



# How the Child Neurology Foundation & Unite Us are Building a Social Services Network for a Community in Need

With a strong infrastructure and the power of collaboration, Unite Us and the Child Neurology Foundation are transforming health outcomes for the neurology community.



#### **Background**

The <u>Child Neurology Foundation</u> (CNF) is a patient advocacy organization on a mission to serve as the collaborative center of education, resources, and support for children and their families living with neurologic conditions. Each year, CNF's work reaches hundreds of thousands of families in all 50 states and more than 70 countries, with programming focused on improving the patient care experience, attacking the effects of isolation, confronting systems-level change, and supporting research for the advancement of new cures and therapies.



children will live with a neurologic condition.<sup>1</sup>

Child Neurology Foundation exists so they never have to walk alone.

<sup>1</sup> https://www.childneurologyfoundation.org/

"We take the burden off of families to find their own support. When a family comes to us, we don't give them a list of organizations they can call themselves. That's just one more task they have to do every day, and they don't need another task. We're finding these organizations and connecting them so they don't have to."





#### Challenge

In 2021, CNF conducted an Annual Needs Assessment to identify and prioritize the needs of their community. They discovered that many families were struggling to access essential social services such as food, transportation, and housing. Clinicians and family support specialists also echoed these concerns, noting their own capacity issues and other obstacles in connecting patients to needed services.

CNF realized they needed a solution to quickly and securely connect families to vital social services, helping them to thrive—not just survive.

#### **Solution**

In early 2022, CNF began vetting social care technology vendors, ultimately partnering with Unite Us to launch the <u>Neurology Social Services Network (NSSN)</u>. Leveraging the <u>Unite Us closed—loop referral system</u> as its infrastructure, the NSSN streamlines closed—loop referrals between patients and social service organizations, allowing families to easily access peer support and additional resources.

"We vetted a lot of tools, but Unite Us stood out as the most user-friendly and secure solution, allowing us to share de-identified data while maintaining independence on the platform. Protecting patient confidentiality was our top priority, and Unite Us was the most secure way to do that."



KIM HINDERY, EXECUTIVE DIRECTOR AT CNF

### **Impact**

Child Neurology
Foundation (CNF) Partners

1,023 Cases C

Cases created by

**755** 

Referrals sent on behalf of families

Through the NSSN, providers across sectors can send and receive secure electronic referrals, monitor their clients' total health journey, and report on tangible outcomes in a centralized, cohesive, and collaborative ecosystem. Acting as a central hub, the CNF team can focus on connecting families to the organizations that make the most sense for their situation.



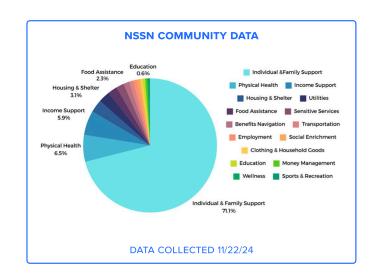


### **Community Collaboration Through a Neural Network**

Bringing together **91+ organizations**, the NSSN helps address social drivers of health (SDOH) and non-medical needs for the neurology community, providing services like transportation, financial assistance, utility support, respite care, employment, housing, and more.

With Unite Us, partners within the NSSN can:

- Identify key family needs and connect families to local social service organizations and to each other for support
- Enhance whole-person health and wellbeing by fostering collaboration across a broad range of services
- Track referral outcomes and measure the impact of patient advocacy organizations to demonstrate impact
- Strengthen organizational capacity through accurate referrals and data visibility on local service delivery
- Leverage de-identified data to advocate for services at local and federal levels
- Offer self-referral avenues through embedded assistance request forms on their site



"Unite Us provides a way for us all to gather information about our community programs to learn where we could do better, or where they're successful, and then share that data with our board or funders. That's huge when we're trying to prove impact."





#### **SUPER USER SPOTLIGHT**

## Rising Tides Lift All Boats: The Downstream Effect with UDNF

Recognizing the critical need to equip patient navigators with better tools to serve participants effectively, the <u>Undiagnosed</u> <u>Diseases Network Foundation</u> (UDNF) joined the NSSN. Led by and for patients and their families, the UDNF fosters collaboration among patients, clinicians, and scientists to enhance the quality of life of undiagnosed and ultra-rare disease patients.

Joining the NSSN enabled UDNF to access the network's comprehensive resource bank, referral system, and documentation system, powered by Unite Us. This has revolutionized how the UDNF supports its clients.

"This collaboration transformed our operational efficiency and participant care delivery. By streamlining workflows, our team's productivity has increased, while referral processing times have dropped significantly.

What started as a strategic partnership has evolved into a powerful alliance that helps more families find answers and access the care they need."



CHRISTIN SISCOE, MSN, RN, CPN, & PATIENT NAVIGATOR AT UDNF

The most tangible impact of this partnership is the ripple effect it has created. By working together, this collaboration has amplified the presence of both the CNF and UDNF in advocacy, awareness, and education.

#### **Lessons Learned**

The partnership between CNF and Unite Us marks a significant advancement in supporting families with neurological conditions, both locally and across state lines.

By establishing a coordinated network of services and offering organizations insights into their impact, the NSSN not only addresses the holistic needs of these families but also paves the way for future innovations in care. This collaboration sets a new standard for community-based support, demonstrating the transformative power of technology and partnerships in meeting people where they are, when they need it most.