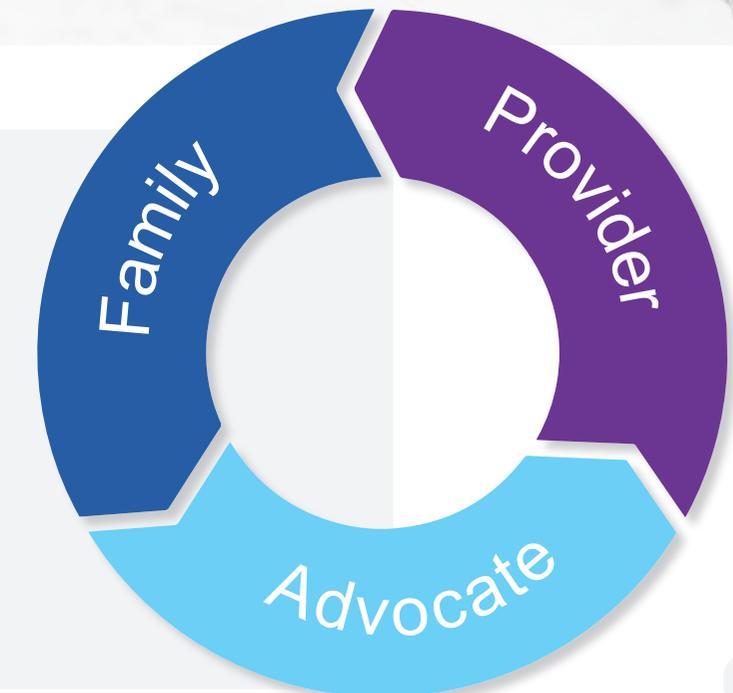
We envision a world in which all children affected by neurologic conditions reach their full potential.

How We'll Get There

We're committed to building a community of partners that navigates the path of disease diagnosis, treatment, and management together so that children and their families achieve the highest quality of care and the highest quality of life, knowing *There is help! There is hope!*

The key to realizing and achieving this vision is through collaboration with advocacy stakeholders, families, children, and providers to develop appropriate programs and resources. All stakeholders in the child neurology community must be equal partners in care, sharing ideas and learning from each other in an interdisciplinary way. This innovative model of interdisciplinary education promotes clinicians, families and advocates as equal partners in care so that all are educating one another throughout the journey of caring for a child living with a neurologic condition.

This interdisciplinary model of education provides a supportive framework for the child neurology community to collaboratively learn from each other's expertise. No one stakeholder is responsible for educating all of the other players – all are responsible for educating each other, enforcing the concept of equal partners in care. Providers educate advocates who educate families who educate providers, and so on.





Achievements

Since the implementation of our last strategic plan in October 2014, the Child Neurology Foundation has taken giant steps in expanding partnerships and leading community collaboration:

- We've effectively partnered with disease-specific organizations, clinicians, and other organizations in the industry, including the Tuberous Sclerosis Alliance for the annual Infantile Spasms Awareness Week, December 1-7.
- As a true convener, we've been able to nurture existing partnerships with advocacy organizations and industry, as well as collaborate to enhance program implementation. For example, through our groundbreaking multidisciplinary Transitions Project Advisory Committee (TPAC) and 2016 Infantile Spasms Advocacy Forum.
- We've developed an array of educational materials to share with advocacy and industry partners to generate stronger outcomes for children/families.
- We have successfully sold out the Child Neurology Society (CNS) provider, family, advocacy CME symposium two years in a row.
- Provided \$3.5 million in research grants to 69 young investigators to advance research in child neurology since our inception in 2001.



Our Strategic Drivers for 2017-2021

Our three strategic drivers are intended to support our vision over the next five years, with each driver intended to complement the efforts of the others. For instance, our interdisciplinary education model—a fundamental element of our work and success – is dependent on community collaboration.

Community Collaboration

We will connect children/families to other families and the medical professionals, advocates, and industry partners they need to feel supported, enhance care, and optimize quality of life. **We will do this by:**

- Developing partnerships and strengthening relationships that foster connective opportunities for children/families, child neurologists, other providers, and advocacy and industry partners.
- Creating a forum to bring advocacy groups together to work on collaborative solutions to cross-cutting issues and challenges in the child neurology community.
- Developing a team of parent partners to offer peer support and technical assistance.
- Guarding against duplication of efforts and mission creep within the community by exhibiting benefits of CNF's function as a connective hub.

Resources available to support this strategy: E-Newsletter, collaborative disease awareness efforts, advocacy forum, professional conferences, Transition of Care project, webinars, website, and parent coach team.



Education

We will connect children/families with the information and resources they need about their conditions to make informed decisions. **Key efforts will include:**

- Maintaining and expanding the child neurology disorder directory:
www.childneurologyfoundation.org/disorders
- Organizing collaborative education opportunities with advocacy and industry partners, children/families, and providers.
- Creating, validating, and publicizing credible, balanced, and health-literate content to expand the range of conditions addressed by our educational resources.
- Integrating the child/family and advocate voice into all education resources.
- Expanding and diversifying our educational partnerships and modalities.

Resources available to support this strategy: E-Newsletter, collaborative disease awareness efforts, advocacy forum, professional conferences, CME symposium at CNS meeting, Transition of Care project, webinars, and website.



Organizational Strength

We will connect with the continuum of organizations serving child neurology and serve as a strong, reliable, and respected partner by capitalizing on organizational strengths and identifying areas of improvement where other partner organizations can fill in. **Key efforts will include:**

- Taking a deliberate approach in continual assessment of our role within the child neurology community.
- Optimizing CNF's financial position to meet our mission.
- Acquiring and retaining committed staff and volunteers.

Resources available to support this strategy: E-Newsletter, professional conferences, collaborative disease awareness efforts, advocacy forum, webinars, and website.



Will You Join Us?

Our progress depends on the strength of our partnerships. Without the collaboration and support from our many varied strategic partners: from parents and siblings to the children/families themselves, to the providers and researchers on the frontlines, and finally our advocacy and industry partners helping us advocate for children and their families affected by child neurologic conditions.

Our Resources

To support our strategic vision, we have created a series of resources, tools, and materials for our partners, children and families to utilize. Many of these materials are adaptable/customizable for specific disease states. At CNF we strive to be accountable stewards of our resources and how they can benefit the entire child neurology community.

E-Newsletter

- Families First, our quarterly source of information for caregivers. We are open to partnering with our advocacy partners on special ad hoc issues on topics of mutual interest.

Collaborative Disease Awareness and Education, including Infantile Spasms Awareness Week (ISAW)

- ISAW is a collaborative initiative sponsored by CNF and the Tuberous Sclerosis Alliance, as well as several other national advocacy organizations. Since partnering on this initiative, we have helped raise awareness of this devastating neurologic disease while also honing our collective brand awareness skills that reach families, providers,

and the general public. In our convening role, we hosted the first Infantile Spasms Advocacy Forum featuring players from advocacy, family advocates, industry, providers, and research who provided interdisciplinary education on gaps in current service models, advocacy and research needs, and possible collaborative strategy aimed at solutions.

- The collaborative disease awareness model we've created can be adapted to further educate and promote advocacy around other diseases, while generating additional opportunities for CNF to gain brand recognition.

Professional Conferences

- We are continuing to expand our presence at clinician membership and national advocacy organizations' conferences. It's important for CNF to have a presence, and to present at other disease-specific meetings due to the large volume of participants, the quality of education provided, and opportunities to network. These occasions add to our credibility as an organization and position us as a thought leader, along with opening up more chances to connect with potential partners, and distribute our and our partners' materials.



Transition of Care Project

- Transitions of care—or how children transition from pediatrics to adult care—is of vital importance to the neurology community with a growing number of pediatric patients entering the adult healthcare system and the known risks to their health when a successful transition process does not occur. Since 2013, CNF has been proud to lead the neurology community’s transition efforts.
- In 2016, our interdisciplinary expert panel published a consensus paper in *Neurology*®, which addresses a significant chasm in clinical practice with less than 50 percent of U.S. youth currently receiving transition services. To assist the neurology community’s implementation of the Common Principles outlined in the consensus statement, CNF launched a Transition Project Advisory Committee (TPAC) also in 2016. TPAC’s work has subsequently focused on child/family education, clinical tools and quality initiatives. Additionally, CNF partners with disease-specific advocacy and provider membership bodies to infuse TPAC’s findings. Partners involved in TPAC include: American Academy of Neurology, American Academy of Pediatrics, Association of Child Neurology Nurses, Child Neurology Society, Lennox-Gastaut Syndrome Foundation, Tuberous Sclerosis Alliance, as well as independent patient, family and allied health professional advocates.

Webinars

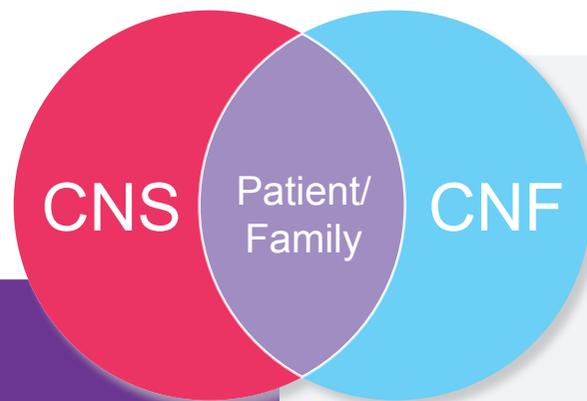
- We host a webinar series, *Child Neurology Community Conversations from the Voices of the Caregiver, Provider, and Advocate*, allowing for conversation between our partners to discuss cross-cutting issues. We can share our custom webinar platform with our industry and advocacy partners for special ad hoc topics of mutual interest.

Website

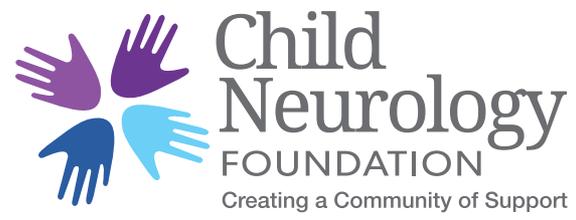
- Our website hosts the Disorder Directory, featuring disease-specific articles written by neurologists, which are paired with personal family stories and resources. This is the first stop for many families when their child is newly diagnosed—a critical juncture for anyone new to living with a child neurologic condition. Furthermore, the website is a customizable hub for community collaboration, including resources for advocacy and industry partners, important tools for providers, and more. With a recent website refresh, childneurologyfoundation.org continues to be a credible and valuable source of information for all of our critical partners.

Research Grants

- CNF has awarded more than \$3.5 million to 69 young investigators whose research identifies treatments and potential cures of child neurologic diseases. And in 2016, for the first time, CNF and CNS partnered to award four grants totaling \$250,000 and one \$3,500 summer medical student scholarship. A specialized CNF/CNS committee was developed to fulfill this function.
- It’s important to note the unique relationship between CNF and CNS and how both organizations partner to improve the lives of children and families living with child neurologic conditions.



Both CNF and CNS provide resources and tools that support children and their families, CNS provides professional development and educational training to the frontline providers caring for children with child neurologic conditions. When combined, CNF and CNS provide holistic education and support to children and their families.



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