2024
CHILD NEUROLOGY SOCIETY
53rd ANNUAL MEETING
Nov. 11-14, 2024 • San Diego, CA

Innovative Programs: Finding Limited Resources

Jessica Nickrand, PhD
Child Neurology Foundation
jnickrand@childneurologyfoundation.org

No disclosures

Who CNF Serves


Children & Family members

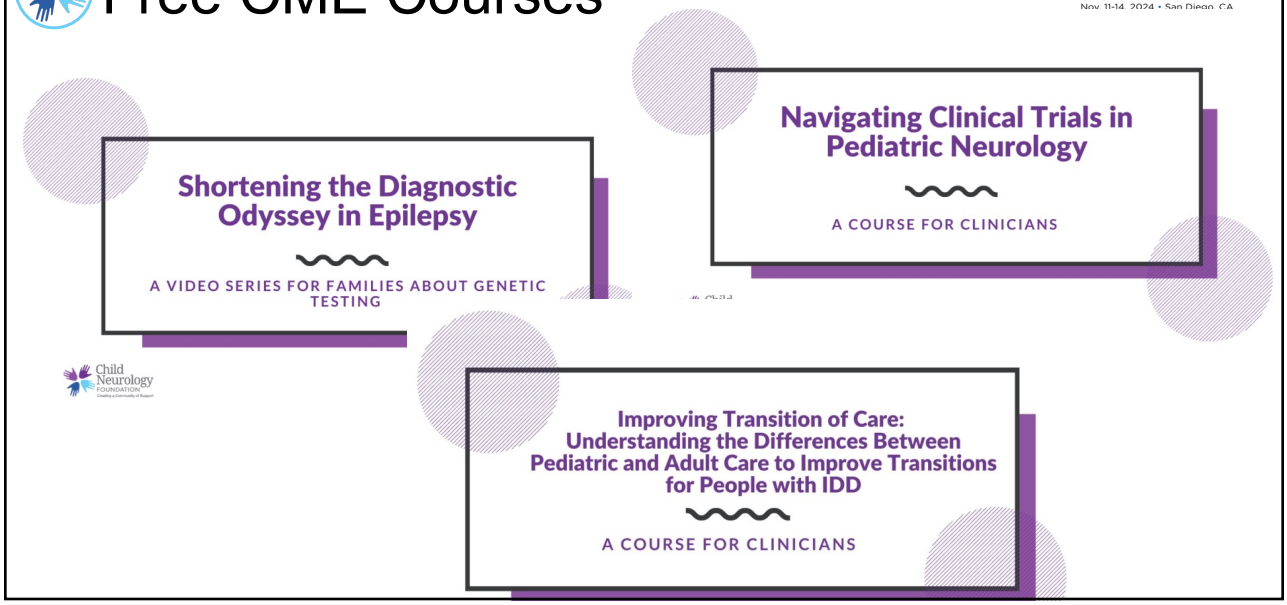

Medical professionals


Researchers

We are the only national organization to serve all children and families affected by neurologic disorders and the medical professionals who support them.



Free CME Courses



Free CME Courses

Shortening the Diagnostic Odyssey in Epilepsy

- A Video Series for Families about Genetic Testing
- A Course for Clinicians
- **New this Week**: Navigating Insurance Coverage for Genetic Testing

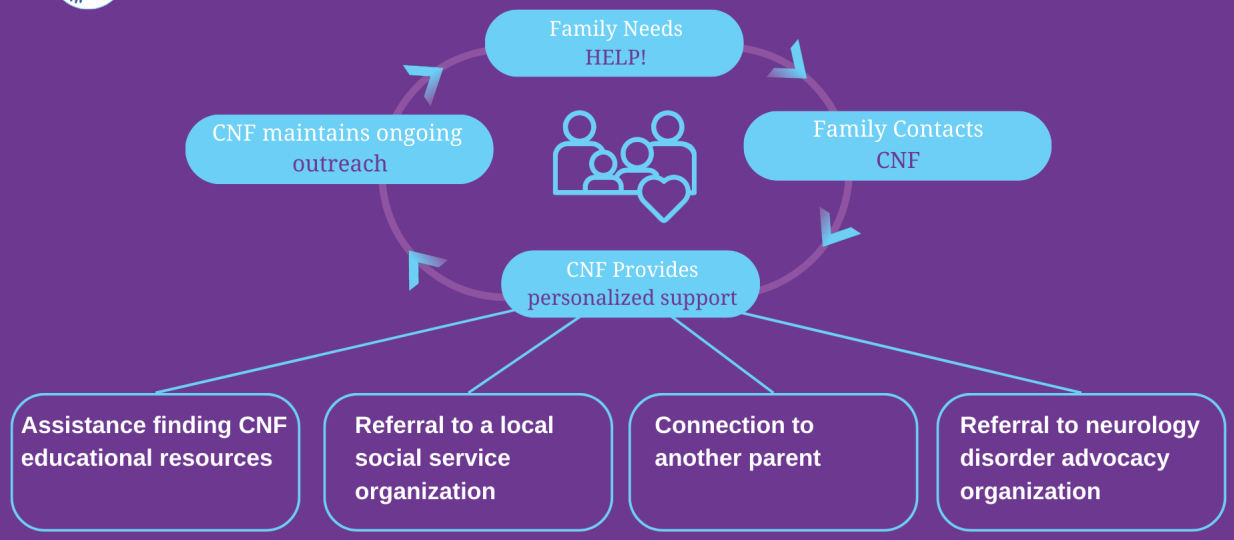
Navigating Clinical Trials in Pediatric Epilepsy

- A Course for Clinicians

Improving Transition of Care: Understanding Differences Between Pediatric and Adult Care to Improve TOC for People with IDD

- A Course for Clinicians

Family Support Cycle



- Assistance finding CNF educational resources
- Referral to a local social service organization
- Connection to another parent
- Referral to neurology disorder advocacy organization



"Support is mental and emotional. It goes beyond financial. It's knowing that you are not alone.

Direct Connection to a Peer Support Specialist:

Almost **60%** of requests are for peer support.

Direct Support for Families

Resource Navigation

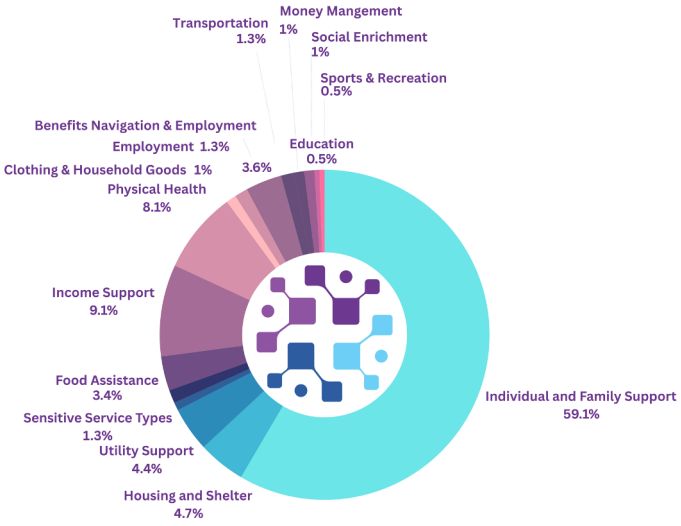
- Licensed bilingual social worker helps families find:
  - Mental health services
  - Financial assistance
  - Transportation assistance
  - Educational support
  - Employment assistance
  - Legal assistance

Referral to Advocacy Organization

- Formalized partnerships with other national patient advocacy organizations to provide 1:1 virtual family support

Program Impact

- Nearly 90 organizations
- Nearly 1,000 cases this year
- Access to 26,000 direct service organizations across the country



Contact Us!

programs@childneurologyfoundation.org

Innovative Programs: Finding Limited Resources

Monika Jones, JD
Founder + Executive Director
Pediatric Epilepsy Surgery Alliance (formally The Brain Recovery Project)
Principle Investigator, Global Pediatric Epilepsy Surgery Registry

No disclosures

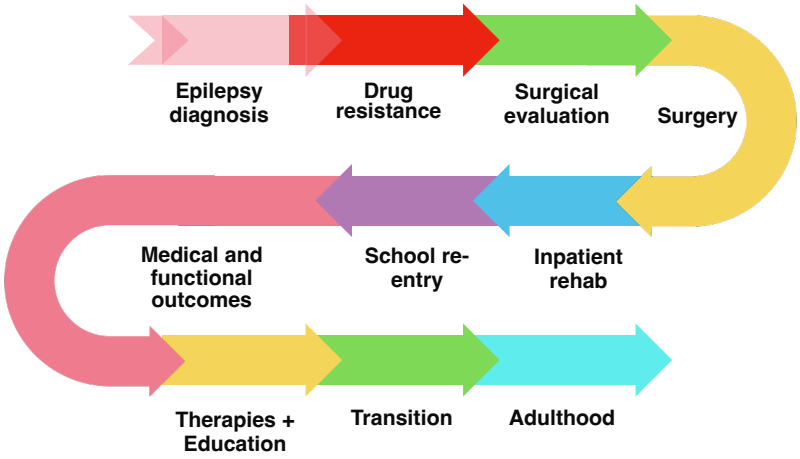




This is medical trauma



Pediatric Epilepsy Surgery Journey



Parent Support Navigators



- Evidence-based
- 6 months of training (including Four Stages of Adaptation, P2P, Managing Epilepsy Well, epilepsy surgery)
- Support for supporters
- 24 parent supporters
- Languages: English, Spanish, French, Portuguese, Hindi, Farsi

PARENT TO PARENT USA

Managing Epilepsy Well Network

Surgical Evaluation Travel Scholarship



- Helps break down financial barriers to prompt epilepsy surgery evaluation + lengthy hospital stays associated with presurgical testing
- Up to $1,000 in financial aid
- Covers costs associated with traveling more than 50 miles from home to a level 4 epilepsy center for surgical evaluation
- Over $70,000 awarded

School Training



- Free
- Evidence-based
- Virtual, two hours
- Topics include: chronic post-operative fatigue, visual field impairments, sensory processing challenges, auditory impairments, literacy acquisition
- Entire educational team
- Over 400 teams trained

Self-Paced Individual Education Plan and Transition Plan courses



- Free
- 10+ hours of "deep dive" content
- Focus on children with neurological conditions

Resources for clinicians

pediatricepilepsy surgeryalliance.

RESEARCH • INFORMATION • COMMUNITY