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

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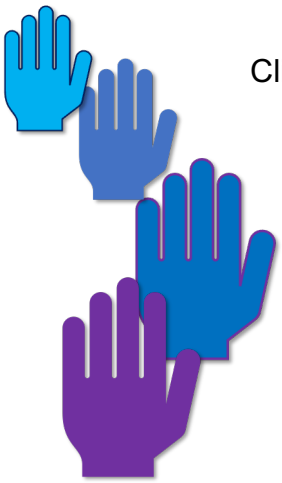
Caring for Children with Medical Complexity

Child Neurology Foundation Symposium
Child Neurology Society Annual Meeting
San Diego, CA
November 11, 2024

Objectives

- As a result of this educational session, participants will:
  - Better understand the challenges faced by patients with medical complexities in a variety of scenarios
  - Be empowered to incorporate innovative solutions to caring for children with medical complexity into their practice

Who's In the Room?



Clinicians

Newer Clinicians

Family

Academics

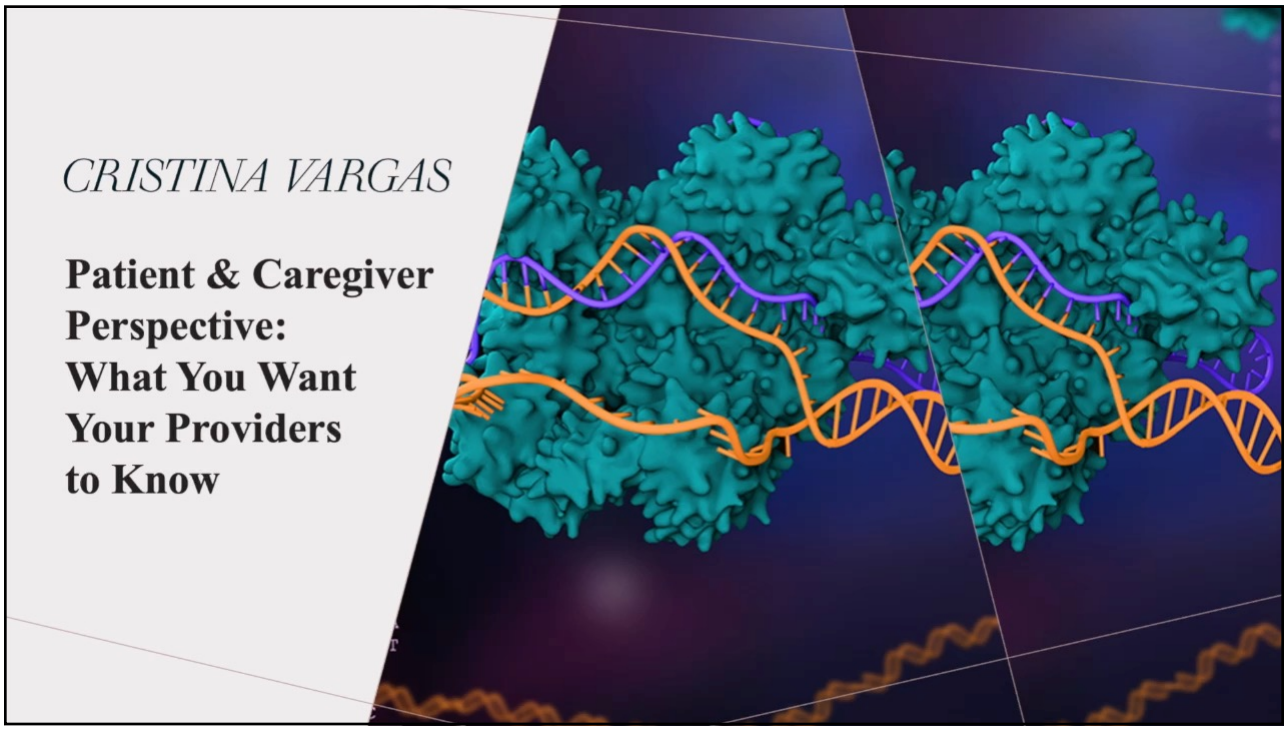
Investigators

Advocates

Industry

Something else…

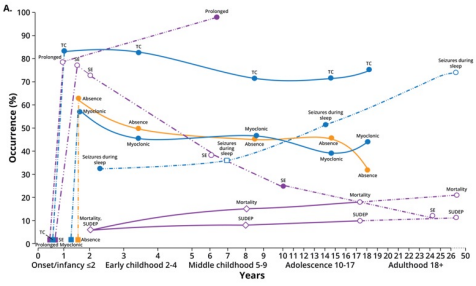
Government



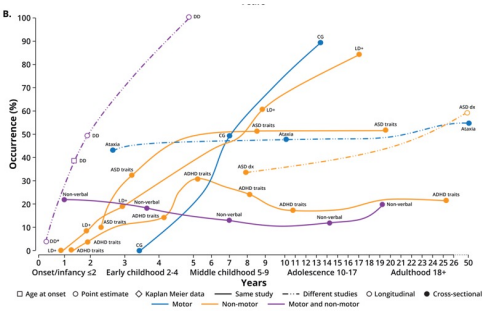
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Caring for a child with medical complexity can be hard for everyone involved

The Patient's Burden: Dravet Sydrome



Seizures

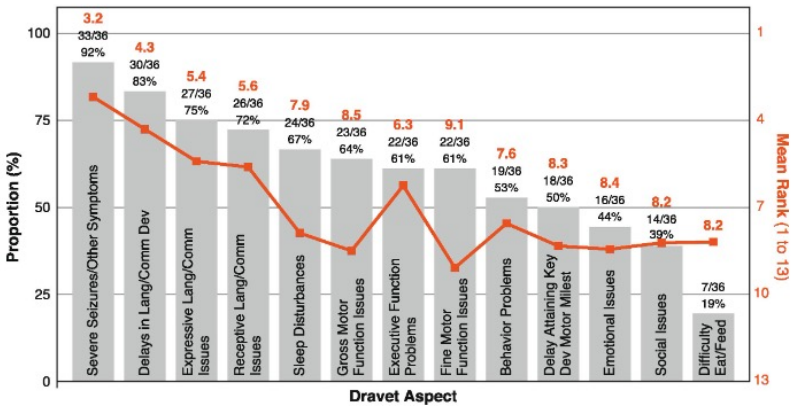


Comorbidities

Sullivan J et al. The clinical, economic, and humanistic burden of Dravet syndrome – A systematic literature review. Epil Behav 2022

The Patient's Burden: Dravet Syndrome

Proportion of survey respondents wanting to see specific aspects of Dravet syndrome alleviated by a new therapy and importance rank.



Juandó-Prats C, et al. DRAVET ENGAGE. Parent caregivers of children with Dravet syndrome: Perspectives, needs, and opportunities for clinical research, Epilepsy Behav. 2021

The Patient's Burden: SCN8A Related Disorders

Comorbidities	>50% Incidence	Severity Level					Change Over Time					
Neurological	Level of Consensus	Severe	Moderate	Mild	No Impairment	Level of Consensus	Worsen	Stable	Mixed	Improve	Resolve	Level of Consensus
1. Fine motor delays	Strong					Moderate						Moderate
2. Gross motor delays	Strong					Moderate						Moderate
3. Movement disorders	Modest					Modest						Moderate
4. Hypotonia	Moderate					Moderate						Modest
5. Cortical blindness/CVI	Moderate					Modest						Modest
6. Autonomic dysfunction	Moderate					Modest						Modest
7. Sleep disturbances	Moderate					Modest						Moderate
8. SUDEP	No consensus					Modest						Modest
DD/ID/Cognitive												
9. Speech/Communication delays	Strong					Moderate						Moderate
10. Intellectual Disability (ID)	Strong					Moderate						Modest
11. Behavioral dysregulation	Moderate					Modest						Modest
12. Emotional dysregulation	Modest					Modest						Moderate
13. Autism Spectrum Disorder (ASD)	No consensus					Modest						Moderate
Organ Systems												
14. Orthopedic issues	Moderate					Modest						Modest
15. Gastrointestinal (GI)	Moderate					Moderate						Moderate
16. Feeding	Moderate					Moderate						Moderate
17. Pulmonary	No consensus					Modest						Moderate

The Caregiver's Burden: Dravet Syndrome

- Multicenter, cross-sectional study of caregivers for people with Dravet[1]
  - 77% had abnormal sleep quality
  - 62% had symptoms of anxiety
  - 51% had symptoms of depression



1. Maltseva M, Schubert-Bast S, Zollner JP et al. Orphannet J Rare Dis 2023;18:98

The Caregiver's Burden

- Financial commitment is significant
- Caregiver employment is challenging
- Caregiver HRQOL, employment status, and age contribute to unmet medical needs[1,2]

1. Almanza-Sepulveda ML, Smith ML, Widjaja E. Epilepsy Behav 2019;99
2. Strzelczyk A, Zuberi SM, Striano P et al. Orphanet J Rare Dis 2023;18

The Physician's Burden



- Burnout is an epidemic
- Burnout leads to personal dissatisfaction, depression, and increased suicide risk
- Burnout leads to physicians leaving the workforce, reducing hours/call availability, worsening the shortage of neurologists
- Factors associated with burnout include: hours worked per week, nights on call, outpatient volume, and higher time in clinical practice

Multiple Challenges Impact Care

- Treating medical complexity requires time, which is a limited resource
- Somebody has to be the team leader for care coordination
- Care extends beyond the clinic walls and beyond the patient
- Resource demand is high
- Transitioning of care in adulthood is difficult



Navigating life with a neurologic disorder can be an **uncertain** and **isolating** journey.



The Child Neurology Foundation is here to ensure that **no one has to go it alone.**

CNF Mission

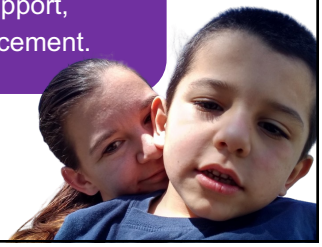
To improve the care experiences of children living with neurologic conditions by



building meaningful connections between families and medical professionals

AND

serving as a collaborative center of education, support, and care advancement.



CNF Community

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14 million children live with a neurologic condition (USA)

Thousands of rare and ultra-rare diagnoses with neurologic components

<3,000 pediatric neurologists

*Source: Federal Interagency Forum on Child and Family Statistics, 2023

Who CNF Serves

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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.



Shared Challenges

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FAMILIES

Overwhelmed and isolated

Nearly 1/2 of caregivers are very or extremely stressed and report being in crisis daily.

9 in 10 caregivers go to work late, leave early, or take time off during the day to provide care.

Many families are coordinating care across 3-10 medical professionals.

50% of caregivers need 'some or significant' help with finances, treatments, and access to a neurologist.

PROVIDERS

Overworked and siloed

>1/2 of neurologists (56%) feel burned out at least once a week; 10% feel burned out every day

98% of neurologists say they do not get enough time with patients during appointments

7 in 10 neurologists report needing more continuing medical education (CME) than they're currently getting

Top 2 barriers preventing neurologists from providing the highest quality of care are:

1) Insurance/Reimbursement concerns
2) Lack of auxiliary support

Family and Individual Needs for Disability Supports (FINDS) Survey – Community Report 2017

CNF Annual Needs Assessment Survey (2021)

Why Now?

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Availability of and access to genetic testing

+

Overworked and undertrained workforce not adept at neurogenetics

+

"Living lift" of families without a social services safety net

=

Exacerbated by COVID-19



Rapidly growing community of diagnosed families at risk of falling through the cracks due to a lack of coordination, education, and social services support

Armed with compassion and driven by data, CNF acts from a place of understanding.





Annual Needs Assessment Survey of caregivers and neurologists

Connecting and Collaborating



We work to connect, not replace, all the players across the child neurology community to enable **the rapid sharing of data and information** needed to improve children's experiences and outcomes.

Stronger Together

We work with:

- 200+ patient advocacy organizations and professional societies
- Thousands of families and providers
- 25,000 local direct service organizations



Programs



Child & Family Support





Education



Care Research and Advancement

CHILD & FAMILY SUPPORT

Focused on improving the patient care experience through direct engagement, social services, and partnership with care professionals



EDUCATION



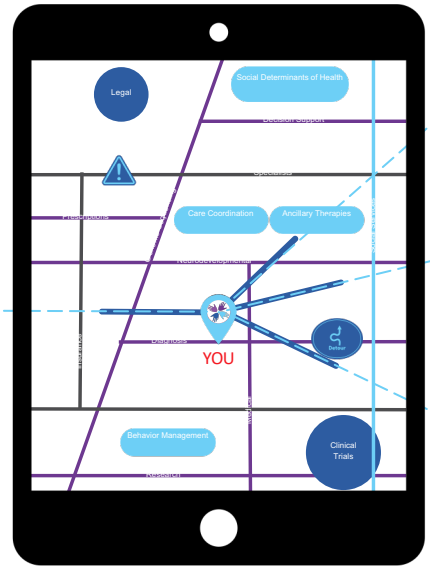
Focused on creating clarity for families and providers through the collection and dissemination of trustworthy information about managing diagnosis, care, and life with a neurologic condition

RESEARCH & CARE ADVANCEMENT

Focused on supporting providers and institutions who care for children with neurologic conditions by building bridges across the neurologic care community



Navigation



Like a GPS system, CNF meets community members where they are and helps them get to where they want to go.

No matter where you are.

CNF will recognize your position.

And empower you for where **YOU** need to go!

Agenda

8:00 am	Introduction – M. Scott Perry, MD, Cook Children's Medical Center
8:03 am	Patient & Caregiver Perspective: What You Want Your Providers to Know – Christina Vargas, Parent
8:18 am	Welcome – M. Scott Perry, MD
8:30 am	Activity – M. Scott Perry, MD
8:40 am	Clinical Methods of Providing Complex Care – John Mytinger MD, Nationwide Children's
9:10 am	Using Technology to Make Caring Easier – Ann Marie Morse, DO, FAASM, Geisinger Health
9:30 am	Break
9:40 am	Innovative Programs: Finding Limited Resources – Monika Jones, JD, Pediatric Epilepsy Surgery Alliance & Jessica Nickrand, PhD, Child Neurology Foundation
10:00 am	Preparing for Transition of Care – Ahmed Abdelmoity, MD, FAAP, FAES & Jean-Baptiste Le Pichon, MD, PhD, FAAP – Children's Mercy Kansas City
10:20 am	Case Study Scenarios – M. Scott Perry, MD
10:50 am	Closing Remarks – M. Scott Perry, MD
11:00 am	Adjourn

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REN Rare Epilepsy Network rareepilepsynetwork.org

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Activity

Discussion questions:

- What are one or two key issues or questions around this topic that you'd like to explore during this symposium?
- Why are you here today?

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Thank you!