Child Neurology FOUNDATION
Creating a Community of Support

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HP2030 HEALTHY PEOPLE 2030 CHAMPION

ROADMAP TO RESOURCES

October 2026
First Edition



A Community Resource Guide for Families & Caregivers

THANK YOU



We are grateful to our generous sponsors for believing in this work, and *for helping us put it into the hands of the families who need it.*

Inspired by **patients.**
Driven by **science.**

RESOURCES

by category

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INTRO

Our Why

At the Child Neurology Foundation, we believe that every family deserves more than a diagnosis. They deserve **connection, guidance, and a community that shows up alongside them** — through every stage of the journey. Roadmap to Resources is an extension of that commitment. It exists because no family should have to piece together support on their own.

About CNF & the Conected Care Network

The Child Neurology Foundation is a nonprofit dedicated to improving the lives of children and families navigating neurologic conditions. Through education, family support, and care advancement, CNF works alongside families, clinicians, and partners to build stronger systems of care. CNF's Connected Care Network brings that community together — ensuring families have access to trusted information and resources wherever they are on the journey.







CNF PROGRAMS



Connected Care Network

A neurologic condition touches every part of a family's life. CNF's Connected Care Network meets families where they are: at school, at the clinic, and at home.
See pages 11 & 12.



Lifespan Care

At eighteen, the move from pediatric to adult neurologic care too often falls apart. Lifespan Care standardizes that transition so families don't have to navigate it alone. *See page 10.*



Our programming & family support services would not be possible without donations. **Donate now to help us continue to provide critical support services for children and families in need.**

WHO IS THIS FOR?



Researchers & Healthcare Professionals
studying neurology & looking for the latest tools to assist patients.

Parents & Family Members
seeking to understand their child's condition & make the best care decisions possible.

Roadmap to Resources was built so that families caring for children with neurologic conditions have a trusted, comprehensive starting point that brings together CNF's own programs alongside the best resources our partner community has to offer.
We see you, and we're here to help.

HOW TO USE THIS BOOK



Example of a Resource:

Child Neurology Foundation 1

2 3q29 Foundation connects people with 3q29 deletion syndrome and their families to condition information, community resources, family support, and guidance for navigating care and daily life.

Also covers: ***Disorder Specific*** • ***Genetic Testing*** 3

4 info@3q29.org 3q29.org

5

1. Name of Resource or Organization
2. A description of the organization and/or services they provide
3. Other areas of specialty or service for this organization
4. Contact information
5. **Scan the QR code to learn more!**

Every photo in this book comes from a real family within the CNF community. *They are the reason why we do what we do.*





CLINICAL TRIALS

A clinical trial is a treatment being tested before it becomes routine. Families who join help decide what works. Ask what's open for your child.





CNF CLINICAL TRIAL RESOURCES

Clinical trials are how new treatments reach children with neurologic conditions. They are also where hope takes a concrete form: a study enrolling now, a therapy being tested, a door that was not open last year.

Families in our community told us they needed help understanding and finding clinical trials. Clinicians told us they needed resources to help families find and evaluate them. Both needs pointed the same direction.

The resources gathered here are our answer. You will find reliable, plain-language information about how trials work, what participation involves, how to find studies relevant to your child's condition, and what questions to ask before deciding. Clinicians will find tools to share with the families they serve. Wherever you are starting, whether you are exploring the idea for the first time or weighing a specific study, we hope this is a useful place to begin.

CenterWatch

CenterWatch provides a searchable directory of clinical trials by condition and location, with study summaries, eligibility information, enrollment status, research-center details, and participation contact information.

customerservice@centerwatch.com **609-945-0101**

centerwatch.com/clinical-trials/listings

ClinicalTrials.gov

ClinicalTrials.gov is a federal database of privately and publicly funded clinical studies, helping families and healthcare professionals find studies, eligibility requirements, locations, and contact information.

register@clinicaltrials.gov

clinicaltrials.gov

CoRDS Registry

The CoRDS Registry lets people with rare or undiagnosed conditions securely share health information with researchers and learn about studies seeking participants who may qualify.

Also covers: Genetic Testing

cords@sanfordhealth.org **(877) 658-9192**

research.sanfordhealth.org/rare-disease-registry

CureMap

CureMap displays recruiting clinical trials on an interactive map and lets users search by condition and location, while enrollment and eligibility details remain subject to study-team confirmation.

info@curemap.org

curemap.org

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

NICHD conducts and supports research on children's health, development, disabilities, pregnancy, and rehabilitation, while providing information about clinical studies, findings, and opportunities to participate in research.

Also covers: Disorder Specific

taylorpe@mail.nih.gov

800-370-2943

nichd.nih.gov

NIH — Finding a Clinical Trial

The National Institutes of Health explains how to find clinical trials through ClinicalTrials.gov and NIH studies, with guidance about participation, informed consent, and questions to ask.

ccopr@nih.gov

800-411-1222
833-JOIN-NIH

nih.gov/health-information/nih-clinical-research-trials-you

NINDS Clinical Trials and Studies

The National Institute of Neurological Disorders and Stroke explains how to find and understand neurological clinical trials and research studies; the page also includes participation information and patient stories.

Also covers: Disorder Specific

braininfo@ninds.nih.gov

800-352-9424

ninds.nih.gov/health-information/clinical-trials-and-studies

Stanford Medicine Children's Health

Stanford Medicine Children's Health provides information about pediatric neurology and neuro-oncology clinical trials studying medications, devices, and other approaches for children with neurologic conditions and tumors.

Also covers: Disorder Specific

mcoburn@stanford.edu

650-736-9551

stanfordchildrens.org/en/services/brain-and-behavior/conditions.html

DISORDER SPECIFIC INFORMATION

General information gets you started. Condition-specific groups get you further. They track the research, know the specialists, and can connect you to families like yours.





FAMILY SUPPORT *THROUGH CNF'S CONNECTED CARE NETWORK*

A child with a neurologic condition and their family need support in more than one place: at school, at the doctor's office, and at home. The Connected Care Network is how CNF shows up in all of them.

CNF's monthly Family Support Handout reaches more than 13,000 schools. The Disorder Directory offers clear overviews and trusted resources for hundreds of neurologic conditions. The Caregiver's Compass is a free mental health course led by a certified counselor. And Willow & Wind provides grief support for families facing the loss of a child, with counselor-led meetings, a podcast, and an online support group.

No single organization can meet every need. That is why the network extends beyond CNF through the Neurology Social Services Network, more than 100 patient advocacy groups and the professionals who work with these families every day. When one member cannot meet a need, they connect the family to a member who can. Members share what they have learned, and together they identify the barriers families keep running into. Patient advocacy organizations interested in joining can reach us at programs@childneurologyfoundation.org.

FAMILY SUPPORT SPECIALIST TRAINING & MORE

We know helping others navigate the life of caring for a child with a neurologic condition is important and complex. Our courses provide education for volunteers and staff at patient advocacy organizations who support families through the social and emotional challenges of diagnosis, treatment, and management of a neurologic condition. *Scan the code to visit our Learning Portal to find the course for you.*



DISORDER DIRECTORY





The **CNF Disorder Directory** is a comprehensive, curated resource for childhood neurological disorders. With the rapid expansion and accessibility of genetic testing, many new neurological conditions are being identified, making it imperative that families land in a safe, reliable, and up-to-date resource from the start. The Directory ensures families, clinicians, and researchers have the information they need to make informed decisions, advocate effectively, and access specialized care.

Key Features

- Comprehensive Listings: Hundreds of disorders with detailed information on symptoms, treatments, and care considerations.
- Reliable & Curated Content: Each disorder entry is developed in collaboration with child neurologists and patient advocacy groups, vetted by CNF's Content Review Committee, and approved by the CRC Chair. As new treatments emerge, the Directory is continuously updated with accurate, current information.
- Family-Focused Resources: Practical guidance, educational materials, and links to support networks.
- Clinical & Research Insights: Access to the latest research, clinical trials, and best practices.
- Connected Care Network: Directs families to the advocacy organization most closely aligned with their child's condition, helping them find the best doctors, access up-to-date clinical trials, and learn about treatment options.
- Searchable & User-Friendly: Easily search by disorder, symptom, or category to quickly find relevant resources.

11q Research and Resource Group

11q Research and Resource Group provides Jacobsen syndrome guides, family connections, conference learning, research updates, and resources addressing medical, developmental, educational, and everyday needs across life stages.

Also covers: Genetic Testing • Transition of Care

info@11q.org

11q.org

1p36 Deletion Support & Awareness

1p36 Deletion Support & Awareness hosts family conferences, expert presentations, developmental-stage discussions, and an online community for caregivers seeking practical information and peer connection across life stages.

Also covers: Genetic Testing • Transition of Care

info@1p36dsa.org

1p36dsa.org

22q Family Foundation

22q Family Foundation offers diagnosis information, family networking, educational events, research updates, and practical resources for people living with 22q11.2 deletion and duplication conditions across childhood and adulthood.

Also covers: Genetic Testing • Transition of Care

info@22qfamilyfoundation.org

22qfamilyfoundation.org

3q29 Foundation

3q29 Foundation connects families through a registry and community network, shares research in plain language, supports studies, and develops evidence-based care recommendations for 3q29 syndromes.

Also covers: Genetic Testing

info@3q29.org

3q29.org

Ketogenic Diet Therapy for Drug-Resistant Epilepsy

Looking Beyond Medications?

For some children with drug-resistant epilepsy and certain neurological conditions, a medical ketogenic diet may be considered as part of their care plan.



KetoVie®

Complete Nutrition for Ketogenic Diet Management

Why Families Choose KetoVie®

- Gentle protein options
- Oral and tube-feeding solutions
- Re-closable lid for on-the-go nutrition
- Designed for ketogenic diet management

Ask your neurologist if a ketogenic diet can help

Conditions for which Ketogenic Diet Therapy may be considered:*

- Dravet Syndrome
- Doose Syndrome
- Infantile Spasms
- Pyruvate Dehydrogenase Deficiency
- Lennox-Gastaut Syndrome
- GLUT1 Deficiency Syndrome (GLUT1DS)
- Rett Syndrome
- Drug-Resistant Epilepsy

KetoVie can help support the missing piece in Ketogenic Nutrition

Explore educational resources, family support tools, and information about ketogenic diet management
Scan the QR code or visit KetoVie.com

Ready to Learn More?

More Choices. More Flexibility. More Possibility.

*Ketogenic diet therapy should be initiated and monitored under the supervision of qualified healthcare professionals. Individual results may vary. KetoVie is a medical food intended for the dietary management of specific diseases or conditions that require a ketogenic diet and should be used under medical supervision.

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4P Support Group

4P Support Group provides Wolf-Hirschhorn syndrome education, parent networks, newsletters, regional gatherings, and biennial conferences while supporting research and collaboration among families and professionals worldwide.

Also covers: Genetic Testing • Transition of Care

info@4p-supportgroup.org

4p-supportgroup.org

A-T Children's Project

A-T Children's Project funds treatment-focused research and offers clinical care references, caregiver guidance, research updates, a global family data platform, and practical resources for living with ataxia-telangiectasia.

Also covers: Genetic Testing

info@atcp.org

atcp.org

ADCY5.org

ADCY5.org offers a patient registry, research participation, no-cost genetic testing, family video calls, online peer groups, and clinician resources for ADCY5-related movement disorder across ages and countries.

Also covers: Genetic Testing

info@adcy5.org

adcy5.org

ADNP Kids Research Foundation

ADNP Kids Research Foundation helps families understand ADNP syndrome through parent guidance, support groups, community stories, awareness activities, and updates about research seeking better care.

Also covers: Genetic Testing

info@adnpkids.com

adnpkids.com

Aicardi Syndrome Foundation

Aicardi Syndrome Foundation provides diagnosis and treatment education, family conferences, peer and grief support, research opportunities, and study updates for people living with Aicardi syndrome.

Also covers: Genetic Testing • Transition of Care

info@aicardisyndromefoundation.org

aicardisyndromefoundation.org

Aidan'z House

Aidan'z House shares family-informed Joubert syndrome education and connects caregivers with condition information, support, and community resources that can help after diagnosis and throughout care.

Also covers: Genetic Testing

info@aidanzhouse.org

aidanzhouse.org/joubertsyndrome

ALD Connect

ALD Connect provides condition education, family support, research updates, and a Spanish-language parent guide for people living with adrenoleukodystrophy and those supporting their ongoing care.

Also covers: Financial Support • Genetic Testing • Mental Health

info@aldconnect.org

aldconnect.org

All Things Kabuki

All Things Kabuki offers parent groups, webinars, family gatherings, grants, genetic-testing information, and research updates for people with Kabuki syndrome and those supporting them worldwide.

Also covers: Genetic Testing • Transition of Care

info@allthingskabuki.org

allthingskabuki.org

Alliance to Cure Cavernous Malformation

Alliance to Cure Cavernous Malformation provides condition education, peer support, patient navigation, genetic information, research opportunities, clinical-trial updates, and connections to experienced specialty care centers.

Also covers: Genetic Testing

info@alliancetocure.org

alliancetocure.org

Alternating Hemiplegia of Childhood Foundation

Alternating Hemiplegia of Childhood Foundation provides crisis and newly diagnosed support, a family directory, research funding, educational meetings, and family assistance for the AHC community.

Also covers: Genetic Testing

info@ahckids.org

ahckids.org

Alyssa V. Phillips Foundation

Alyssa V. Phillips Foundation awards grants for cerebral palsy-related equipment, therapies, vehicle modifications, and other services after families first pursue insurance or public funding for children and adults.

Also covers: Financial Support • Transition of Care

info@alyssavphillipsfoundation.com

alyssavphillipsfoundation.com

American Academy for Cerebral Palsy and Developmental Medicine

The American Academy for Cerebral Palsy and Developmental Medicine provides professional education, clinical resources, research, and guidance supporting people with cerebral palsy and other childhood-onset disabilities.

info@aacpdm.org

aacpdm.org

American Academy of Neurology

The American Academy of Neurology provides evidence-based guidelines, patient education, specialist information, and clinical resources addressing the diagnosis, treatment, care, and management of neurologic conditions.

guidelines@aan.com
aan.com/practice/guidelines
800-879-1960; 612-928-6000

American Academy of Pediatrics

The American Academy of Pediatrics provides evidence-based guidance, clinical tools, and caregiver education addressing autism, developmental concerns, disability services, developmental screening, and pediatric health care.

Also covers: Early Intervention & Education

mcc@aap.org
aap.org/en/patient-care/autism
866-843-2271

American Brain Foundation

American Brain Foundation funds research across brain diseases and disorders, connecting researchers, patient organizations, and donors to advance improved prevention, diagnosis, treatments, and cures across the lifespan.

info@americanbrainfoundation.org
americanbrainfoundation.org
866-770-7570

American Childhood Cancer Organization

American Childhood Cancer Organization provides children with cancer and their families with education, emotional support, care kits, advocacy resources, and guidance throughout treatment and survivorship.

Also covers: Financial Support • Transition of Care • Trauma and Grief

staff@acco.org
acco.org
855-858-2226

American Epilepsy Society

The American Epilepsy Society advances epilepsy care through professional education, research, clinical guidance, and collaboration among healthcare professionals, scientists, advocates, and others serving epilepsy communities.

education@aesnet.org
aesnet.org

American Migraine Foundation

American Migraine Foundation offers doctor-reviewed migraine education, a clinician finder, treatment and clinical-trial information, peer support, and school or adulthood guidance for young people and caregivers.

Also covers: Transition of Care

info@americanmigrainefoundation.org
americanmigrainefoundation.org

American Speech-Language-Hearing Association

The American Speech-Language-Hearing Association provides public and professional information on communication, speech, language, hearing, feeding, and swallowing; its tools include provider directories, evidence maps, practice guidance, and continuing education.

Also covers: Early Intervention & Education

productsales@asha.org
888-498-6699
asha.org

Angelman Syndrome Foundation—Family Champions

Angelman Syndrome Foundation advances research and provides education, clinical resources, family support, and community connections for people with Angelman syndrome and those who care for them.

Also covers: Behavioral Health • Clinical Trials • Early Intervention & Education • Financial Support • Genetic Testing • Mental Health • Navigating Insurance • Transition of Care

amoore@angelman.org
angelman.org

Anita Kaufmann Foundation

Anita Kaufmann Foundation delivers epilepsy education, seizure first-aid training, school and workplace awareness programs, and community outreach designed to reduce stigma and improve safety nationwide.

Also covers: Mental Health

info@akfus.org

akfus.org

Anti-NMDA Receptor Encephalitis Foundation

Anti-NMDA Receptor Encephalitis Foundation offers patient and caregiver support, physician connections, recovery stories, educational resources, research news, clinical-trial information, and practical guidance from diagnosis through rehabilitation.

Also covers: Mental Health • Transition of Care

info@antinmdafoundation.org

antinmdafoundation.org

Association for Creatine Deficiencies

The Association for Creatine Deficiencies provides education, research updates, family support, community programs, and Spanish-language condition information for people living with cerebral creatine deficiency syndromes.

Also covers: Genetic Testing

info@creatineinfo.org

creatineinfo.org

ATP1A3 Foundation

ATP1A3 Foundation advances research on ATP1A3-related conditions, shares disorder and study information, connects families with researchers, and supports international meetings focused on care and treatments.

Also covers: Genetic Testing

info@atp1a3foundation.org

atp1a3foundation.org

Autism in Black

Autism in Black provides education, advocacy, coaching, and community support for Black families raising autistic children; its caregiver-centered programming addresses diagnosis, school navigation, family well-being, and culturally responsive support.

Also covers: Mental Health

info@autisminblack.org

autisminblack.org

Autism Science Foundation

Autism Science Foundation shares research findings, funds studies, explains how evidence may influence care, and connects autistic people and families with opportunities to participate in research.

Also covers: Behavioral Health • Clinical Trials • Early Intervention & Education • Mental Health

contactus@autismsciencefoundation.org

autismsciencefoundation.org/what-is-autism

Autism Society

The Autism Society connects autistic people and their support networks to a national helpline, local affiliates, training, safety programs, and topic-based information for children, teens, and young adults.

Also covers: Behavioral Health • Early Intervention & Education • Transition of Care

Info@AutismSociety.org

800-328-8476

autismsociety.org

Autism Society of Minnesota: Pathways for BIPOC Families

Pathways for BIPOC Families centers Black, Indigenous, and other families of color navigating autism through education about diagnosis, schools, services, family advocacy, and community support.

info@ausm.org

ausm.org/pathways-for-bipoc-families-an-educational-series-centering-bipoc-experience

Autism Speaks

Autism Speaks provides introductory autism information and connects people to individualized information and referrals through its Autism Response Team; the site also includes toolkits, research information, and lifespan supports.

Also covers: Early Intervention & Education • Transition of Care

FamilyServices@AutismSpeaks.org **888-288-4762**
Spanish:888-772-9050
autismspeaks.org

Autism Urban Connections

Autism Urban Connections supports Black families connected to autism in the Pittsburgh region through family education, service information, peer support, caregiver advocacy, and community-based programs.

info@autismurbanconnections.org
fisafoundation.org/autism-urban-connections

Autistic People of Color Fund

Autistic People of Color Fund provides direct financial assistance to autistic people of color for services, equipment, housing, education, transportation, and other needs identified by applicants.

Also covers: Financial Support • Mental Health

autisticpocfund@gmail.com
autisticpoc.org

Autistic Self Advocacy Network (ASAN)

The Autistic Self Advocacy Network advances disability rights, self-advocacy, public policy, community education, and accessible resources developed by and for autistic people across the lifespan.

info@autisticadvocacy.org
autisticadvocacy.org/about-asan/about-autism

Autoimmune Encephalitis Alliance

Autoimmune Encephalitis Alliance provides diagnosis and recovery toolkits, support groups, clinician connections, research updates, caregiver resources, and clinical-trial information for families navigating autoimmune encephalitis care and rehabilitation.

Also covers: Mental Health • Transition of Care

info@aealliance.org

aealliance.org

B Brave Foundation

B Brave Foundation supports families of children with rare degenerative neurological disorders through financial assistance, caregiver education, communication and care-coordination tools, and grief or healing support.

Also covers: Mental Health • Trauma and Grief

sarascaparotti@bbravefoundation.org

bbravefoundation.org

Bainbridge-Ropers Syndrome Foundation

Bainbridge-Ropers Syndrome Foundation connects ASXL3 families, shares diagnosis and care information, supports community gatherings, and promotes registry and study participation to improve understanding of Bainbridge-Ropers syndrome.

Also covers: Genetic Testing

info@brsfoundation.org

brsfoundation.org

Barth Syndrome Foundation

Barth Syndrome Foundation provides clinical care guidance, family support, a patient registry, emergency resources, research opportunities, and expert connections for people living with Barth syndrome.

Also covers: Genetic Testing

info@barthsyndrome.org

barthsyndrome.org

BDSRA foundation

SUPPORTING FAMILIES. ADVANCING RESEARCH. DRIVING HOPE.

The world's largest support and research organization dedicated to Batten disease.

The BDSRA Foundation provides trusted education, family support, advocacy, clinical resources, research funding, and connections to expert care, clinical trials, and Centers of Excellence for families worldwide.



WHAT WE PROVIDE

FAMILY SUPPORT
Providing guidance, connection, education, advocacy, and community support for families navigating Batten disease.

RESEARCH & CLINICAL TRIALS
Driving and funding innovative research while helping families connect with natural history studies, clinical trials, and emerging therapies.

EXPERT CLINICAL CARE
Supporting a growing network of Batten Disease Clinical Centers of Excellence and Affiliate Centers to improve coordinated multidisciplinary care.

EDUCATION & RESOURCES
Offering trusted disease education, webinars, conferences, family resources, bereavement support, and professional education.

WHO IS THIS RESOURCE FOR?

FAMILIES · CAREGIVERS · CLINICIANS · RESEARCHERS · ADVOCATES · INDUSTRY PARTNERS · ALL

RESOURCES & SUPPORT CATEGORIES

- Disorder-Specific Information
- Clinical Trials
- Mental Health & Family Support
- Genetic Testing & Diagnosis
- Transition of Care
- Trauma & Grief
- Research & Advocacy
- Care Coordination
- Navigating Insurance
- Early Intervention & Education

Connecting families, clinicians, researchers, and advocates to improve care today while driving research toward better treatments and a cure.

Scan to learn more about Batten disease resources, research, clinical care, and family support.
https://bdsrafoundation.org/

BATTEN DISEASE CLINICAL CENTERS OF EXCELLENCE AND CLINICAL RESEARCH PROGRAMS

The BDSRA Foundation supports a growing network of Batten Disease Clinical Centers of Excellence and Affiliate Centers dedicated to providing coordinated multidisciplinary care and advancing research for individuals and families affected by Batten disease.

Together, these Centers are part of the Batten Disease Clinical Research Consortium (BDCRC), funded through an NIH Rare Disease Clinical Research Network award.

CoE
A BDSRA Foundation Designation
Center of Excellence

BDCRC
Batten Disease
Clinical Research Consortium

bdsrafoundation.org · info@bdsrafoundation.org · @bdsrafoundation

Hope for today. Research for tomorrow. A cure for Batten disease.

Baziwe Cares

Baziwe Cares offers information, advocacy, and community support for families connected to autism and other developmental disabilities; it helps caregivers connect with culturally responsive resources and better understand service systems.

baziwecaresinc@gmail.com

baziwecares.org

BDSRA Foundation

The Batten Disease Support and Research Association provides condition education, family support, community programs, clinical information, advocacy, and research opportunities for people living with Batten disease.

gretchenfieschko@yahoo.com

bdsrafoundation.org

Black Autism Coalition

Black Autism Coalition provides culturally responsive autism education, advocacy, family support, and community programs created around the experiences of Black autistic people and their caregivers.

info@blackautismcoalition.com

blackautismcoalition.org

Black Autism Support Society

Black Autism Support Society offers peer connection, family activities, education, and community support for Black families connected to autism, including information about available programs and services.

Also covers: Mental Health

krandle@blackautismsupport.com

blackautismsupport.com/about-us

Black Down Syndrome Association

Black Down Syndrome Association provides culturally responsive information, peer connection, and family support addressing education, health care, community participation, and adulthood for people with Down syndrome.

Also covers: Transition of Care

support@blackdownsyndrome.org

blackdownsyndrome.org

Bobby Jones Chiari & Syringomyelia Foundation

Bobby Jones Chiari & Syringomyelia Foundation offers patient education, surgical guidance, online support, medical training, and research programs serving families and clinicians navigating Chiari and syringomyelia worldwide.

Also covers: Transition of Care

info@bobbyjonescsf.org

bobbyjonescsf.org

Brain Injury Association of America Concussion Resources

Brain Injury Association of America connects families with local brain injury specialists and behavior-focused support after traumatic or acquired brain injury through its national helpline and resources.

Also covers: Behavioral Health

skelly@biausa.org **800-444-6443**

biausa.org/public-affairs/media/principles-of-applied-behavior-analysis-in-neurorehabilitation

Brain Tumor Network

Brain Tumor Network provides free nurse navigation, medical-record review, second-opinion coordination, personalized clinical-trial searches, and practical support for people facing a brain tumor diagnosis and treatment decisions.

Also covers: Navigating Insurance • Transition of Care

BTNadm@braintumornetwork.org

braintumornetwork.org

Bryce's Journey

Bryce's Journey provides education, family support, community programming, and social opportunities for children with autism, ADHD, and related developmental or behavioral needs and their caregivers.

Also covers: Behavioral Health

brycesjourney@outlook.com

brycesjourney.org/about

Bryon Riesch Paralysis Foundation

Bryon Riesch Paralysis Foundation awards charitable grants for mobility equipment, home or vehicle modifications, postsecondary scholarships, and research seeking treatments for paralysis and neurological disorders.

Also covers: Transition of Care

info@brpf.org

brpf.org

CACNA1A Foundation

The CACNA1A Foundation connects caregivers, healthcare professionals, and scientists through condition education, family support, research participation, and efforts advancing diagnosis and treatments for CACNA1A-related disorders.

shira@cacna1a.org

cacna1a.org

Canavan Foundation

Canavan Foundation explains Canavan disease, carrier screening, genetic counseling, reproductive options, treatment research, and family resources that support informed decisions after diagnosis and family planning.

Also covers: Genetic Testing

info@canavanfoundation.org

canavanfoundation.org

Cayenne Wellness Center and Children's Foundation—Sickle Cell Brain and Stroke Education

Cayenne Wellness provides education about stroke, brain health, and central nervous system complications of sickle cell disease, including prevention information and resources for families and providers.

info@cayennewellness.org

cayennewellness.org/events/ask-the-expert-brain-stroke-feb

CDG CARE

CDG CARE provides education, family support, clinical resources, advocacy, and research information for people living with congenital disorders of glycosylation and those supporting their care.

info@cdgcare.org

cdgcare.org

CdLS Foundation

The CdLS Foundation provides condition education, family service coordination, clinic and research information, transition resources, and bereavement support for people with Cornelia de Lange syndrome.

Also covers: Genetic Testing • Transition of Care • Trauma and Grief

info@cdlsusa.org

cdlsusa.org

Centers for Disease Control

The CDC explains how cerebral palsy prevalence and characteristics are tracked through the ADDM Network and how surveillance data can guide services and community planning.

Also covers: Behavioral Health • Early Intervention & Education • Genetic Testing • Mental Health

cdcinfo@cdc.gov **800-232-4636**

cdc.gov/cerebral-palsy/about/index.html

Cerebral Palsy Foundation

Cerebral Palsy Foundation develops practical resources about early detection, intervention, healthcare, education, employment, and daily life for people with cerebral palsy, caregivers, and healthcare professionals.

Also covers: Transition of Care

info@yourcpf.org **212-520-1686**

cerebralpalsyfoundation.org

Cerebral Palsy Guide

Cerebral Palsy Guide explains public benefits, nonprofit grants, fundraising, legal options, and other financial resources that may help families manage cerebral-palsy-related care expenses and daily needs.

Also covers: Financial Support

amie.kroessig@cerebralpalsyguide.com **855-220-1101**

cerebralpalsyguide.com/community/financial-support-organizations

Cerebral Palsy Research Network

Cerebral Palsy Research Network brings researchers, clinicians, people with cerebral palsy, and families together to improve care through research, education, community programs, and shared health information.

info@cprn.org **402-302-2776**

cprn.org

CFC International

CFC International supports people with cardio-facio-cutaneous syndrome through education, family connection, awareness, registries, and research for individuals with CFC syndrome, caregivers, healthcare professionals, and researchers.

tdyer@cfcsyndrome.org

cfcsyndrome.org

Children and Adults with Attention-Deficit/Hyperactivity Disorder

Whether you're a parent, adult with ADHD, educator, healthcare professional, or someone seeking trusted ADHD information, CHADD offers evidence-based education, practical tools, and a supportive community.

Get Support

National Resource Center on ADHD Helpline:
1-866-200-8098 (M–F, 1–5 PM ET)

FIND A LOCAL SUPPORT GROUP

ADHD FACT SHEETS & ARTICLES

VISIT CHADD.ORG

CHADD

CHADD provides ADHD education, a specialist directory, support groups, training, and resources for children, adults, caregivers, educators, and healthcare professionals across home, school, work, and healthcare settings.

Also covers: Behavioral Health • Early Intervention & Education • Transition of Care

customer_service@chadd.org

866-200-8098

chadd.org

ChadTough Defeat DIPG Foundation

ChadTough Defeat DIPG Foundation funds pediatric diffuse glioma research and provides disease education, one-to-one nurse support, family resources, research news, and opportunities to advance treatments for DIPG and DMG.

Also covers: Clinical Trials • Trauma and Grief

info@chadtough.org

chadtough.org

CHAMP1 Research Foundation Registry and Research Portal

CHAMP1 Research Foundation maintains a patient registry and shares research updates, study opportunities, and participation information for families, advocacy groups, clinicians, and researchers studying CHAMP1 disorder.

Also covers: Clinical Trials

info@champ1foundation.org

champ1foundation.org/champ1-families

Channeling Hope Foundation

Channeling Hope Foundation connects families living with NALCN-, UNC80-, UNC79-, and FAM155-related disorders to condition education, clinicians, community support, research opportunities, and newly diagnosed guidance.

Also covers: Clinical Trials • Genetic Testing

jwahl@channelinghope.org

620-937-1825

channelinghope.org

Charlie Foundation
FOR KETOGENIC THERAPIES



Charlie Abrahams suffered multiple daily seizures and debilitating effects from medications when he started the ketogenic diet in 1993. He discontinued the diet in 1997 and has been seizure and drug free ever since.

The Charlie Foundation for Ketogenic Therapies was established in 1994 by Jim and Nancy Abrahams to advocate for ketogenic diet therapy for children with epilepsy. Their son Charlie recovered from a catastrophic epilepsy by adhering to a medically supervised ketogenic diet. Our organization has since expanded its mission beyond epilepsy. With growing evidence that ketogenic diets can improve a variety of brain disorders and thwart certain cancers, we have evolved into a global leader in providing ketogenic diet resources for many conditions and for people of all ages.

33 YEARS
of providing information for diet therapies

Resources available on www.charliefoundation.org

Global hospital listing of centers and professionals who provide ketogenic therapy

Keto store with education resources and equipment

Expert opinion videos

No & Low Carb Personal Care Products Guide

Keto recipes with videos



CHARGE Syndrome Foundation

CHARGE Syndrome Foundation offers medical, developmental, educational, and family resources, including Familia CHARGE, a Spanish-speaking support group connecting families with condition education and peer support.

Also covers: Financial Support • Genetic Testing • Transition of Care

info@chargesyndrome.org

chargesyndrome.org

Charlie Foundation for Ketogenic Therapies

The Charlie Foundation for Ketogenic Therapies provides education about ketogenic diet therapies for people with epilepsy, other neurologic conditions, and select cancers, and guidance for caregivers.

bethzk@charliefoundation.org

charliefoundation.org

Chelsea Hutchison Foundation

Chelsea Hutchison Foundation teaches epilepsy and SUDEP safety, helps families obtain seizure-response dogs and monitoring devices, and offers support, education, and restorative family experiences after diagnosis.

Also covers: Trauma and Grief

info@chelseahutchisonfoundation.org

chelseahutchisonfoundation.org

Child Neurology Foundation

Child Neurology Foundation provides education, peer support, care-navigation tools, and a disorder directory for people living with pediatric-onset neurologic conditions, caregivers, and healthcare professionals across the lifespan.

Also covers: Behavioral Health • Clinical Trials • Genetic Testing • Mental Health • Navigating Insurance • Transition of Care • Trauma and Grief

programs@childneurologyfoundation.org

childneurologyfoundation.org **888-417-3435**

Child Neurology Society Education Center

Child Neurology Society Education Center offers clinical guidance and family-friendly brochures about pediatric neurologic and neurobehavioral conditions for healthcare professionals, caregivers, children, and young people.

Also covers: Behavioral Health

nationaloffice@childneurologysociety.org

childneurologysociety.org **651-486-9447**

ChildKind International

ChildKind International helps healthcare organizations improve pediatric pain care through certification, clinician education, shared best practices, and an open-access library of pain-management policies and resources.

Also covers: Behavioral Health • Mental Health

info@childkindinternational.org

childkindinternational.org

Children's Brain Tumor Foundation

The Children's Brain Tumor Foundation provides education and support programs for children with brain or spinal cord tumors, survivors, caregivers, and siblings while advancing research.

swagner@cbtf.org

cbtf.org

Children's Craniofacial Association

Children's Craniofacial Association supports people with facial differences and their families through education, advocacy, family networking, care packages, and financial help for qualifying medical travel.

Also covers: Financial Support • Trauma and Grief

contactCCA@ccakids.com **800-535-3643**

ccakids.org

Children's Hemiplegia and Stroke Association

Children's Hemiplegia and Stroke Association offers pediatric stroke education, online support, family retreats, orthotic grants, scholarships, and research opportunities for children with hemiplegia and caregivers.

Also covers: Early Intervention & Education • Transition of Care

info@chasa.org

chasa.org

Children's Tumor Foundation

Children's Tumor Foundation provides neurofibromatosis and schwannomatosis education, specialty-clinic listings, a patient registry, research updates, and clinical-trial connections while funding treatment development for families worldwide.

Also covers: Clinical Trials • Genetic Testing

info@ctf.org

ctf.org

Chinese Autism Resources and Empowerment Services

Chinese Autism Resources and Empowerment Services offers Chinese-language support groups, workshops, consultations, and family education helping caregivers understand autism, services, advocacy, and available community resources.

Also covers: Mental Health

info@caresseattle.org

caresseattle.org

Chromosome 18 Registry & Research Society

Chromosome 18 Registry & Research Society offers condition-specific guides, family coordinators, lifespan resources, conferences, a research registry, and clinical management information for chromosome 18 conditions worldwide.

Also covers: Clinical Trials • Genetic Testing

office@chromosome18.org

chromosome18.org

COURAGEOUS PARENTS NETWORK

Nonprofit organization providing curated resources and programming to **orient**, **equip** and **empower** families and others navigating a serious pediatric medical condition, with focus on the lived experience of caregivers.

Navigating Medical Complexity

Orienting and guiding caregivers to grow in agency and confidence. Many resources available in Spanish.

Topics include
Diagnosis | Anticipatory Grief | Goals of Care | Working with the Care Team | Family and Community | Interventions Clinical Trial | Advance Care Planning

MedicalComplexity.org

NeuroJourney

Information and support for families caring for a child with severe neurological impairment, in the phases they might experience along the journey. Content available in multiple languages.

Phases
Adapting to Diagnosis | Building Strengths
Adjusting to Changes | Navigating Decline

NeuroJourney.org

Also from CPN

Events | Media Library | Blog



Cleveland Clinic

Cleveland Clinic explains sudden unexpected death in epilepsy, including possible causes, risk factors, prevention strategies, and questions people with epilepsy can discuss with their care team.

CHPHeal@ccf.org
216-444-2200
my.clevelandclinic.org/health/diseases/sudep

Coffin-Siris Syndrome Foundation

Coffin-Siris Syndrome Foundation offers new-diagnosis guidance, family conferences, a specialty clinic, an international registry, financial help for clinic visits, current research opportunities, and care guidance.

Also covers: Genetic Testing • Transition of Care

info@coffinsiris.org
coffinsiris.org

College Autism Network

College Autism Network provides research, training, and resources that help colleges improve access and support autistic students as they prepare for, enter, and complete higher education.

Also covers: Mental Health • Transition of Care

info@collegeautismnetwork.org
collegeautismnetwork.org

Courageous Parents Network

Courageous Parents Network offers videos, podcasts, guides, learning pathways, and clinician materials for caregivers of children with serious medical conditions and the healthcare professionals supporting them.

Also covers: Mental Health • Trauma and Grief

blair@courageousparentsnetwork.org
courageousparentsnetwork.org

CP Family Network

Cerebral Palsy Family Network explains potential financial resources, including IDEA services, grants, SSI, SNAP, Medicaid, and CHIP, for families supporting children and adolescents with cerebral palsy.

Also covers: Financial Support

families@cpfamilynetwork.org **800-273-2645**

cpfamilynetwork.org/resources/blog/7-sources-of-financial-assistance-for-supporting-a-child-with-cerebral-palsy

CSNK2A1 Foundation

CSNK2A1 Foundation provides Okur-Chung syndrome education, a clinician guide, family connection, free genetic-testing pathways, a patient registry, research participation, conferences, and grant-funded studies for families worldwide.

Also covers: Clinical Trials • Genetic Testing

info@csnk2a1foundation.org

csnk2a1foundation.org

CSNK2B Foundation

CSNK2B Foundation provides condition education, family connection, community support, research updates, and participation opportunities while supporting treatment development for people with CSNK2B-related neurodevelopmental syndrome worldwide.

Also covers: Clinical Trials • Genetic Testing

csnk2bfoundationus@gmail.com

csnk2b.org

CTNNB1 Connect and Cure

CTNNB1 Connect and Cure provides newly diagnosed resources, genetics education, a patient registry, natural-history studies, a biorepository, family conferences, and updates on treatment research and care.

Also covers: Clinical Trials • Genetic Testing

info@ctnnb1-connect-and-cure.org

ctnnb1-connect-and-cure.org

Cure AP-4

Cure AP-4 shares care and research information for AP-4 hereditary spastic paraplegia while supporting an international registry, natural-history studies, drug screening, and gene-therapy development for families worldwide.

Also covers: Clinical Trials • Genetic Testing

info@cureap4.org

cureap4.org

Cure CMD

Cure CMD provides multilingual care guides, clinical information, research updates, and family resources for congenital muscular dystrophies, including guidance for appointments, emergencies, and daily care.

Also covers: Clinical Trials • Genetic Testing

info@curecmd.org

curecmd.org

CURE Epilepsy

CURE Epilepsy funds research intended to prevent, treat, and ultimately cure epilepsy while sharing research updates and educational information with people living with epilepsy and families.

info@cureepilepsy.org

cureepilepsy.org

312-255-1801
844-231-2873

CURE GABA-A

CURE GABA-A supports families connected to GABA-A receptor gene variants through education, physician connections, community, and research; the foundation shares resources for newly diagnosed families and advances studies toward treatments.

Also covers: Clinical Trials • Genetic Testing

info@curegabaa.org

curegabaa.org

DETECT. ALERT. ACT.

A Connected Seizure Management Solution for People with Epilepsy

EpiWatch® is an FDA-cleared, Apple Watch–based seizure detection, alerting and seizure monitoring system designed to support timely intervention, caregiver alerting, and activation of seizure response.

EpiWatch®
epiwatch.com



EPIWATCH PERFORMANCE AT A GLANCE

DETECT

Seizure detection and monitoring on Apple Watch

- **Continuous monitoring** using a familiar consumer wearable device
- Detection of **generalized tonic-clonic seizures (TCS)**
- **Real-time alerts** initiated directly from the watch
- **Designed for everyday use** — no additional hardware required



Tonic-Clonic Seizure (TCS) Detection

98%

of TCS detected

Low False Alarm Rate (FAR)

- ~1 false alert every 12 days
- (~0.08 false alarms per 24 hours)

FDA 510(k) cleared | March 2025 for ages 5 and up.

ALERT

Rapid caregiver notification and alerting

- **Automatic alerts sent** to a predefined care contact network
- **Time-stamped seizure events** with seizure event notification
- **Enables rapid situational awareness** during and immediately after a seizure
- **Supports timely delivery** of on-demand (rescue) therapies *(Clinician prescription required for on-demand therapies)*



ACT

From detection to intervention

- **Facilitates activation** of the patient's individualized **Seizure Action Plan**
- **Supports appropriate use of rescue therapies** (per clinician direction)
- **Enhances coordination** between patients, caregivers, and clinicians
- **Help reduce delays** in care during seizure emergencies



Download on the App Store

Why Clinicians Value EpiWatch

- FDA-cleared digital health platform for epilepsy care
- Clinically validated
- High detection performance with low false alarm rate
- Empowers patients and caregivers with actionable information
- Complements standard clinical management — not a replacement for clinical care

Intended Use

EpiWatch is intended to detect and alert for tonic clonic seizures in individuals ages 5+. It is not intended to diagnose epilepsy or replace clinical judgment. Prescription required.

EpiWatch®

Cure Mito Foundation

Cure Mito Foundation connects people with Leigh syndrome and mitochondrial disease through family support, education, advocacy, research participation, and efforts advancing patient-centered treatment development for families.

sophia@curemito.org

curemito.org

Cure SMA

Cure SMA provides spinal muscular atrophy education, family support, research updates, and Spanish-language Smart Moves resources covering development, treatment, daily care, and school participation for patients, providers, and researchers.

Also covers: Clinical Trials • Genetic Testing • Navigating Insurance • Transition of Care

communitysupport@curesma.org

curesma.org

Cure SPG50

Cure SPG50 supports people with SPG50 and AP-4-associated hereditary spastic paraplegia through condition education, family connection, advocacy, research participation, and efforts advancing treatment development for families worldwide.

info@CureSPG50.org

curespg50.org

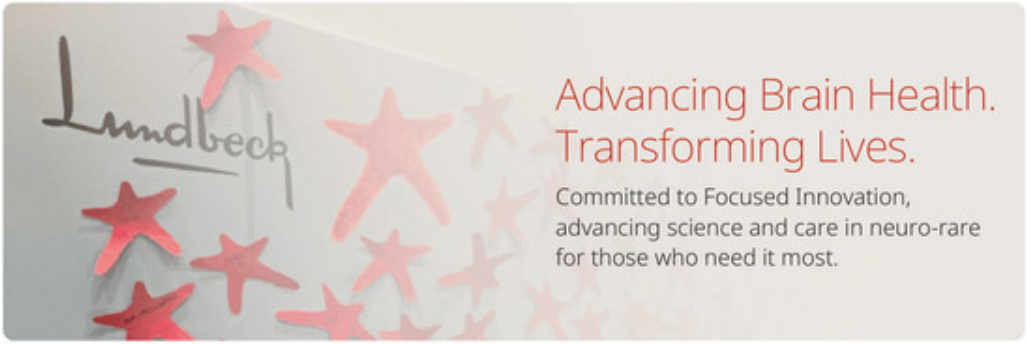
CURE SYNGAP1

CURE SYNGAP1 provides condition education, Spanish-language resources, family connection, research updates, and study information for children and adults living with SYNGAP1-related disorder and those supporting them.

Also covers: Clinical Trials • Genetic Testing • Transition of Care

info@cureSYNGAP1.org

curesyngap1.org



Where our story began

For more than 70 years, Lundbeck has focused solely on advancing brain health.

Our US journey began in 2009, partnering with rare neurological communities whose resilience taught us that progress takes more than science — it takes understanding, partnership and trust.

That spirit lives in our Starfish logo. Inspired by the story of the child who saved starfish one at a time, it reflects our belief that every action matters and every person reached makes a difference.

Where we are today

Today, Lundbeck US provides treatments for neurological and psychiatric diseases while deepening our commitment to neuro-rare innovation to advance science and care for those who need it most.

Our innovative pipeline is focused on neurological and neuro-rare diseases that require highly specialized care, reflecting our role as a Focused Innovator tackling some of the most complex challenges in neuroscience.

Our dedication extends to deep patient advocacy partnerships and employees who participate in advocacy events, standing shoulder-to-shoulder with individuals and families affected by brain diseases.

Where we're headed

We are working to advance innovative neuroscience treatments and aim to have 5-6 clinical developmental programs in mid-to-late-stage development by the end of 2026, including investigational Phase 3 therapies like:

- Bexicaserin for seizures associated with Developmental and Epileptic Encephalopathies (DEEs).
- Amlenetug for use in the treatment of Multiple System Atrophy (MSA).

Bexicaserin and Amlenetug are investigational therapies that have not been approved by any regulatory authority. Additional research and information are needed to fully evaluate their safety and efficacy.

Lundbeck hopes to be able to deliver meaningful progress for people impacted by neuro-rare diseases.

For advocacy-related inquiries, please email USPatientAdvocacy@lundbeck.com

Learn more:

lundbeck.com/us
@LundbeckUS
@lundbeckus
Lundbeck

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CureGRIN Foundation

CureGRIN Foundation provides GRIN disorder education, a welcome kit, family connections, a patient census, research participation, clinical-trial information, and grants supporting treatment development for families and clinicians.

Also covers: Clinical Trials • Genetic Testing

info@curegrin.org

curegrin.org

CVI Now Resources

CVI Now, a Perkins School for the Blind program, provides family-centered information and tools about cerebral or cortical visual impairment for children and young adults.

CVICenter@perkins.org

perkins.org/cvi-now

Danielle Byron Henry Migraine Foundation

Danielle Byron Henry Migraine Foundation provides migraine education, school resources, advocacy, and family support for children and young adults living with migraine disease and their caregivers.

Also covers: Mental Health • Transition of Care

elizabeth@daniellefoundation.org **801-699-5571**

daniellefoundation.org

DDX3X Foundation

DDX3X Foundation connects newly diagnosed families, maintains a patient registry, hosts scientific conferences, funds research grants, and advances cell, gene, and pharmaceutical approaches for DDX3X syndrome.

info@ddx3x.org

ddx3x.org

DEEP

Community Connections.
Transformative Outcomes.

Resource Center

The DEEP Resource Center is a curated hub for caregivers and professionals caring for those with developmental and epileptic encephalopathies (DEEs) and other complex neurodevelopmental disorders (NDDs).



It features high-quality, expert-informed resources, including:
Expansive Resources: Developed by DEEP and in collaboration with our vast network of partners.
Curated Content: Content developed by our partners and other trusted external organizations

EXPLORE TRUSTED RESOURCES

Webinars | Videos | Blogs | Toolkits | Guides | Publications

WHO ARE THESE RESOURCES FOR?
Rare Disease Caregivers & Clinicians

Scan to explore!

LEARN MORE & EXPLORE RESOURCES
www.dee-p.org

DEEP Resource Center

The DEEP Resource Center brings condition information, research opportunities, care guidance, and community support together for caregivers and professionals supporting developmental and epileptic encephalopathies nationwide.

Also covers: Early Intervention & Education • Financial Support • Genetic Testing • Mental Health • Navigating Insurance • Transition of Care • Trauma and Grief

shannon@deepconnections.net

deepconnections.net

Doose Syndrome Epilepsy Alliance

The Doose Syndrome Epilepsy Alliance supports people with epilepsy with myoclonic-atonic seizures through education, connection, and advocacy; its website also shares financial-assistance information that may help families manage condition-related expenses.

Also covers: Financial Support

info@doosesyndrome.org

doosesyndrome.org/parents-and-caregivers/finding-support/financial-support

Down Syndrome Diagnosis Network

Down Syndrome Diagnosis Network offers new-diagnosis guidance, private parent groups, one-to-one mentors, retreats, provider tools, and culturally responsive communities, including support for Spanish-speaking families nationwide.

Also covers: Early Intervention & Education

info@dsdiagnosisnetwork.org

dsdiagnosisnetwork.org

Down Syndrome Guild of Dallas

Down Syndrome Guild of Dallas provides education, programs, and family support, including Grupo de Familias Unidas for Spanish-speaking families raising children and adults with Down syndrome.

Also covers: Transition of Care

grupo@downsyndromedallas.org

downsyndromedallas.org

Caring for someone with Dravet or Lennox-Gastaut syndrome? CareCompass™ can help.

CARECOMPASS
SEAMLESSLY BUILDING PERSONALIZED CAREGIVER GUIDES



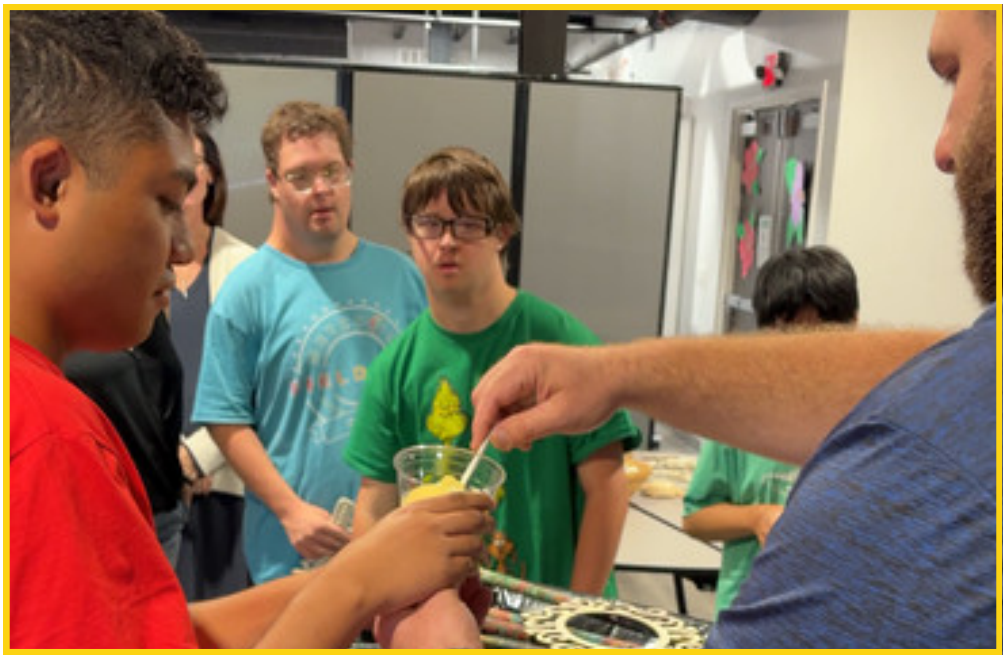
Learn how **CareCompass** can support you in managing your loved one's care-related information.

With this free online resource, you can build a care guide to keep track of vital details and visualize your loved one's care schedule. It allows you to easily collaborate with your loved one's care team and also reflect in a safe space through a journal feature.

FREE TO USE!

Scan now to join or visit
www.care-compass.io

Intended for caregivers of people living with Dravet or Lennox-Gastaut syndrome. The caregiver must be over the age of 18 and a legal resident of the United States.



Dravet Syndrome Foundation

Dravet Syndrome Foundation advances research, education, awareness, and family support for Dravet syndrome and related epilepsies, including Spanish-language education and connection through La Red Familiar.

Also covers: Clinical Trials • Genetic Testing

shannon@dravetfoundation.org **203-392-1955**

dravetfoundation.org

DTDS Foundation

The DTDS Foundation connects people living with dopamine transporter deficiency syndrome to condition education, family support, research participation opportunities, healthcare professionals, and researchers advancing understanding and treatment.

Also covers: Early Intervention & Education

kelly@dtdsfoundation.org

dtdsfoundation.org

Dup15q Alliance

Dup15q Alliance provides condition education, family support, clinic and research information, and Spanish-language resources addressing diagnosis, development, medical concerns, treatment, ongoing care, and research participation.

Also covers: Clinical Trials • Genetic Testing

info@dup15q.org

dup15q.org

DYRK1A Syndrome International Association

DYRK1A Syndrome International Association provides welcome materials, family meetups, an online community, expert-reviewed condition information, research participation, conferences, and updates for families across countries and languages.

Also covers: Clinical Trials • Genetic Testing

info@dyrk1a.org

dyrk1a.org

Doctor Appointment Checklist

Helping you feel prepared and confident

DTDS Quick Facts

Full name:

Dopamine Transporter Deficiency Syndrome

Also Known As:

DAT Deficiency

Gene Associated: **SLC6A3**

Inheritance: **Autosomal Recessive**

NOTES

Before Your Appointment

- ☐ Write down your top 3–5 questions
- ☐ Track recent symptoms or changes
- ☐ List current medications and doses
- ☐ Gather test results or reports
- ☐ Note any therapy updates

During Your Appointment

- ☐ Share your main concerns first
- ☐ Ask for clarification if needed
- ☐ Take notes (or ask someone to help)
- ☐ Confirm understanding of diagnosis or changes
- ☐ Ask about treatment options

Questions You May Want to Ask

- ☐ What might be causing these symptoms?
- ☐ Are there additional tests we should consider?
- ☐ What are our treatment options?
- ☐ What should we monitor at home?
- ☐ When should we follow up?

Before You Leave

- ☐ Understand next steps
- ☐ Confirm prescriptions or referrals
- ☐ Schedule follow-up appointments

After Your Appointment

- ☐ Review your notes
- ☐ Track any new symptoms or responses
- ☐ Follow through on next steps

Remember: You are your child's strongest advocate

Dysautonomia International

Dysautonomia International offers condition education, support groups, a doctor directory, school and workplace accommodation guides, research participation, advocacy tools, and funding for autonomic disorder studies.

Also covers: Clinical Trials • Transition of Care

info@dysautonomiainternational.org

dysautonomiainternational.org

E.WE Foundation

E.WE Foundation supports families living with trisomy 18 and other rare diagnoses through education, resource connections, counseling, advocacy, and family support for complex or life-limiting conditions.

Also covers: Mental Health • Trauma and Grief

admin@theewefoundation.org

theewefoundation.org/resources

Empowering Epilepsy

Empowering Epilepsy provides education, support groups, wellness programs, and community events helping people understand seizures, develop self-management skills, reduce stigma, and connect with others in their communities.

Also covers: Trauma and Grief

Leigh@empoweringepilepsy.org

empoweringepilepsy.org/support-groups

Empowering People's Independence

Empowering People's Independence provides seizure first-aid training, support groups, self-management programs, camps, and community services for children and adults living with epilepsy and their caregivers.

skorba@epiny.org

epiny.org

585-442-4430 x2250


• Neurelis is an innovation-driven neuroscience company providing a differentiated approach to target unmet medical needs in epilepsy and other neurological disorders.
• Our exceptional team and tireless efforts have enabled us to become market-leaders focused on the goal of enhancing patient care and outcomes.
• For information, please visit http://www.neurelis.com.
NEURELIS
US-PRC-26-00034-v1 02/2026



Encephalitis411

Encephalitis411 provides information, monthly support groups, a care-crisis assistance hotline, newsletters, and virtual or in-person events for encephalitis survivors, caregivers, clinicians, therapists, and families worldwide.

Info@encephalitis411.org
1-833-411-3350
encephalitis411.org

Epilepsy Alliance America

Epilepsy Alliance America is a national network of community organizations providing practical support, education, care navigation, and local services for people with epilepsy and their caregivers.

lisa.gallipoli@epilepsyallianceamerica.org
epilepsyallianceamerica.org

Epilepsy Alliance Ohio

Epilepsy Alliance Ohio provides epilepsy education, counseling, support groups, referrals, seizure-response training, and practical assistance helping people navigate school, employment, healthcare, and daily life with confidence.

Also covers: Financial Support • Mental Health • Transition of Care

allison.rone@epilepsy-ohio.org
513-721-2905
epilepsy-ohio.org

Epilepsy Foundation

Epilepsy Foundation provides seizure and epilepsy education, treatment and safety information, family resources, and a Spanish-language learning portal with self-paced courses for caregivers and families.

Also covers: Clinical Trials • Financial Support • Navigating Insurance • Transition of Care

ContactUs@efa.org
800-332-1000
epilepsy.com



It's time for a change. Choose a treatment to stimulate the life you desire.

Discover if VNS Therapy™ could be right for you

Scanthecodeto takethequiz

Follow us on Facebook

Follow us on Instagram

Visit VNSTherapy.com

LivaNova

VNS Therapy™ is a neuromodulation treatment designed for people with drug-resistant epilepsy 4 years of age and older with partial onset seizures. It is an add-on treatment that can lead to a better quality of life.

Safety information is available at VNSTherapy.com/safety.



EPILEPSY ALLIANCE AMERICA

National Community. Local Solutions.

Providing hope and possibilities for individuals and families affected by epilepsy.

- Seizure Recognition & Response Training
- Summer Camp Programs
- Scholarships
- Seizure ID Program
- Self Management Programs
- Support Groups

www.epilepsyallianceamerica.org


SCN2A-RELATED AUTISM & EPILEPSY
FAMILIESCN2A®
FOUNDATION
The leading patient advocacy organization for SCN2A-related disorders
KNOW SOMEONE WITH
AUTISM & EPILEPSY?
It could be SCN2A.
The FamilieSCN2A Foundation supports individuals and families affected by SCN2A-related disorders through patient support, research advancement, and provider education. We are committed to accelerating progress, expanding awareness, and helping families feel informed, connected and not alone.
Patient Support
Conneting families to resources, community, and meaningful support across every stage of the journey.
Research
Advancing research, strengthening collaboration, and helping move better treatments and care forward.
Provider Education
Equipping clinicians and professionals with trusted information about SCN2A-related disorders.
SCN2A-related disorders are associated with epilepsy, autism, developmental delay, and other neurodevelopmental features. Earlier recognition can help families access answers, support and care.
SCAN HERE
Learn more.
Find support.
Build awareness.
SCN2A.ORG

Epilepsy Services Foundation

Epilepsy Services Foundation provides education, support groups, transportation assistance, scholarships, and family programs for people with epilepsy; it serves children, teens, adults, and caregivers and includes transition-related support.

Also covers: Financial Support • Transition of Care

info@epilepsysf.org **813-374-8907**

epilepsysf.org

EveryLife Foundation for Rare Diseases

EveryLife Foundation for Rare Diseases advances public policy, research participation, newborn screening, and patient advocacy while helping people with rare diseases engage in federal decision-making.

Also covers: Clinical Trials • Navigating Insurance

info@everylifefoundation.org

everylifefoundation.org

Exceptional Lives

Exceptional Lives provides plain-language information and individualized guidance to help parents and caregivers navigate disability services, education, public benefits, and support systems for their children.

Also covers: Navigating Insurance • Transition of Care

info@exceptionallives.org **844-354-1212**

exceptionallives.org/resources

FamilieSCN2A Foundation

FamilieSCN2A Foundation advances research, education, advocacy, and family connection for SCN2A-related disorders, with Spanish-language welcome materials and support available to newly connected families and caregivers.

Also covers: Clinical Trials • Genetic Testing • Trauma and Grief

amanda.gale@scn2a.org

scn2a.org

Fiesta Educativa

Fiesta Educativa provides Spanish-language disability education, special-education training, parent support, and advocacy helping Latino families understand their rights and navigate school and service systems with confidence.

info@fiestaeducativa.org
fiestaeducativa.org

Fighting for Kaiden Foundation

Fighting for Kaiden Foundation provides families living with spinal muscular atrophy with equipment, supplies, education, and community support that may fill gaps left by insurance.

Also covers: Financial Support

info@fightingforkaiden.org
443-995-3002
fightingforkaiden.org

Five P Minus Society

Five P Minus Society provides Cri du Chat syndrome information, family conferences, professional education, peer connection, and practical resources supporting people with 5p deletion throughout life.

Also covers: Genetic Testing • Transition of Care

director@fivepminus.org
fivepminus.org

Foundation for Angelman Syndrome Therapeutics

The Foundation for Angelman Syndrome Therapeutics advances treatment research for Angelman syndrome and provides community education, including Spanish-language information and resources through FAST Latin America.

Also covers: Clinical Trials • Genetic Testing

niki.armstrong@cureangelman.org
cureangelman.org

Foundation to Fight H-ABC

Foundation to Fight H-ABC provides education, lifespan care resources, advocacy, research updates, and family connection for people living with TUBB4A-related leukodystrophy and their caregivers worldwide.

Also covers: Clinical Trials • Genetic Testing • Transition of Care

contact@h-abc.org

h-abc.org

FOXG1 Research Foundation

FOXG1 Research Foundation provides condition and genetics education, family support, clinic and registry information, research updates, and clinical-trial resources for people living with FOXG1 syndrome.

Also covers: Clinical Trials • Genetic Testing

contact@foxg1research.org

foxg1research.org

FRAXA Research Foundation

FRAXA Research Foundation funds Fragile X treatment studies, fellowships, and clinical trials while sharing plain-language information about testing, clinics, therapies, and research participation for families and professionals.

Also covers: Clinical Trials • Genetic Testing • Transition of Care

info@fraxa.org

fraxa.org

Friedreich's Ataxia Research Alliance

Friedreich's Ataxia Research Alliance advances treatment research and offers a clinical-trial finder, patient registry, educational materials, research updates, and participation opportunities for the Friedreich ataxia community.

Also covers: Clinical Trials • Genetic Testing

info@curefa.org

curefa.org

Fundación Puertorriqueña Síndrome Down

Fundación Puertorriqueña Síndrome Down provides education, therapeutic services, family support, inclusion programs, and employment preparation for people with Down syndrome across childhood, adolescence, and adulthood.

Also covers: Behavioral Health • Transition of Care

info@sindromedownpr.org

sindromedownpr.org

GBS/CIDP Foundation International

GBS CIDP Foundation International provides education, peer support, specialist information, and community resources for people living with GBS, CIDP, and related inflammatory or immune-mediated neuropathies.

info@gbs-cidp.org

gbs-cidp.org



GiGi's Playhouse

GiGi's Playhouse offers free Down syndrome programs in literacy, math, speech, fitness, social skills, and career development, serving families from prenatal diagnosis through adulthood worldwide.

Also covers: Early Intervention & Education • Transition of Care

info@gigisplayhouse.org

gigisplayhouse.org

Global Foundation for Peroxisomal Disorders

Global Foundation for Peroxisomal Disorders offers family support groups, an equipment exchange, patient registry, research and trial information, bereavement resources, education, and community conferences for families and professionals.

Also covers: Clinical Trials • Genetic Testing

info@thegfpd.org

thegfpd.org

Global Genes

Global Genes provides rare-disease education, advocacy tools, community connections, and organizational support for people and families, healthcare professionals, researchers, and patient-led advocacy groups across the world.

Also covers: Genetic Testing • Trauma and Grief

support@globalgenes.org

globalgenes.org

Glut1 Deficiency Foundation

Glut1 Deficiency Foundation provides condition and genetics education, treatment guidance, family support, research updates, and study opportunities for people living with Glut1 deficiency and their caregivers.

Also covers: Clinical Trials • Genetic Testing

info@g1dfoundation.org

g1dfoundation.org

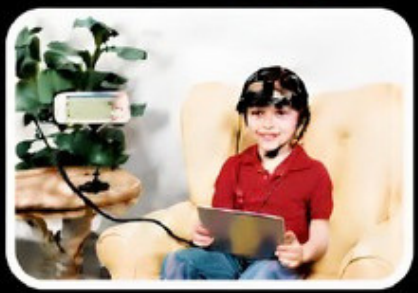
REDEFINING TESTING WITH CHILDREN IN MIND



Approachable neurodiagnostic care for children and families.

About Us

NeuroElite Services LLC provides EEG testing for children and families. Services are available in-office, in-home, or in care settings, helping patients and caregivers access comfortable, reliable neurological diagnostic testing.



Why Choose Us?

- Child-friendly, patient-first care that helps reduce stress
- Ideal for children with sensory sensitivities or delicate skin
- Clear communication throughout the testing process
- Meticulous testing standards and accurate information for referring clinicians.
- Compatible with QEEG systems and research software



Compassionate care. Clear answers. Peace of mind.

Contact Us

562-526-4278
Anaheim, CA
NeuroElite.org

NeuroElite Services LLC

GRIN2B Foundation Research

GRIN2B Foundation curates scientific papers and connects families with the BioGENE, TIGER, and Simons Searchlight studies examining brain activity, development, and GRIN2B-related conditions through research participation opportunities.

Also covers: Clinical Trials

ryan.barash@grin2b.com

grin2b.com/research

Grupo SALTO

Grupo SALTO provides Spanish-language autism education, parent support, sibling programs, arts activities, and social opportunities helping families build connections and navigate services in the Chicago area.

Also covers: Behavioral Health

gruposalto@gruposalto.org

gruposalto.org

Hao-Fountain Syndrome Foundation

Hao-Fountain Syndrome Foundation connects USP7 families through a private community, family meetings, newly diagnosed guidance, clinical resources, a patient registry, research participation, and study updates.

Also covers: Clinical Trials • Genetic Testing

admin@usp7.org

usp7.org

HCU Network America

HCU Network America provides condition education, peer connection, care-navigation tools, research information, and assistance programs for children and adults living with homocystinurias and their caregivers.

Also covers: Clinical Trials • Genetic Testing • Transition of Care

info@hcunetworkamerica.org **630-360-2087**

hcunetworkamerica.org

Healthy Children

HealthyChildren.org helps caregivers and adolescents with cerebral palsy plan for adult healthcare, insurance, decision-making support, community services, education, employment, greater independence, and daily living skills.

Also covers: Transition of Care

866-843-2271

info@healthychildren.org

healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/helping-a-child-with-cerebral-palsy-move-into-adulthood.aspx

Help Undiagnosed Children Foundation

Help Undiagnosed Children Foundation helps medically and financially eligible young people obtain free or reduced-cost genetic testing and supports reanalysis of uncertain previous test results.

Also covers: Early Intervention & Education • Financial Support • Genetic Testing

info@hucf.org

hucf.org

Hereditary Neuropathy Foundation

Hereditary Neuropathy Foundation provides education, research opportunities, and family support for inherited neuropathies, including Spanish-language Charcot-Marie-Tooth education and resources through its No Camines Solo initiative.

Also covers: Clinical Trials • Genetic Testing

Courtney@hnf-cure.org

hnf-cure.org

Heterotaxy Connection

Heterotaxy Connection brings together patients, families, clinicians, and researchers through education, peer support, conferences, clinical resources, and research opportunities; its resources can support families from diagnosis through adult congenital care.

Also covers: Clinical Trials • Transition of Care

connect@heterotaxy.org

385-482-2155

heterotaxy.org

Hispanic Society for Rare Diseases

Hispanic Society for Rare Diseases provides Spanish-language rare-disease information and helps patient organizations communicate more effectively with Spanish-speaking families through education, resources, and community outreach.

Also covers: Genetic Testing • Navigating Insurance

eli@hispanicsocietyrarediseases.org

hispanicsocietyrarediseases.org

HNRNPH2 Foundation

HNRNPH2 Foundation connects families living with HNRNPH2-related neurodevelopmental disorder, shares care and research information, supports community events, and encourages participation in registries and studies worldwide.

Also covers: Clinical Trials • Genetic Testing

info@hnrnph2.org

hnrnph2.org

Hope for HIE

Hope for HIE provides education, peer support, research updates, mental health resources, grief support, and multilingual materials for families navigating hypoxic ischemic encephalopathy across the lifespan.

Also covers: Clinical Trials • Mental Health • Trauma and Grief

Outreach@hopeforhie.org

hopeforhie.org/clinciansandpartners/printableresources

Hope for Hypothalamic Hamartomas

Hope for Hypothalamic Hamartomas provides diagnosis-to-adulthood education, treatment-center information, family conferences, a patient registry, research grants, professional training, and practical support for caregivers and clinicians.

Also covers: Clinical Trials • Transition of Care

info@hopeforhh.org

hopeforhh.org

Human Epilepsy Project

The Human Epilepsy Project maintains a resource list that connects people with epilepsy, clinicians, and researchers to advocacy organizations, research initiatives, registries, and related programs.

Also covers: Clinical Trials

diventura@epilepsyconsortium.org **856-848-1012**

humanepilepsyproject.org/resources

Hunter's Hope Foundation

Hunter's Hope Foundation helps leukodystrophy families through newborn-screening advocacy, care and treatment education, family-care programs, research funding, equipment support, and annual community gatherings for connection nationwide.

hope@huntershope.org

huntershope.org

Hydrocephalus Association

Hydrocephalus Association provides education, a support helpline, community programs, and Spanish-language information about diagnosis, treatment, shunts, ETV care, warning signs, and daily life for families.

Also covers: Clinical Trials • Transition of Care

info@hydroassoc.org

hydroassoc.org/resources

ICNApedia

ICNApedia provides global clinical case studies, articles, and resource lists for pediatric neurologists and other clinicians seeking practical information about childhood neurologic conditions and treatment.

Also covers: Behavioral Health

office@icnapedia.org

icnapedia.org

International Alliance for Pediatric Stroke

International Alliance for Pediatric Stroke advances awareness, education, research, and family support while providing an online Pediatric Stroke Family Tool Kit for caregivers and professionals.

info@iapediatricstroke.org

iapediatricstroke.org

International Foundation for CDKL5 Research

International Foundation for CDKL5 Research provides care guidance, family representatives, genetics education, research updates, and clinical-trial information for people and families living with CDKL5 deficiency disorder.

Also covers: Clinical Trials • Genetic Testing • Mental Health

FSR@CDKL5.com

cdkl5.com/clinical-care

International FOXG1 Foundation Research

International FOXG1 Foundation connects families, clinicians, and researchers with FOXG1 syndrome research updates, registries, study participation opportunities, community information, and efforts supporting future treatment development.

Also covers: Clinical Trials

info@foxg1.org

foxg1.org/research

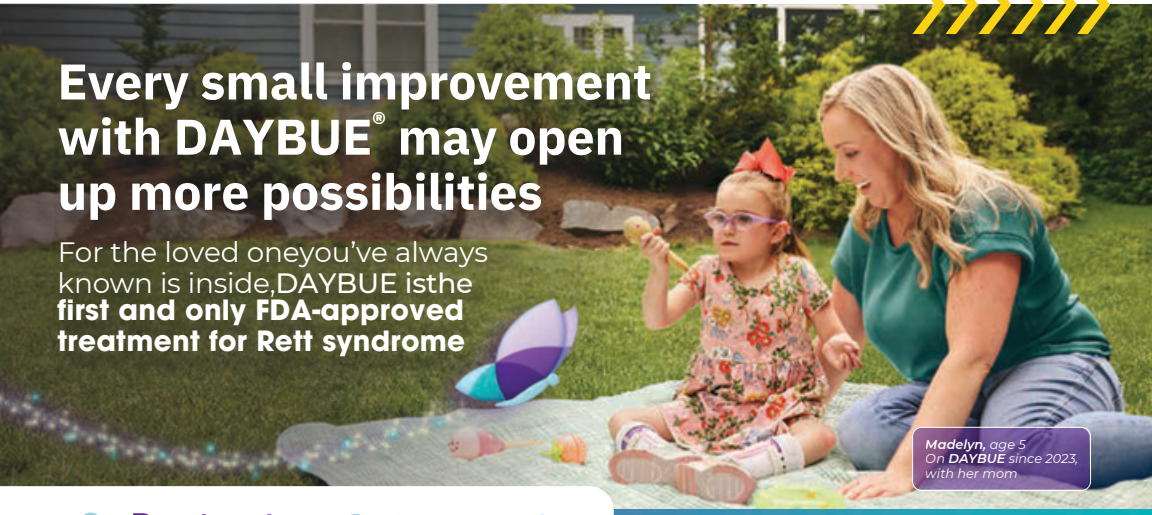
International Rett Syndrome Foundation

International Rett Syndrome Foundation provides medical and communication guidance, clinic connections, family support, genetics education, research news, clinical-trial information, and lifespan resources for Rett syndrome.

Also covers: Clinical Trials • Genetic Testing • Transition of Care

info@rettsyndrome.org

rettsyndrome.org/healthcare-providers/communication-in-rett-syndrome



Daybue® (trofinetide) oral solution

Daybue® Stix (trofinetide) for oral solution

See what's been possible

Scan theQR codeand visit DAYBUE.com/stories for caregiver perspectives

Indication and Important Safety Information

What is DAYBUE or DAYBUE STIX?

DAYBUE or DAYBUE STIX are prescription medicines used to treat Rett syndrome in adults and children 2 years of age and older. It is not known if DAYBUE or DAYBUE STIX is safe and effective in children under 2 years of age.

What are the possible side effects of DAYBUE or DAYBUE STIX?

- **Diarrhea:** Diarrhea is a common side effect of DAYBUE or DAYBUE STIX that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Before starting treatment with DAYBUE or DAYBUE STIX, stop taking laxatives. Tell your healthcare provider if you have diarrhea while taking DAYBUE or DAYBUE STIX. Your healthcare provider may ask you to increase the amount you drink or take antidiarrheal medicine as needed.
- **Vomiting:** Vomiting is a common side effect of DAYBUE or DAYBUE STIX. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.
- **Weight loss:** DAYBUE or DAYBUE STIX can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE or DAYBUE STIX.
- **The most common side effects of DAYBUE or DAYBUE STIX include diarrhea and vomiting.** Other side effects include fever, seizure, anxiety, decreased appetite, tiredness, and the common cold. These are not all the possible side effects of DAYBUE or DAYBUE STIX. Tell your healthcare provider if you have any side effects that bother you or do not go away.

What should I tell my healthcare provider before taking DAYBUE or DAYBUE STIX?

Before taking DAYBUE or DAYBUE STIX, tell your healthcare provider about all of your medical conditions, including if you:

- have kidney problems.
- are pregnant or plan to become pregnant. It is not known if DAYBUE or DAYBUE STIX will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if DAYBUE or DAYBUE STIX passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while taking DAYBUE or DAYBUE STIX.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking DAYBUE or DAYBUE STIX with certain medicines may affect how the other medicines work and can cause serious side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You can also call Acadia Pharmaceuticals Inc. at 1-844-4ACADIA (1-844-422-2342).

DAYBUE is available as an oral solution (200 mg/mL).

DAYBUE STIX for oral solution powder is available in 5,000 mg, 6,000 mg, and 8,000 mg packets.

Please see Brief Summary of Important Information about DAYBUE on the following page.

ACADIA

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PATIENT INFORMATION

DAYBUE® (day-BYOO)
(trofinetide)
oral solution

DAYBUE® STIX (day-BYOO STIX)
(trofinetide)
for oral solution

What is DAYBUE or DAYBUE STIX?

- DAYBUE or DAYBUE STIX are prescription medicines used to treat Rett syndrome in adults and children 2 years of age and older.

It is not known if DAYBUE or DAYBUE STIX is safe and effective in children under 2 years of age.

Before taking DAYBUE or DAYBUE STIX, tell your healthcare provider about all of your medical conditions, including if you:

- have kidney problems.
- are pregnant or plan to become pregnant. It is not known if DAYBUE or DAYBUE STIX will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if DAYBUE or DAYBUE STIX passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while taking DAYBUE or DAYBUE STIX.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Taking DAYBUE or DAYBUE STIX with certain medicines may affect the way other medicines work and can cause serious side effects.

Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I take DAYBUE or DAYBUE STIX?

- Take DAYBUE or DAYBUE STIX exactly as your healthcare provider tells you to take it.
- If you have kidney problems, talk to your healthcare provider about the right dose of DAYBUE or DAYBUE STIX.
- If you take laxatives, stop taking them before starting treatment with DAYBUE or DAYBUE STIX.
- DAYBUE or DAYBUE STIX may be given by mouth or through a gastrostomy (G) tube. If DAYBUE or DAYBUE STIX is given through a gastrojejunal (GJ) tube, the G-port must be used.
- DAYBUE or DAYBUE STIX may be taken with or without food.
- Your pharmacist should provide an oral syringe or dosing cup that is needed to measure your prescribed dose of DAYBUE or the amount of liquid to mix with DAYBUE STIX powder. A household measuring cup, teaspoon, or tablespoon is not an adequate measuring device.
- **If you are taking DAYBUE oral solution:**
  - Throw away any unused DAYBUE oral solution after 14 days of first opening the bottle.
- **If you are taking DAYBUE STIX for oral solution:**
  - Open each packet only when you are ready to use it.
  - DAYBUE STIX powder must be dissolved in cold to room temperature water or water-based beverage (juice, tea, lemonade, or liquid hydration).
  - Your healthcare provider will tell you how much cold to room temperature water or water-based beverage to use to dissolve the powder in each packet.
  - Empty the entire contents of the DAYBUE STIX packets needed for your prescribed dose into the measured liquid. Do not attempt to use part of a packet.
  - Stir until the powder is completely dissolved.
  - After the powder is dissolved, take the prepared oral solution right away. **Do not** store for future use.
  - Throw away any prepared oral solution that was not taken.
- Your healthcare provider may change your dose or stop treatment with DAYBUE or DAYBUE STIX if needed.
- If you vomit after taking a dose of DAYBUE or DAYBUE STIX, **do not take** another dose to make up for that dose. Wait and take the next dose at your usual time. Call your healthcare provider if your vomiting does not stop.
- If you miss a dose of DAYBUE or DAYBUE STIX, skip that dose and take your next dose at your usual time. **Do not** take 2 doses to make up the missed dose.

What are the possible side effects of DAYBUE or DAYBUE STIX?
DAYBUE or DAYBUE STIX may cause side effects, including:

- **Diarrhea.** Diarrhea is a common side effect of DAYBUE or DAYBUE STIX that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Tell your healthcare provider if you have diarrhea while taking DAYBUE or DAYBUE STIX. Your healthcare provider may ask you to increase the amount you drink or take antidiarrheal medicine as needed.
- **Weight loss.** DAYBUE or DAYBUE STIX can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE or DAYBUE STIX.
- **Vomiting.** Vomiting is a common side effect of DAYBUE or DAYBUE STIX. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.

The most common side effects of DAYBUE or DAYBUE STIX include diarrhea and vomiting.

These are not all the possible side effects of DAYBUE or DAYBUE STIX. Tell your healthcare provider if you have any side effects that bother you or do not go away. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store DAYBUE or DAYBUE STIX?

- **DAYBUE oral solution:**
  - Store DAYBUE oral solution bottle in the refrigerator between 36°F to 46°F (2°C to 8°C). Do not freeze.
  - Keep DAYBUE oral solution bottle in an upright position.
  - Keep the child-resistant cap on the bottle tightly closed.
- **DAYBUE STIX for oral solution:**
  - Store DAYBUE STIX for oral solution powder packets at room temperature between 68°F to 77°F (20°C to 25°C).

Keep DAYBUE, DAYBUE STIX, and all medicines out of the reach of children.

General information about the safe and effective use of DAYBUE or DAYBUE STIX.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use DAYBUE or DAYBUE STIX for a condition for which it was not prescribed. Do not give DAYBUE or DAYBUE STIX to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about DAYBUE or DAYBUE STIX that is written for health professionals.

What are the ingredients in DAYBUE or DAYBUE STIX?

Active ingredient: trofinetide

DAYBUE oral solution inactive ingredients: FD&C Red No. 40, maltitol, methylparaben sodium, propylparaben sodium, purified water, strawberry flavor, and sucralose.

DAYBUE STIX for oral solution inactive ingredients: natural strawberry flavor and sucralose.

Marketed by Acadia Pharmaceuticals Inc., San Diego, CA 92130 USA

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For more information, go to www.daybue.com or call 1-844-422-2342.

This Patient Information has been approved by the U.S. Food and Drug Administration
Issued: 12/2025

Johns Hopkins Pediatric Neurology

Johns Hopkins Pediatric Neurology provides evaluation and treatment for children with a wide range of neurologic conditions, including epilepsy, movement disorders, neuromuscular disorders, neurofibromatosis, and cerebral palsy.

paigeace@jhu.edu **301-938-8909**

hopkinsmedicine.org/neurology-neurosurgery/specialty-areas/pediatric-neurology

Jordan's Guardian Angels

Jordan's Guardian Angels advances PPP2R5D research and treatment development while offering a new-family packet, genetics education, study updates, clinical-trial information, and connection across the global Jordan's syndrome community.

Also covers: Clinical Trials • Genetic Testing • Transition of Care

info@jordansguardianangels.org

jordansguardianangels.org

JoshProvides Epilepsy Assistance Foundation

JoshProvides offers epilepsy support groups, safety education, and grants for diagnostic testing, seizure-detection devices, treatment travel, transportation, and trained seizure-response dogs for children and adults with epilepsy.

Also covers: Financial Support

info@joshprovides.org

joshprovides.org

KAT6 Foundation

KAT6 Foundation offers newly diagnosed guidance, family resources, a patient registry, community events, assistive-equipment and therapy grants, and research programs for KAT6A and KAT6B syndromes.

Also covers: Clinical Trials • Genetic Testing

info@kat6foundation.org

kat6foundation.org

Kayven's Helping Hands

Kayven's Helping Hands provides epilepsy education, family support, literacy activities, and enrichment assistance; its programs help children and families connected to seizures while strengthening access to community opportunities.

Also covers: Financial Support

celebratekayven@gmail.com **316-364-7853**

kayvenshelpinghands.org

KBG Foundation

KBG Foundation connects families through regional ambassadors, family and clinic days, local resources, educational events, and a natural-history study advancing understanding of KBG syndrome worldwide.

Also covers: Genetic Testing • Transition of Care

info@kbgfoundation.com

kbgfoundation.com

KCNA2 Collaborative

KCNA2 Collaborative provides families with KCNA2-related epilepsy and movement disorder education, peer connection, research updates, patient data opportunities, and links to clinicians and studies worldwide.

Also covers: Clinical Trials • Genetic Testing

info@kcna2collaborative.org

kcna2collaborative.org

KCNA2 Epilepsy, Inc.

KCNA2 Epilepsy, Inc. provides education, peer connection, and practical guidance for families connected to KCNA2-related disorders; it also shares registry, research, and clinical-trial opportunities with the international KCNA2 community.

Also covers: Clinical Trials • Genetic Testing

kcna2epilepsy@gmail.com **216-954-6556**

kcna2epilepsy.org

KCNQ2 Cure Alliance

KCNQ2 Cure Alliance offers newly diagnosed support, a doctor finder, education, family grants, research and trial information, a biorepository, and community summits for KCNQ2 disorders.

Also covers: Clinical Trials • Genetic Testing

info@kcnq2cure.org

kcnq2cure.org

KCNT1 Epilepsy Foundation

KCNT1 Epilepsy Foundation connects families, clinicians, and researchers with condition education, research updates, support resources, financial guidance, and Spanish-language information about KCNT1-related disorders for patients, providers, and researchers.

Also covers: Clinical Trials • Financial Support • Genetic Testing

info@kcnt1epilepsy.org

kcnt1epilepsy.org

KIF1A.ORG Research Participation

KIF1A.ORG connects people living with KIF1A-associated neurological disorder and their families to patient registries, natural-history studies, research updates, and opportunities to participate in research worldwide.

Also covers: Clinical Trials

impact@kif1a.org

kif1a.org/research

Kleefstra Syndrome Community

Kleefstra Syndrome Community provides family callbacks, conferences, care information, adult-life resources, a patient registry, research updates, and participation opportunities for people with Kleefstra syndrome worldwide.

Also covers: Genetic Testing • Transition of Care

info@kleefstrasyndrome.org

kleefstrasyndrome.org

Kleine-Levin Syndrome Foundation

Kleine-Levin Syndrome Foundation maintains a patient registry, physician directory, medical literature library, peer community, and awareness materials while supporting research into recurrent hypersomnia and related symptoms.

info@klsfoundation.org

klsfoundation.org

Koolen-de Vries Syndrome Foundation

Koolen-de Vries Syndrome Foundation offers condition education, a family contact registry, peer support, clinic and travel guidance, community summits, research updates, and Spanish-language videos for families worldwide.

Also covers: Genetic Testing • Transition of Care

info@koolendevries.org

koolendevries.org

Korean American Disabled People's Association

Korean American Disabled People's Association provides culturally responsive information, family networking, advocacy, and community programs helping Korean Americans with disabilities and caregivers navigate services and support.

Also covers: Transition of Care

kadpa.usa@gmail.com

kadpa.org

Korean American Special Education Center

Korean American Special Education Center provides bilingual developmental screening, education, parent support, and clinical or therapeutic programs for Korean-speaking families of children with developmental differences.

Also covers: Behavioral Health

info@kasecca.org

kasecca.org/en/services-2

NOW ENROLLING!

Jazz Pharmaceuticals Focal Onset Seizure Study

The purpose of this study is to assess the safety and efficacy of cannabidiol oral solution (CBD-OS) as an adjunctive treatment in reducing the frequency of focal seizures.

Key Eligibility Requirements:

1. 12 to 75 years old at time of screening
2. Documented diagnosis of focal epilepsy
3. Currently being treated with at least one, but no more than four, antiseizure medications on a stable regimen

For more information, please visit www.epifostrial.com or click on this QR code:

EpiFOS STUDY

KrabbeConnect

KrabbeConnect provides education, family navigation, research information, assistance resources, and grief support for Krabbe disease, including Spanish-language information about screening, diagnosis, treatment, care, and bereavement.

Also covers: Clinical Trials • Financial Support • Genetic Testing • Trauma and Grief

Info@KrabbeConnect.org

krabbeconnect.org

Landon's Legacy Foundation

Landon's Legacy Foundation provides seizure response and safety training, disability and rare-disease advocacy, community education, family resource connections, grants, scholarships, and inclusive outreach in Arizona.

Also covers: Financial Support

info@landonslegacyfoundation.org **347-987-1610**

landonslegacyfoundation.org

Learning Disabilities Association of America

Learning Disabilities Association of America provides information, advocacy, webinars, and resources addressing learning disabilities across education, employment, evaluation, accommodations, mental health, and daily life at every age.

Also covers: Early Intervention & Education • Transition of Care

info@ldaamerica.org

ldaamerica.org

LGS Foundation

The LGS Foundation provides Lennox-Gastaut syndrome education, family support, community connection, and research information while advancing awareness and improved care for people with LGS and related epilepsies.

Also covers: Clinical Trials

amber@lgsfoundation.org

lgsfoundation.org

LGS FOUNDATION®
LENNOX-GASTAUT SYNDROME



STANDING TOGETHER.
STRONGER TOGETHER.

Dedicated to improving the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

For FAMILIES

EDUCATION
- New Family Welcome Kits
- About LGS Treatments Kits
- Learning & Resource Center

SUPPORT
- Online Support
- In-Person Meet Ups
- Elevate Patient Assistance Program
- Family Ambassadors & Patient Navigators

EVENTS
- International Family & Professional Conference
- Walk for LGS Research
- International LGS Awareness Day

For PROFESSIONALS

RESEARCH
- Cure LGS 365 Research Grants
- LGS Research Meeting of the Minds
- LGS Learn from Every Patient Database (global patient registry and natural history study)
- Research Opportunities

RESOURCES
- Free LGS Educational Materials
- Continuing Medical Education (CME)
- LGS Publications

Learn More & Get Involved

www.lgsfoundation.org

info@lgsfoundation.org

SCAN HERE

Living for Epilepsy Foundation

Living for Epilepsy Foundation provides epilepsy education, awareness, advocacy, support, and medical-identification resources while working to reduce stigma within Cleveland's African American community and beyond.

info@livingforepilepsy.org

livingforepilepsy.org

Malan Syndrome Foundation

Malan Syndrome Foundation connects families through international conferences, support groups, and Spanish-language resources while sharing clinical guidance, research studies, and updates about NFIX-related Malan syndrome.

Also covers: Clinical Trials • Genetic Testing

info@malansyndrome.org

malansyndrome.org

Manos Unidas International

Manos Unidas International provides culturally responsive autism and developmental screening, family education, and support helping Spanish-speaking caregivers identify concerns, seek evaluations, and connect with appropriate services.

Also covers: Behavioral Health

info@manosunidasinternational.org

manosunidasinternational.org/autism-and-neuro-developmental-screenings-with-winlock-pediatrics

Margaret Hackett Family Program

Margaret Hackett Family Program at the University of Chicago provides education, family support, and care guidance for people living with congenital central nervous system anomalies and caregivers.

Also covers: Transition of Care

mhfcp@bsd.uchicago.edu

773-795-0622

mhfcp.uchicago.edu

Raising the Volume
ON MCT8 DEFICIENCY



MCT8 deficiency, also known as Allan-Herndon-Dudley syndrome, is a rare X-linked disorder that disrupts the balance of thyroid hormone in the brain and body, leading to severe neurodevelopmental challenges, a number of symptoms caused by chronically elevated levels of the biologically active thyroid hormone T3, and lifelong support needs.

SLC16A2 gene mutation | Affects males primarily | Symptoms from infancy

SYMPTOMS

Appear in the first 2–3 months of life: poor head control, ongoing loss of body weight, developmental impairment, sleep disruption, and elevated T3 levels

DIAGNOSIS

Thyroid hormone panel, including T3, combined with genetic testing for mutations in the SLC16A2 gene to confirm diagnosis

FAMILIES AND CAREGIVERS
lifewithmct8deficiency.com

You Are Not Alone
Access real stories from the MCT8 community, practical tools and educational resources.

HEALTHCARE PROFESSIONALS
mct8deficiency.com

Find the Clinical Resources You Need Today

ADVOCACY GROUPS
lifewithmct8deficiency.com

Amplify Awareness
Shareable tools to educate, empower, and accelerate diagnosis.

Date of preparation: June 2026. US-TIRA-2600040. ©2026 Egetis Therapeutics. All rights reserved.

EGETIS THERAPEUTICS

MED13L Foundation

MED13L Foundation provides new-diagnosis support, genetic-report education, a family census, community map, patient registry, biorepository information, and opportunities to join research supporting future treatments for families.

Also covers: Clinical Trials • Genetic Testing

info@med13l.org

med13l.org

MEF2C Foundation

The MEF2C Family Foundation connects people living with MEF2C-related disorders and their caregivers while advancing condition education, advocacy, research, family support, treatment development, and clinician collaboration.

hello@mef2c.org

mef2c.org

Melanin Children Matter

Melanin Children Matter connects families of color with education and research related to autism, rare conditions, disability, and health inequities affecting children with complex healthcare needs.

lakeianard@melaninchildrenmatter.org

melaninchildrenmatter.org/research

MitoAction

MitoAction provides mitochondrial disease education, planning tools, support programs, outreach, and research initiatives, including Spanish-language family gatherings and resources for caregivers and healthcare professionals navigating daily care.

Also covers: Clinical Trials • Early Intervention & Education • Financial Support • Mental Health • Navigating Insurance

kira@mitoaction.org

mitoaction.org

Inspired by **patients.**
Driven by **science.**

TK2d: A rare mitochondrial disease

Thymidine kinase 2 deficiency (TK2d) is a primary mitochondrial myopathy, which means that it mainly affects muscles

It is also a type of mitochondrial disease called mitochondrial DNA (mtDNA) depletion/deletion syndrome. Thymidine kinase 2 (TK2) is an enzyme that helps make and maintain your mtDNA.



What causes TK2d?

TK2d is caused by mutations in the *TK2* gene, which decrease the enzyme activity that helps make and repair your mtDNA. Because there isn't enough healthy mtDNA, the mitochondria cannot work the way they should. This means muscles do not have enough energy and cannot function properly, which can lead to weakness in many muscle groups.





Patient advocacy organizations and community pages can provide valuable information, helpful resources, and support for those affected by TK2d.

learn more

TK2d.com

Patient Community Organizations and Resources

play a critical role in supporting and connecting individuals with similar experiences, as well as providing information and educational resources.

MitoAction
MitoAction is striving to make a measurable impact in the lives of those affected by mitochondrial diseases through support, education, advocacy and granting wishes to families.

mito411@mitoaction.org
MyMito App
(888) 648-6228
@mitoaction
WEBSITE

Muscular Dystrophy Association (MDA)
MDA provides access to support and programs that empower the lives of people living with neuromuscular diseases through 150+ multidisciplinary MDA Care Centers, community education programs, camp and recreation, gene therapy support, advocacy opportunities, and more.

ResourceCenter@mdausa.org
1-833-ASK-MDA1 (1-833-275-6321)
WEBSITE

United Mitochondrial Disease Foundation (UMDF)
UMDF offers a wide range of programs and services that equip patients and families with trusted education, practical resources, and personalized support through its dedicated Support & Education team and nationwide network of 100-plus Support Ambassadors

support@umdf.org
(888) 900-6486
@theUMDF
@UMDF
WEBSITE



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Date of Preparation: July 2026 US-DA-2600602.

Inspired by **patients.**
Driven by **science.**

TK2d: Una enfermedad mitocondrial rara

La deficiencia de timidina cinasa 2 (TK2d) es una miopatía mitocondrial primaria, lo que significa que afecta principalmente los músculos.



También se clasifica como un tipo de enfermedad mitocondrial conocida como síndrome de agotamiento o deleción del ADN mitocondrial (ADNmt). La timidina cinasa 2 (TK2) es una enzima que participa en la formación y conservación del ADNmt.

¿Qué causa la TK2d?

La TK2d se produce por mutaciones en el gen *TK2*; estas mutaciones reducen la actividad de la enzima que ayuda a producir y reparar el ADNmt. Debido a que no hay suficiente ADNmt sano, las mitocondrias no pueden funcionar como deberían. Esto significa que los músculos no tienen suficiente energía y no pueden funcionar correctamente, lo que puede provocar debilidad en muchos grupos musculares.





Los grupos de apoyo a pacientes y las páginas de la comunidad pueden brindar información valiosa, recursos útiles y apoyo a las personas afectadas por la TK2d.

obtener más información

TK2d.com

Las organizaciones y recursos de la comunidad de pacientes

desempeñan un papel fundamental a la hora de brindar apoyo y poner en contacto a personas con experiencias similares, además de proporcionar información y recursos educativos.

MitoAction
MitoAction trabaja para lograr un impacto tangible en la vida de quienes viven con enfermedades mitocondriales a través del apoyo, la educación, la defensa de sus derechos y el cumplimiento de los deseos de las familias.

mito411@mitoaction.org
Aplicación MyMito
(888) 648-6228
@mitoaction
SITIO WEB

Muscular Dystrophy Association (MDA)
La MDA proporciona acceso a apoyo y programas que empoderan las vidas de las personas que tienen enfermedades neuromusculares a través de más de 150 centros de atención multidisciplinarios de la MDA, programas de educación comunitaria, campamentos y actividades recreativas, apoyo para terapia génica, oportunidades de promoción y mucho más.

ResourceCenter@mdausa.org
1-833-ASK-MDA1 (1-833-275-6321)
SITIO WEB

United Mitochondrial Disease Foundation (UMDF)
UMDF ofrece una amplia gama de programas y servicios que brindan a los pacientes y sus familias información confiable, recursos prácticos y apoyo personalizado a través de su equipo especializado de Apoyo y Educación y de una red nacional de más de 100 embajadores de apoyo.

support@umdf.org
(888) 900-6486
@theUMDF
@UMDF
SITIO WEB



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Fecha de preparación: julio de 2026 US-DA-2600603.

MLD Foundation

MLD Foundation offers urgent next-step guidance, specialist information, treatment and newborn-screening education, family conferences, peer connection, research updates, and advocacy for metachromatic leukodystrophy from diagnosis onward.

Also covers: Clinical Trials • Genetic Testing

info@mldfoundation.org

mldfoundation.org

Moebius Syndrome Foundation

Moebius Syndrome Foundation provides medical, school, and adult-life resources, family conferences, provider listings, a patient registry, research funding, scholarships, grants, and a community app worldwide.

Also covers: Genetic Testing • Transition of Care

info@moebiussyndrome.org

moebiussyndrome.org

Mowat-Wilson Syndrome Foundation

Mowat-Wilson Syndrome Foundation offers diagnosis and care information, family networking, conferences, research updates, medical resources, and community support for people with ZEB2-related Mowat-Wilson syndrome worldwide.

Also covers: Genetic Testing • Transition of Care

info@mowat-wilson.org

mowat-wilson.org

MoyraStrong Foundation

MoyraStrong Foundation helps families navigating rare epilepsy, genetic disorders, or complex medical conditions obtain equipment, therapy assistance, education, advocacy, grief support, and practical care resources.

Also covers: Financial Support • Navigating Insurance • Trauma and Grief

admin@moyrastrongfoundation.org

moyrastrongfoundation.org

MSUD Family Support Group

MSUD Family Support Group provides medical guidelines, nutrition and sick-day resources, a clinic finder, pregnancy information, webinars, family meetings, patient registry access, and research updates.

Also covers: Genetic Testing • Transition of Care

info@msud-support.org

msud-support.org

Multicultural Autism Action Network

Multicultural Autism Action Network provides culturally responsive autism education, advocacy, navigation, and family support helping multicultural communities understand services and prepare for education, healthcare, and adulthood.

Also covers: Transition of Care

info@maanmn.org

maanmn.org/who-we-are

Muscular Dystrophy Association

Muscular Dystrophy Association provides care-center connections, disease education, community support, advocacy, and research information, including a Spanish-language school guide for students with neuromuscular conditions and families.

Also covers: Clinical Trials • Financial Support • Transition of Care

ResourceCenter@mdausa.org

mda.org/research/clinical-trials

Myasthenia Gravis Association

Myasthenia Gravis Association offers support groups, education, clinic partnerships, and community programs for people with myasthenia gravis, their caregivers, healthcare professionals, and local support networks.

allisonfoss@mgassociation.org

mgassociation.org

Myasthenia Gravis Foundation of America

Myasthenia Gravis Foundation of America provides education, support, advocacy, research information, and community programs for people with myasthenia gravis, caregivers, healthcare professionals, researchers, and community partners.

mgfa@myasthenia.org

myasthenia.org

MyChild at CerebralPalsy.org

MyChild at CerebralPalsy.org provides educational information about cerebral palsy, treatment, care planning, financial considerations, and family support for people with cerebral palsy, caregivers, and healthcare professionals.

Also covers: Navigating Insurance

ContactUs@MyChildwithCP.com

800-692-4453

cerebralpalsy.org

MyGOAL Autism

MyGOAL Autism provides family education, support programs, and grants that help eligible families cover treatments, nutritional needs, enrichment activities, and other autism-related expenses for children and young adults.

Also covers: Behavioral Health • Early Intervention & Education • Transition of Care

info@mygoalinc.org

mygoalinc.org

Myhre Syndrome Foundation

Myhre Syndrome Foundation offers an emergency guide, clinician directory, patient registry, family map, community conferences, and a research roadmap focused on SMAD4-related care and treatment development.

Also covers: Genetic Testing

cthomas@myhresyndrome.org

myhresyndrome.org

National Association for Down Syndrome

National Association for Down Syndrome provides education, advocacy, family support, and community programs, including bilingual information and connections for Spanish-speaking families from diagnosis through adulthood.

Also covers: Transition of Care • Trauma and Grief

info@nads.org

nads.org/programs/support-for-spanish-speaking-families

National Ataxia Foundation

National Ataxia Foundation offers type-specific education, specialist and support-group directories, genetic-testing guidance, a patient registry, clinical-trial listings, annual conferences, research funding, and treatment development opportunities.

Also covers: Clinical Trials • Genetic Testing

naf@ataxia.org

763-553-0020

ataxia.org

National Autism Association

National Autism Association provides education, safety resources, advocacy information, and family programs addressing urgent concerns for autistic people, their caregivers, and others supporting the autism community.

naa@nationalautism.org

nationalautismassociation.org

National Brain Tumor Society

National Brain Tumor Society provides personalized navigation, support groups, a peer mentor program, diagnosis and treatment tools, a clinical-trial finder, and research or advocacy opportunities.

Also covers: Clinical Trials • Navigating Insurance • Transition of Care

info@braintumor.org

800-934-2873

braintumor.org

National Center for Biotechnology Information (NCBI)

The National Center for Biotechnology Information provides public access to biomedical and genomic research through databases, books, scientific literature, genetic references, and other clinical information resources.

Also covers: Behavioral Health • Genetic Testing • Transition of Care • Trauma and Grief

pubmedcentral@ncbi.nlm.nih.gov
269-492-9310
ncbi.nlm.nih.gov

National Children's Cancer Society / Beyond the Cure

National Children's Cancer Society provides financial assistance during treatment and offers Beyond the Cure education, scholarships, and long-term resources for childhood cancer survivors and their families.

Also covers: Financial Support • Transition of Care

info@thenccs.org
314-241-1600; 800-532-6459
thenccs.org

National Down Syndrome Society

National Down Syndrome Society provides health, education, employment, financial-wellness, and adulthood resources while offering advocacy programs, local connections, and support across the Down syndrome lifespan.

Also covers: Early Intervention & Education • Transition of Care

info@ndss.org
800-221-4602
ndss.org

National Fragile X Foundation

National Fragile X Foundation offers treatment recommendations, clinic finders, family chapters, research opportunities, online training, and Spanish-language webinars and guides for families and professionals navigating Fragile X conditions.

Also covers: Clinical Trials • Genetic Testing • Transition of Care

info@fragilex.org
800-688-8765
fragilex.org

National Niemann-Pick Disease Foundation

National Niemann-Pick Disease Foundation provides education, family support, care-clinic information, financial assistance, advocacy, and research opportunities for people living with ASMD or NPC and caregivers.

Also covers: Clinical Trials • Financial Support • Genetic Testing • Transition of Care

nnpdf@nnpdf.org **877-287-3672**

nnpdf.org

National Organization for Rare Disorders (NORD)

National Organization for Rare Disorders provides rare-disease education, advocacy, patient assistance, organizational support, and connections to information for people with rare conditions and their families.

Also covers: Financial Support • Genetic Testing • Mental Health

InformationServices@rarediseases.org

rarediseases.org **(800) 469-0283**

National PKU Alliance

National PKU Alliance offers education, mentoring, community programs, insurance support, clinic information, registries, and research opportunities for people living with phenylketonuria and caregivers across the lifespan.

Also covers: Clinical Trials • Genetic Testing • Navigating Insurance • Transition of Care

info@npkua.org **855-675-8211**

npkua.org

National Tay-Sachs & Allied Diseases Association

National Tay-Sachs and Allied Diseases Association provides family services, genetic education, research updates, peer support, bereavement care, and Spanish-language information for related rare conditions and families.

Also covers: Clinical Trials • Genetic Testing • Mental Health • Trauma and Grief

info@ntsad.org

ntsad.org/support-for-families/

National Urea Cycle Disorders Foundation

National Urea Cycle Disorders Foundation provides emergency and nutrition guidance, family support, medical education, research updates, and study participation information for people with urea cycle disorders.

Also covers: Clinical Trials • Genetic Testing

info@nucdf.org

nucdf.org

NBIA Disorders Association

NBIA Disorders Association offers diagnosis and care information, family support, research updates, study recruitment, and grants advancing treatments for neurodegeneration with brain iron accumulation disorders.

Also covers: Clinical Trials • Genetic Testing

info@nbiadisorders.org

nbiadisorders.org

Neev Kolte & Brave Ronil Foundation

Neev Kolte and Brave Ronil Foundation supports families navigating diffuse midline glioma or DIPG through education, advocacy, community connection, research funding, and resources for newly diagnosed families.

Also covers: Clinical Trials • Financial Support • Trauma and Grief

info@neevronil.org

braveronil.org

NF California

NF California provides education, community connection, support groups, events, and advocacy for people with neurofibromatosis; its Rising Adults programming helps address the transition from pediatric to adult life and care.

Also covers: Transition of Care

debbie@nfcalifornia.org

707-469-0467

nfcalifornia.org

NF Network

NF Network provides neurofibromatosis education, clinic and provider information, family support, advocacy tools, webinars, research updates, and opportunities to participate in studies and trials nationwide.

Also covers: Clinical Trials • Genetic Testing

admin@nfnetwork.org

nfnetwork.org

Nicklaus Children's Hospital Neuroscience Institute

Nicklaus Children's Neuroscience Institute provides pediatric neurologic and neurosurgical care through multidisciplinary treatment, research, and family-centered services for children and young adults with neurologic conditions, caregivers, and referring healthcare professionals.

Also covers: Behavioral Health • Clinical Trials • Early Intervention & Education • Genetic Testing • Mental Health

jenna.miller-haj@nicklaushealth.org

nicklauschildrens.org/medical-services/neuroscience-institute

NR2F1 Foundation

NR2F1 Foundation provides education, family support, genetic information, a patient registry, research updates, and participation opportunities for people living with Bosch-Boonstra-Schaaf optic atrophy syndrome and their caregivers.

Also covers: Clinical Trials • Genetic Testing

jennifer.coughlin@nr2f1.org

nr2f1.org

Ohio Center for Autism and Low Incidence (OCALI)

OCALI provides families, educators, and healthcare professionals with training, tools, and guidance supporting children and adults with autism, disabilities, and other low-incidence conditions across Ohio and beyond.

Also covers: Behavioral Health

ocali@ocali.org

866-886-2254

ocali.org

Once Upon a Gene

Once Upon a Gene shares rare-disease family stories, practical information, advocacy guidance, and community resources through podcasts, articles, and conversations led by caregivers and patient advocates.

Also covers: Mental Health • Trauma and Grief

hello@onceuponagene.com **406-546-0497**

effieparks.com

Organic Acidemia Association

Organic Acidemia Association provides disorder guides, nutrition and formula-coverage resources, newborn-screening information, a global registry, family forums, webinars, research news, and clinical-trial listings for patients and caregivers.

Also covers: Genetic Testing • Navigating Insurance

oaanews@oaanews.org

oaanews.org

Organization for Autism Research

Organization for Autism Research applies research to everyday challenges by providing evidence-based information, school and employment resources, scholarships, and guidance for autistic people and their families.

programs@researchautism.org

researchautism.org/families/about-autism

Owen's Hope Foundation

Owen's Hope Foundation provides therapeutic, educational, life-skills, and family support for children and young adults with autism, ADHD, executive-function challenges, behavioral or mental health needs, and trauma histories.

Also covers: Behavioral Health • Mental Health • Transition of Care • Trauma and Grief

contact@owenshope.org

owenshope.org

PACS1 Syndrome Research Foundation

PACS1 Syndrome Research Foundation maintains a family contact registry, funds laboratory studies, convenes research conferences, and shares scientific progress focused on treatments for PACS1 syndrome.

Also covers: Clinical Trials • Genetic Testing

info@pacs1foundation.org

pacs1foundation.org

PANDAS Network

PANDAS Network provides parent, clinician, and educator guides, a practitioner directory, an online forum, research summaries, treatment information, and support resources for PANS and PANDAS.

Also covers: Behavioral Health • Mental Health

info@pandasnetwork.org

pandasnetwork.org

PANDAS Physicians Network Clinical Guidance

PANDAS Physicians Network provides clinical guidance helping healthcare professionals recognize sudden-onset neurobehavioral symptoms, distinguish PANDAS or PANS from psychiatric conditions, and understand evaluation and treatment considerations.

Also covers: Behavioral Health • Mental Health

support@pandasppn.org

pandasppn.org

Parent Project Muscular Dystrophy

Parent Project Muscular Dystrophy provides care guidance, advocacy, family support, and research information for Duchenne and Becker muscular dystrophy, including comprehensive Spanish-language medical and school materials.

Also covers: Clinical Trials • Genetic Testing • Navigating Insurance • Transition of Care

info@parentprojectmd.org

parentprojectmd.org

Partners Against Mortality in Epilepsy (PAME)

Partners Against Mortality in Epilepsy brings together people with epilepsy, bereaved families, clinicians, researchers, and advocates to improve understanding and prevention of epilepsy-related deaths through education and collaboration.

pame@aesnet.org
pameonline.org

PCDH19 Alliance

PCDH19 Alliance funds research, shares seizure and behavioral-health information, connects families, and offers a Spanish-language brochure explaining PCDH19 epilepsy, symptoms, inheritance, safety, and study opportunities.

Also covers: Clinical Trials • Genetic Testing

julie@pcdh19info.org
pcdh19info.org

Pediatric Brain Tumor Foundation

Pediatric Brain Tumor Foundation provides family navigation, education, and emotional support across diagnosis, treatment, school, survivorship, and bereavement, with extensive Spanish-language resources for families and professionals.

Also covers: Behavioral Health • Clinical Trials • Financial Support • Mental Health • Navigating Insurance • Transition of Care • Trauma and Grief

patientadvocacy@curethekids.org 800-253-6530
curethekids.org

Pediatric Epilepsy Surgery Alliance

Pediatric Epilepsy Surgery Alliance provides research-informed education, peer support, and practical programs for children with medication-resistant epilepsy and their caregivers before and after epilepsy surgery.

Also covers: Clinical Trials • Financial Support • Trauma and Grief

info@pesalliance.org 833-675-3335 ext. 4
epilepsysurgeryalliance.org

When seizures don't stop, you still have options.

If your child continues to have seizures despite medication, it may be time to ask about a comprehensive epilepsy surgery evaluation.

The Pediatric Epilepsy Surgery Alliance helps families understand options and navigate the road ahead.



Our free resources include:

- One-on-one support from experienced parents
- Trusted information about epilepsy surgery
- Guidance for school and life after surgery
- Educational webinars and family resources
- Travel Scholarships for qualifying families
- A supportive community that understands.

You do not have to figure this out alone. Learn more and connect with us at pesalliance.org.

Caregiver-led. Science-driven. Here for families before and after epilepsy surgery.

Pediatric Neurology Care & Treatment

Tufts Medicine provides pediatric neurology evaluation and care from infancy through young adulthood for conditions involving the brain, spine, peripheral nerves, muscles, development, movement, and seizures.

jeremy.lechan@tuftsmedicine.org **617-636-0104**

tuftsmedicine.org/services-treatments/pediatrics/neurology-pediatrics

Phelan-McDermid Syndrome Foundation

Phelan-McDermid Syndrome Foundation provides condition and genetics education, family support, a Spanish-accessible DataHub, research and clinical-trial updates, mental health resources, and bereavement support for families.

Also covers: Clinical Trials • Genetic Testing • Mental Health • Trauma and Grief

info@pmsf.org

pmsf.org

Pitt Hopkins Research Foundation

Pitt Hopkins Research Foundation offers family resources, research news, a patient registry, study recruitment, clinical-trial information, and community events while funding treatment-focused Pitt Hopkins research.

Also covers: Clinical Trials • Genetic Testing

info@pitthopkins.org

pitthopkins.org

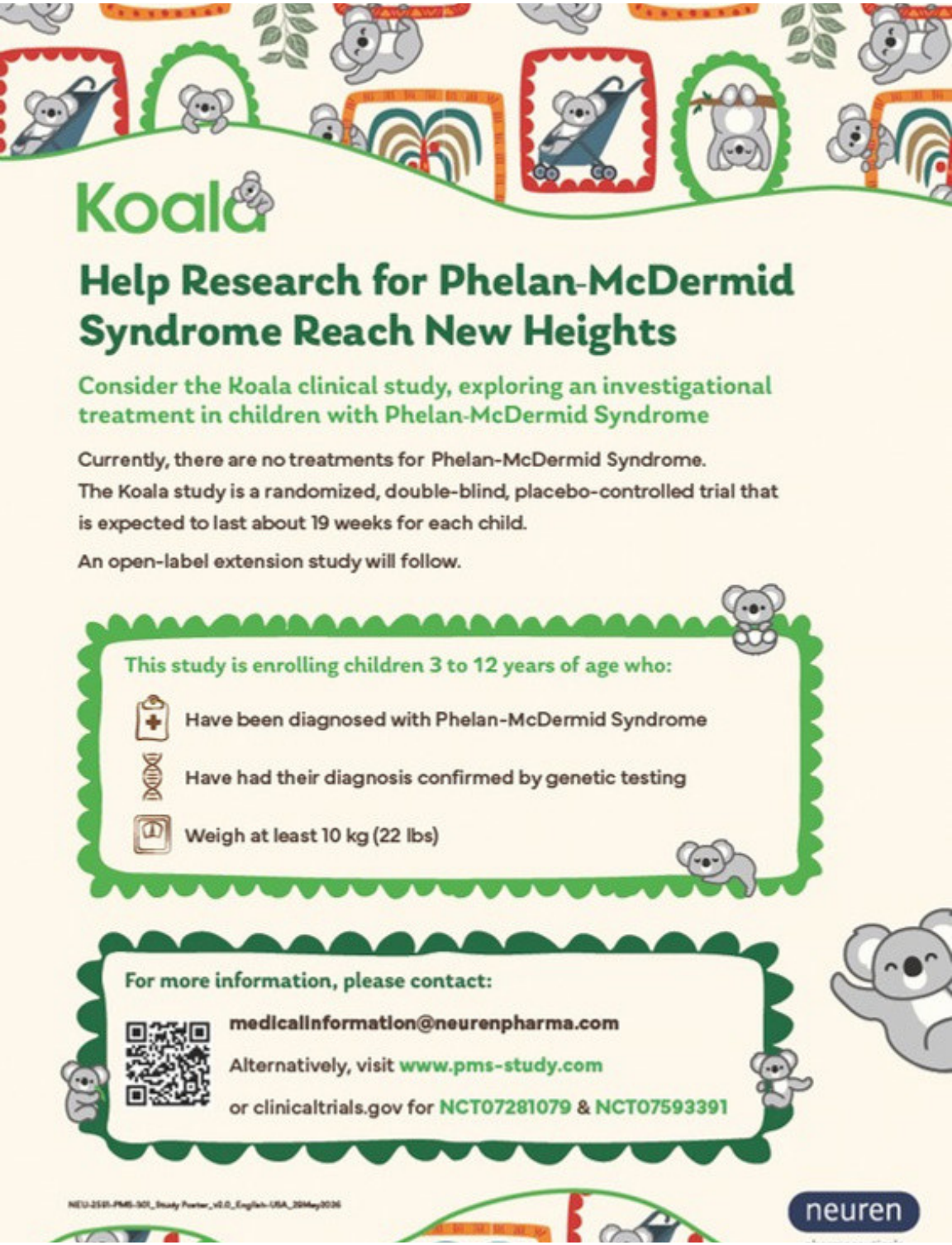
PMG Awareness Organization

PMG Awareness Organization provides newly diagnosed guidance, condition education, family stories, awareness programs, and community connection for people with polymicrogyria, their caregivers, relatives, and professionals.

Also covers: Genetic Testing

information@pmgawareness.org **949-329-5975**

pmgawareness.org


Koala
Help Research for Phelan-McDermid Syndrome Reach New Heights
Consider the Koala clinical study, exploring an investigational treatment in children with Phelan-McDermid Syndrome
Currently, there are no treatments for Phelan-McDermid Syndrome.
The Koala study is a randomized, double-blind, placebo-controlled trial that is expected to last about 19 weeks for each child.
An open-label extension study will follow.
This study is enrolling children 3 to 12 years of age who:
Have been diagnosed with Phelan-McDermid Syndrome
Have had their diagnosis confirmed by genetic testing
Weigh at least 10 kg (22 lbs)
For more information, please contact:
medicalinformation@neurenpharma.com
Alternatively, visit www.pms-study.com
or clinicaltrials.gov for NCT07281079 & NCT07593391
neuren

Pompe Alliance

Pompe Alliance supports people with Pompe disease through education, peer mentoring, financial assistance, research recruitment, advocacy, and care-provider information; its resources serve families and individuals across the lifespan.

Also covers: Clinical Trials • Financial Support • Transition of Care

pompealliance@gmail.com
216-338-5736
pompealliance.com

Prader-Willi Syndrome Association USA

Prader-Willi Syndrome Association USA provides condition education, crisis support, behavioral guidance, school resources, adult-life planning, and Spanish-language early-care information for families, caregivers, and professionals nationwide.

Also covers: Behavioral Health • Genetic Testing • Transition of Care

info@pwsausa.org
941-312-0400
pwsausa.org/wp-content/uploads/2018/03/NICU-spanish.pdf

PRISMS

PRISMS provides Smith-Magenis medical guidelines, clinic travel assistance, regional family representatives, multilingual guidebooks, webinars, conferences, a patient registry, peer support, and sponsored research for families and professionals.

Also covers: Genetic Testing • Transition of Care

info@prisms.org
prisms.org

Project 8p Research

Project 8p operates an IRB-approved chromosome 8p registry and biorepository, collecting surveys, medical records, and biological samples to identify unmet needs and accelerate treatment research.

Also covers: Clinical Trials

info@project8p.org
project8p.org/research

PURA Syndrome Foundation

PURA Syndrome Foundation offers newly diagnosed guidance, family and sibling support, a clinician network, multilingual patient registry, biobank, research studies, resources, and an annual conference.

Also covers: Clinical Trials • Genetic Testing

info@purasyndrome.org

purasyndrome.org

Rare Disease Diversity Coalition

Rare Disease Diversity Coalition advances health equity through policy, research, patient education, and programs addressing barriers to genetic testing and care in historically underserved rare-disease communities.

Also covers: Genetic Testing

rddc@bwhi.org

rarediseasediversity.org

Rare Epilepsy Network

Rare Epilepsy Network connects rare epilepsy organizations, families, and researchers through shared education, registry information, and research opportunities, with Spanish-language resources available through its website.

Also covers: Clinical Trials • Genetic Testing

info@rareepilepsynetwork.org

rareepilepsynetwork.org

RareRising

RareRising provides rare-disease education, advocacy, community connection, and leadership development, including Somos Rare, its Spanish-language initiative supporting Hispanic and Latino families navigating rare conditions and research opportunities.

Also covers: Clinical Trials • Genetic Testing • Navigating Insurance

info@rarerising.org

rarerising.org

Raymond A. Wood Foundation

Raymond A. Wood Foundation supports families living with hypothalamic-pituitary brain tumors through education, advocacy, research, and Spanish-language resources addressing diagnosis, treatment, recovery, and long-term care.

Also covers: Clinical Trials • Mental Health • Trauma and Grief

outreach@rawoodfoundation.org

rawoodfoundation.org

Realm of Caring Foundation

Realm of Caring Foundation provides free, evidence-informed guidance, education, research, and community support for people of all ages exploring cannabinoid therapy with their families and healthcare professionals.

Also covers: Clinical Trials

info@realmofcaring.org

719-347-5400

realmofcaring.org

Remember the Girls

Remember the Girls provides education, advocacy, and peer connection for females with X-linked conditions, including carriers who may experience symptoms or face related healthcare decisions.

Also covers: Genetic Testing • Transition of Care

info@rememberthegirls.org

rememberthegirls.org

ReNU Syndrome United

ReNU Syndrome United builds community, provides family and clinician information, raises awareness, and advances research for people living with RNU4-2-related ReNU syndrome and those supporting them.

Also covers: Genetic Testing

united@renusyndrome.org

renusyndrome.org

Riaan Research Initiative

Riaan Research Initiative advances research toward treatments for Cockayne syndrome and related DNA-repair disorders while connecting families with research updates, natural-history studies, and participation opportunities.

Also covers: Clinical Trials • Genetic Testing

jo.kaur@riaanresearch.org

riaanresearch.org/research

Ring14 International Research

Ring14 International connects families living with ring chromosome 14 and related conditions to research information, registries, study participation opportunities, clinical knowledge, and international community resources.

Also covers: Clinical Trials

info@ring14.org

ring14.org/research

Ring14 USA

Ring14 USA supports people living with rare chromosome 14 disorders through condition education, family programs, awareness, community connection, research information, and opportunities for participation and advocacy.

Also covers: Clinical Trials

info@ring14usa.org

ring14usa.com

SATB2 Gene Foundation Research

SATB2 Gene Foundation organizes research participation through its patient registry, natural-history projects, surveys, and study announcements, helping families contribute data that guides diagnosis, care, and treatment development.

Also covers: Clinical Trials

research@satb2gene.org

satb2gene.org/research

SCN8A Alliance

SCN8A Alliance offers consensus-based treatment guidance, newly diagnosed and sibling kits, multilingual family meetings, clinician and specialty-center directories, a registry, financial resources, and research opportunities.

Also covers: Clinical Trials • Genetic Testing

info@scn8aalliance.org

scn8aalliance.org

Seizure Tracker

Seizure Tracker offers tools for recording seizures, medications, treatments, and possible triggers, helping families organize information and share clearer records with their healthcare professionals during appointments.

Also covers: Transition of Care

info@seizuretracker.com

seizuretracker.com

SETBP1 Society Research

SETBP1 Society links families to Simons Searchlight, RARE-X, SCoReS, and other studies collecting natural-history data, biosamples, and community priorities for SETBP1-related research and future treatment development.

Also covers: Clinical Trials

haley@setbp1.org

setbp1.org/research

Sick Cells—Caregiver Resources: Stroke Prevention

Sick Cells provides caregivers with sickle cell disease information about stroke prevention, neurological warning signs, screening, treatment, and emergency response for children and young adults.

info@sickcells.org

sickcells.org/resources/caregiver-resources

Sickle Cell 101—Sicklepedia: Stroke

Sickle Cell 101 explains stroke and silent cerebral infarcts as neurological complications of sickle cell disease, including risks, symptoms, screening, treatment, emergency response, and prevention information.



hello@sc101.org

sc101.org/sicklepedia/stroke

Sickle Cell Community Consortium Parent-to-Parent Initiative—School and Stroke Resources

The Parent-to-Parent Initiative equips caregivers with school and health resources that address stroke, silent stroke, neurological warning signs, and learning effects associated with sickle cell disease.



p2p@sicklecellconsortium.org

sicklecellconsortium.org/parent2parent

Siegel Rare Neuroimmune Association

Siegel Rare Neuroimmune Association provides education, peer support, clinician resources, and research information for children and adults living with rare neuroimmune disorders and their families.



info@wearesrna.org

(855) 380-3330

wearesrna.org

Simons Searchlight

Simons Searchlight is an international research program and registry connecting people with eligible rare genetic neurodevelopmental conditions and their families to research participation opportunities and results.

Also covers: Clinical Trials • Genetic Testing



coordinator@simonssearchlight.or

simonssearchlight.org

Sinergia Autism Initiative

Sinergia Autism Initiative provides bilingual family support, education, service coordination, respite, social-skills programming, and transition assistance for underserved New York City families of autistic young people.

Also covers: Behavioral Health • Transition of Care

autisminitiative@sinergiany.org

sinergiany.org/autism-initiative

Skraban-Deardorff Syndrome Foundation

Skraban-Deardorff Syndrome Foundation hosts family meetings and an education series while funding neurodevelopmental assessments, cell studies, drug discovery, and plans for a mouse model and biorepository.

Also covers: Clinical Trials • Genetic Testing

info@skdeas.org

skdeas.org

SLC6A1 Connect

SLC6A1 Connect provides newly diagnosed guidance, genetic-testing information, family connections, patient registries, natural-history studies, research updates, scientific resources, and community symposia for SLC6A1 disorders worldwide.

Also covers: Clinical Trials • Genetic Testing

info@slc6a1connect.org

slc6a1connect.org

SMA Foundation Research

SMA Foundation advances research intended to accelerate treatments for spinal muscular atrophy and shares scientific information with healthcare professionals, researchers, advocacy organizations, and the SMA community.

Also covers: Clinical Trials

info@smafoundation.org

smafoundation.org/research

Smith-Kingsmore Syndrome Foundation

Smith-Kingsmore Syndrome Foundation offers a family medical guide in 23 languages, peer support, conferences, a global patient registry, and research updates focused on MTOR variants.

Also covers: Clinical Trials • Genetic Testing

info@smithkingsmore.org

smithkingsmore.org

Sociedad Puertorriqueña de Epilepsia

Sociedad Puertorriqueña de Epilepsia provides Spanish-language epilepsy education, community programs, and support in Puerto Rico; caregivers can use its resources to learn about seizures, treatment, safety, and available services.

info@sociedadepilepsiapr.org

sociedadepilepsiapr.org

Somali Parents Autism Network

Somali Parents Autism Network serves Minnesota's Somali community with parent groups, workshops, advocacy, and help connecting families to schools, clinicians, early intervention, and autism services.

info@somaliautism.org

somaliautism.org

Sonrisas y Luz

Sonrisas y Luz offers Spanish-language autism education, family support, community activities, and caregiver connection; its programs help families obtain information while building supportive relationships around the needs of autistic children.

Also covers: Mental Health

hola@sonrisasyluz.org

sonrisasyluz.org

South Carolina Advocates for Epilepsy

South Carolina Advocates for Epilepsy offers education, seizure-response training, peer support, and practical resources for people living with epilepsy; its programs address pediatric, teen, college, employment, and adult needs.

Also covers: Transition of Care

info@scepilepsy.org **843-991-7144**

scepilepsy.org

Spastic Paraplegia Foundation

Spastic Paraplegia Foundation provides HSP and PLS education, support groups, clinician and therapy directories, childhood resources, research recruitment, and grants advancing diagnosis and treatment for children and adults.

Also covers: Clinical Trials • Genetic Testing

information@sp-foundation.org

sp-foundation.org

Special Needs Network

Special Needs Network provides developmental screening, diagnosis, therapies, family navigation, education, and transition support for underserved Los Angeles communities, including school, healthcare, and adult-service resources.

Also covers: Behavioral Health • Transition of Care

Info@snnla.org

snnla.org

Spina Bifida Association

Spina Bifida Association provides education, advocacy, clinic information, and lifespan resources, including Spanish-language family engagement, community support, and guidance for caregivers through its Hispanidad Committee.

Also covers: Transition of Care

jpanlener@sbaa.org

spinabifidaassociation.org

No one should face a rare disease alone.



Across the world, people impacted by Sturge-Weber connect to share real experiences, ask questions, and find support that truly understands.

At The Sturge-Weber Foundation, families don't just find information—they find guidance, hope, and strength in a community that gets it.

The Sturge-Weber Foundation: more than a foundation. *We're a family.*

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE®

Join our community today.

Birthmarks | Glaucoma | Seizures

www.Sturge-Weber.org

Stupid Cancer

Stupid Cancer creates peer connection, educational programs, advocacy opportunities, and age-appropriate resources addressing relationships, work, mental health, survivorship, and isolation for young adults with cancer.

Also covers: Mental Health • Transition of Care

contact@stupidcancer.org

stupidcancer.org

Sturge-Weber Foundation

Sturge-Weber Foundation offers family mentoring, clinical-care information, research participation, and Spanish-language education for people with Sturge-Weber syndrome, Klippel-Trenaunay syndrome, and related vascular birthmarks across the lifespan.

Also covers: Clinical Trials • Early Intervention & Education • Genetic Testing • Mental Health

jterrell@sturge-weber.org

sturge-weber.org

STXBP1 Foundation

STXBP1 Foundation offers newly diagnosed guidance, specialty-clinic listings, sibling kits, safety and transition resources, research studies, clinical-trial information, global family connection, and funded treatment research.

Also covers: Clinical Trials • Genetic Testing

info@stxbp1disorders.org

stxbp1disorders.org

SUDEP Action

SUDEP Action provides information about epilepsy-related deaths, bereavement support, risk-awareness tools, and research initiatives for people with epilepsy, grieving families, caregivers, healthcare professionals, and researchers worldwide.

Also covers: Trauma and Grief

support@sudep.org

sudep.org

Supernova Parenting

Supernova Parenting provides caregiver education, peer support, and family guidance for parents raising children with autism or developmental and behavioral needs, including caregiver emotional wellness.

Also covers: Behavioral Health • Mental Health

Hello@supernovaparenting.org

supernovaparenting.org

Tatton Brown Rahman Syndrome Community Research

Tatton Brown Rahman Syndrome Community runs TBRS Connect, a patient registry, community summits, research funding, and a biorepository that unite families, clinicians, and scientists worldwide.

Also covers: Clinical Trials • Genetic Testing

kit@tbrsyndrome.org

tbrsyndrome.org

Teen Cancer America

Teen Cancer America helps hospitals build adolescent and young-adult cancer programs offering age-appropriate spaces, psychosocial support, fertility guidance, clinical-trial access, education, career help, and survivorship care.

Also covers: Mental Health • Transition of Care

info@teencanceramerica.org

teencanceramerica.org

TESS Research Foundation

TESS Research Foundation supports families connected to SLC13A5 citrate transporter disorder and advances research toward treatments; it provides family resources, scientific updates, patient engagement, and opportunities to contribute to research.

Also covers: Clinical Trials • Genetic Testing

info@tessresearch.org

tessresearch.org

The Akari Foundation

The Akari Foundation provides Spanish-language education, advocacy, community programs, and family support helping Latino families understand Duchenne muscular dystrophy, disability services, care options, and school needs.

Also covers: Transition of Care

Info@TheAkarifoundation.org

lafundacionakari.org

The Cameron Boyce Foundation

The Cameron Boyce Foundation advances epilepsy and SUDEP awareness, education, and research while providing information and programs for young people living with epilepsy, caregivers, and educators.

Also covers: Trauma and Grief

ben@thecameronboycefoundation.org

thecameronboycefoundation.org

The Circle of Vietnamese Parents

The Circle of Vietnamese Parents offers culturally and linguistically responsive education, family support, and advocacy related to autism, developmental disabilities, special education, and mental health.

Also covers: Mental Health

info@vtcmv.org

en.vtcmv.org/about-us/who-we-are

The Color of Autism Foundation

The Color of Autism Foundation provides culturally responsive autism education, parent training, family support, and employment or transition programs for Black autistic people and their families.

Also covers: Transition of Care

info@thecolorofautism.org

thecolorofautism.org/about-us

The Cure Starts Now

The Cure Starts Now funds pediatric brain tumor research and provides Warrior family support, peer connections, financial assistance information, disease education, and updates from its research network.

Also covers: Clinical Trials • Trauma and Grief

info@thecurestartsnow.org

thecurestartsnow.org

The Cute Syndrome Foundation Global SCN8A Survey Series

The Cute Syndrome Foundation's global SCN8A survey collects natural-history information and connects participating families with relevant research studies, clinical trials, updates, and future participation opportunities.

Also covers: Clinical Trials

info@thecutesyndrome.com

tcsfsurveys.iamrare.org

The Danny Did Foundation

The Danny Did Foundation provides epilepsy and SUDEP education, seizure-safety resources, device information, and family support intended to improve communication and reduce preventable epilepsy-related deaths.

info@dannydid.org

800-278-6101

dannydid.org

The GAPS Society

The GAPS Society provides autism education, caregiver connection, advocacy resources, and future-planning support; it helps families address immediate service needs while preparing for greater independence and adult life.

Also covers: Transition of Care

crys@thegapssociety.org

thegapssociety.org

The LCC Foundation

The LCC Foundation supports people living with Labrune syndrome through condition education, newly diagnosed guidance, family connection, clinical information, research updates, and resources for patients and caregivers.

Also covers: Clinical Trials • Genetic Testing

info@thelccfoundation.org **636-248-9930**

thelccfoundation.org

The Mark Shaparin Foundation

The Mark Shaparin Foundation educates families, healthcare professionals, and the public about Sudden Unexpected Death in Epilepsy, including SUDEP risk factors, prevention, and patient-provider conversations.

info@markshaparinfoundation.org

markshaparinfoundation.org

The Rory Belle Foundation

The Rory Belle Foundation connects people living with NARS1 disorder, supports families, shares knowledge with clinicians, and advances research and treatment discovery for the NARS1 community.

Also covers: Genetic Testing

rachel@therorybellefoundation.org

therorybellefoundation.org

The Sumaira Foundation

The Sumaira Foundation provides education, family support, research updates, mental health resources, advocacy, and insurance guidance for people living with NMOSD, MOGAD, and related neuroimmune conditions.

Also covers: Clinical Trials • Mental Health • Navigating Insurance

info@sumairafoundation.org

sumairafoundation.org

TSC Alliance®

Hope no matter how complex™

The TSC Alliance improves quality of life for everyone affected by tuberous sclerosis complex (TSC) by catalyzing new treatments, driving research toward a cure and expanding access to lifelong support.

Learn more at tscalliance.org.

The TBCK Foundation

The TBCK Foundation provides condition education, family support, genetics information, a patient registry, research updates, and resources in English and Spanish for the global TBCK community.

Also covers: Clinical Trials • Genetic Testing

info@tbckfoundation.org

tbckfoundation.org

Tough Genes

Tough Genes supports families connected to IRF2BPL-related disorder through education, peer connection, newly diagnosed guidance, and research; the organization raises awareness and funds work toward better understanding and treatments.

Also covers: Clinical Trials • Genetic Testing

info@toughgenes.org

734-537-0005

toughgenes.org

Tourette Association of America

Tourette Association of America provides education, referrals, and individualized support for Tourette syndrome and tic disorders, including Spanish-language information about school, treatment, behavior, and mental health.

Also covers: Behavioral Health • Clinical Trials • Mental Health

support@tourette.org

tourette.org/resources/

TSC Alliance

TSC Alliance provides education, care guidance, family support, advocacy, and research information for tuberous sclerosis complex, with extensive Spanish-language resources and support navigation available throughout its website.

Also covers: Clinical Trials • Genetic Testing • Mental Health • Navigating Insurance • Transition of Care

support@tscalliance.org

tscalliance.org

UChicago Medicine Comer Children's

UChicago Medicine Comer Children's provides epilepsy education, seizure-safety information, support resources, and connections to national organizations for children with epilepsy and the caregivers supporting them.

outreach2@uchospitals.edu **773-702-1000**
uchicagomedicine.org/comer/conditions-services/pediatric-neurology-neurosurgery/conditions-services/pediatric-epilepsy-seizures/resources-support

Undiagnosed Diseases Network Foundation

Undiagnosed Diseases Network Foundation provides education, peer connection, research updates, and diagnostic resources for people with undiagnosed or ultra-rare conditions and the families supporting them.

Also covers: Genetic Testing • Navigating Insurance

info@udnf.org
udnf.org

United Cerebral Palsy

United Cerebral Palsy advances inclusion and independence for people with disabilities through advocacy, education, research, affiliate programs, community services, and resources supporting families across the lifespan.

info@ucp.org
ucp.org

United Leukodystrophy Foundation

United Leukodystrophy Foundation provides condition education, family support, community connection, and research information while sharing relevant clinical-trial opportunities for people living with leukodystrophies and caregivers.

Also covers: Clinical Trials

office@ulf.org
ulf.org/research/clinical-trials

United Mitochondrial Disease Foundation

United Mitochondrial Disease Foundation offers a support line, care-network guidance, education, webinars, clinical-trial listings, insurance resources, community groups, and research programs for mitochondrial disease worldwide.

Also covers: Clinical Trials • Genetic Testing

info@umdf.org

umdf.org

V-ATPase Alliance

The v-ATPase Alliance unites people living with rare v-ATPase genetic disorders while providing condition information, family education, advocacy, community support, research updates, and opportunities supporting therapeutic development.

anarita@vatpasealliance.org

vatpasealliance.org

Vietnamese Family Autism Advisory Board

Vietnamese Family Autism Advisory Board provides Vietnamese-language education, family classes, support, case assistance, and early-intervention or IEP guidance for families of autistic and developmentally disabled children.

tkirkpatrick@hopecentralhealth.org

vfaab.org

Wake Up Narcolepsy

Wake Up Narcolepsy advances awareness, education, supportive programs, and research toward improved treatments while providing resources for people living with narcolepsy, caregivers, healthcare professionals, and researchers.

jrose@wakeupnarcolepsy.org

wakeupnarcolepsy.org

Wake Up Narcolepsy

Wake Up Narcolepsy (WUN) is a 501(c)(3) nonprofit organization dedicated to driving Narcolepsy awareness, education and research towards improved treatments and a cure.

Online Peer Support Groups:

Our free, targeted support groups are available every day of the week to individuals worldwide. They are designed to bring together individuals who have been affected by Narcolepsy and provide the community necessary to thrive.

School & Work Resources

Find templates, videos and other guidance on advocating for yourself or your loved ones, disclosing a diagnosis, accessing accommodations and navigating the educational system and workplace.

Sleep & Mental Health

Exhaustion and poor mental health can quickly become a vicious cycle, especially with a chronic disorder like Narcolepsy. We're talking about the crucial relationship and letting you know you're not alone in navigating it.

wakeupnarcolepsy.org *P.O. Box 60293, Worcester, MA 01606*
WakeUpNarcolepsy *info@wakeupnarcolepsy.org*

xMinds BIPOC Resources and Outreach

xMinds connects families with culturally responsive autism organizations, community events, parent education, and information about therapies, services, and advocacy through its BIPOC resources and outreach program.

Also covers: Behavioral Health • Transition of Care

info@xminds.org

xminds.org/BIPOC-Resources

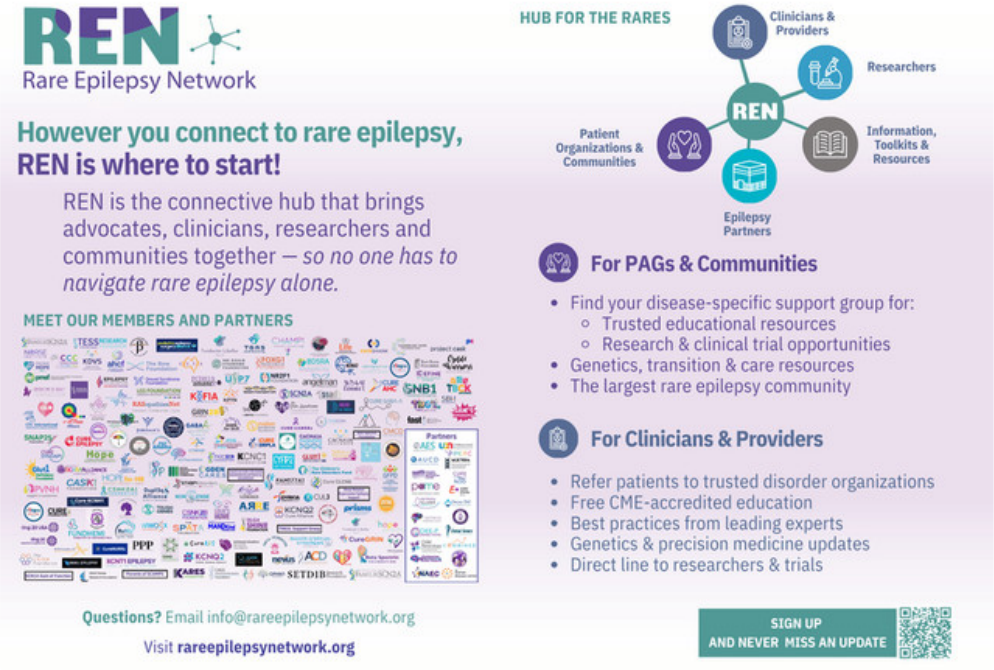
ZTTK SON-Shine Foundation

ZTTK SON-Shine Foundation provides family resources, clinical information, advocacy, global connection, and research updates for people with SON-related ZTTK syndrome, their caregivers, clinicians, and researchers.

Also covers: Clinical Trials • Genetic Testing

sboyle@zttk.org

zttk.org



GENETIC TESTING INFO FROM CNF

Families come to genetic testing with the same question: what is causing this, and what happens next? **A genetic diagnosis can open doors**, to targeted treatment, to connection with other families, and to answers that years of appointments have not provided.

Our genetic testing page is here to guide you through the process, one step at a time. You will find a course on navigating insurance coverage, plain-language explanations of the different types of genetic testing and what each one can tell you, guidance on cost and financial assistance, and an introduction to genetic counselors and the support they offer. Wherever you are in this journey, whether you are preparing for a first appointment or waiting on results, you do not have to figure it out alone. *Scan the QR code to read more!*



GENETIC TESTING

Genetic testing looks for a cause in your child's DNA. An answer can change care, show what to expect, and connect you to other families.



American Cancer Society

American Cancer Society's guide helps families decide whether inherited-cancer testing may fit their history and explains insurance coverage, privacy protections, home tests, and genetic counseling.

ACSOrders@cancer.org
866-227-7912
800-227-2345
cancer.org/cancer/risk-prevention/genetics/genetic-testing-for-cancer-risk.html

American College of Medical Genetics and Genomics

The American College of Medical Genetics and Genomics develops professional standards, practice resources, education, and policy guidance to improve medical genetics and genomics services for medical geneticists and genetic counselors.

acmg@acmg.net
301-718-9603
acmg.net

Consultagene

Consultagene is a service of the Department of Molecular and Human Genetics at Baylor College of Medicine; they share a guide for understanding genetic medicine.

consultageneclinic@bcm.edu
consultagene.org/en

Genetic Alliance

Genetic Alliance brings together individuals, families, and organizations through advocacy, research partnerships, registries, and tools that support people navigating genetic conditions and community-led health initiatives.

Also covers: Clinical Trials • Genetic Testing

info@geneticalliance.org
202-966-5557
geneticalliance.org

Genetic and Rare Diseases Information Center (GARD)

The Genetic and Rare Diseases Information Center provides federal, plain-language information about rare and genetic conditions, symptoms, diagnosis, treatment, research, relevant patient organizations, and support resources.

Also covers: Genetic Testing

gardinfo@nih.gov
rarediseases.info.nih.gov

National Cancer Institute

The National Cancer Institute's fact sheet distinguishes inherited testing from tumor testing and explains family-history review, sample collection, result types, costs, and professional genetic counseling.

NCIinfo@nih.gov **800-422-6237**
cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet

National Human Genome Research Institute

The National Human Genome Research Institute explains the Genetic Information Nondiscrimination Act and what it does and does not protect in health insurance and employment.

Also covers: Navigating Insurance

lockhani@mail.nih.gov **301-827-7284**
genome.gov/about-genomics/policy-issues/Genetic-Discrimination

NSGC Find a Genetic Counselor

NSGC Find a Genetic Counselor is a searchable directory for locating genetic counselors by specialty, location, and appointment format, helping families identify appropriate genetics professionals.

nsgc@nsgc.org
findageneticcounselor.nsgc.org

GeneDx

Genetic testing can provide answers and a clear path forward



What is genetic testing?

Genetic testing analyzes a person's DNA to identify changes that may explain their symptoms or condition, which plays an important role in guiding next steps.

80%

Approximately 80 percent of rare diseases have an underlying genetic cause.[1]

For patients with developmental delay, intellectual disability, congenital anomalies, epilepsy, cerebral palsy, or autism spectrum disorder, exome or genome genetic testing should be the first test offered.[2-5]

With answers, families can:

- Choose more effective medications or treatments[6,7]
- Connect with other families and advocacy groups specific to their condition
- Identify risks to other family members or prepare for future family planning[6,7]
- Get insurance coverage for medical equipment or therapies
- Enable participation in clinical trials[6]

Scan the QR code to learn how to *access testing*, or visit genedx.co/access-testing-cnf

References:
1. Butler L., et al. Exome-based testing for patients with seizures: Advantages over panel-based testing. Poster presented at American Epilepsy Society Annual Meeting; December 2, 2023; Orlando, FL. 2. Srivastava S, Love-Nichols JA, Dies KA, et al. Genet Med. 2019 Nov;21(11):2413–2421. 2. Manickam K, McClain MR, Demmer LA et. al; ACMG Board of Directors. Genet Med. 2021Nov;23(11):2029-2037. 3. Smith L, Malinowski J, Ceulemans S, et. al. J Genet Couns. 2023 Apr;32(2):266-280. 4. Srivastava S, Lewis SA, Cohen JS, et al. JAMA Neurol. 2022 Dec 1;79(12):1287-1295. 5. RodanLH, et al. Genetic Evaluation of the Child With Intellectual Disability or Global Developmental Delay: Clinical Report. Pediatrics. 2025 Jun 23:e2025072219. doi: 10.1542/peds.2025-072219. Epub ahead of print. 6. Malinowski J, Miller DT, Demmer L, et al. Systematic evidence-based review: outcomes from exome and genome sequencing for pediatric patients with congenital anomalies or intellectual disability. Genet Med. 2020 Jun;22(6):986-1004. doi: 10.1038/s41436-020-0771-z. 7. Srivastava S, Cole JJ, Cohen JS, et al. Survey of the Landscape of Society Practice Guidelines for Genetic Testing of Neurodevelopmental Disorders. Ann Neurol. 2024 Nov;96(5):900-913. doi: 10.1002/ana.27045.

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PLUGS, Patient and Caregiver Resources

This webpage from Seattle Children's and PLUGS shares patient and caregiver information related to genetic testing; its tools can help people understand coverage and navigate access challenges.

Also covers: Navigating Insurance

PLUGS@seattlechildrens.org

schplugs.org/patient-and-caregiver-resources

Start Genetic

Start Genetic, an initiative of CureSHANK, provides education and advocacy promoting earlier genetic evaluation, diagnosis, and research participation for people with Phelan-McDermid syndrome and related neurodevelopmental conditions.

takeaction@startgenetic.org

startgenetic.org

Unique: Understanding Rare Chromosome and Gene Disorders Guides

Unique publishes family-friendly guides about rare chromosome and gene disorders, developed with input from clinicians and families to explain diagnoses, health concerns, development, and care.

help@rarechromo.org

rarechromo.org/disorder-guides



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MKT-CORP-ADS-10590-EN v1 09.18.26

BEHAVIORAL HEALTH

Caring for a child's mind matters as much as caring for their body. These resources cover mood, anxiety, behavior, and where to find real help.





BEHAVIOR MANAGEMENT

Parenting can be hard work under any circumstances, and children with neurologic conditions can have behaviors that make it harder still.

Traditional approaches, like consequences and rewards, may not work. Sometimes they make things worse. Finding what actually helps is one of the most common concerns families in the child neurology community bring to us.

That is why CNF made the management of disruptive and harmful behaviors a focus of our education work. The need has not gone away, and behavior management remains one of our ongoing programs.

The resources gathered here are for you. You will find practical strategies, guidance from clinicians and other parents, and support for the days that feel impossible.

Center on PBIS Resources

Center on PBIS provides evidence-based school resources for implementing positive behavioral interventions and supports, including guidance, assessments, training materials, and tools for educators and families.

jeffs@uoregon.edu

pbis.org

Chickasaw Nation Pediatric Collaborative

Chickasaw Nation Pediatric Collaborative supports integrated pediatric behavioral healthcare through screening, consultation, care coordination, and referrals for families addressing emotional, behavioral, developmental, or neurologic concerns.

Also covers: Mental Health

PxTeam@Chickasaw.net

chickasawnationhealth.net/Services/Mental-Health/Chickasaw-Nation-Pediatric-Collaborative

International Society for Neuroregulation & Research

International Society for Neuroregulation and Research provides a clinician directory for families seeking neurofeedback and related neuroregulation services for pediatric brain, behavioral, or developmental concerns.

office@isnr.org

800-847-4986

isnr.org

Kennedy Krieger Institute

Kennedy Krieger Institute provides clinical care, rehabilitation, education, research, and community services for children, adolescents, and adults with neurologic, developmental, behavioral, and learning-related conditions across the lifespan.

Also covers: Disorder Specific

kennedykrieger.org

888-554-2080

MIGHTIER™

Managing Emotions Is Tough. Let's Make It Fun.

Mightier's biofeedback program helps kids control emotions, build confidence and feel calmer. Everything you need is shipped right to your home.

Clinically validated to help kids with:

Anger | Anxiety | ADHD | Autism

Tested and validated by

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

Boston Children's Hospital

87% of families see emotional and behavioral improvement with just 45 minutes of play per week.





Games that teach calm

Kids wear a heart sensor while they play, practice coping skills, and strengthen their ability to manage emotions in real life. Calming down is part of the game.

Offline programming

Therapeutic crafts, games and stories are mailed monthly do your door, letting your family explore emotional concepts together through play.

Caregiver companion app

Track progress, access resources, and play games through your parent app.

"Our son struggled with shifting moods, oppositional behavior and explosiveness. We turned to Mightier. It's literally changed our world."

-Mightier Parent

Visit **www.mightier.com** to learn more and sign up.
Use discount code **PT_CNF** at checkout to receive **15% off** your initial purchase!

Society of Pediatric Psychology (APA Division 54)

Society of Pediatric Psychology provides evidence-based information and professional resources connecting behavioral and psychological care with pediatric medical conditions for families, clinicians, researchers, and healthcare professionals.

info@pedpsych.org

pedpsych.org

Southcentral Foundation Child and Family Developmental Services

Southcentral Foundation provides multidisciplinary assessment and treatment for developmental, behavioral, and neurologic concerns, coordinating family-centered care for Alaska Native and American Indian children and youth.

Also covers: Disorder Specific • Genetic Testing

info@southcentralfoundation.com

southcentralfoundation.com/services/cfds

STAR Institute for Sensory Processing

STAR Institute provides sensory-processing assessments, intensive therapy, family education, professional training, and research resources for children, caregivers, educators, clinicians, and researchers addressing sensory differences in daily life.

Info@sensoryhealth.org

303-221-7827

sensoryhealth.org

"HOW DO I KEEP MY CHILD SAFE AT NIGHT?"

the safety sleeper®

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Convertible Entry



End of Bed Entry



Standard Side Entry

AN ENCLOSED BED DESIGNED FOR INDIVIDUALS WITH SPECIAL NEEDS

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EMAIL: CUSTOMERCARE@ABRAMSNATION.COM

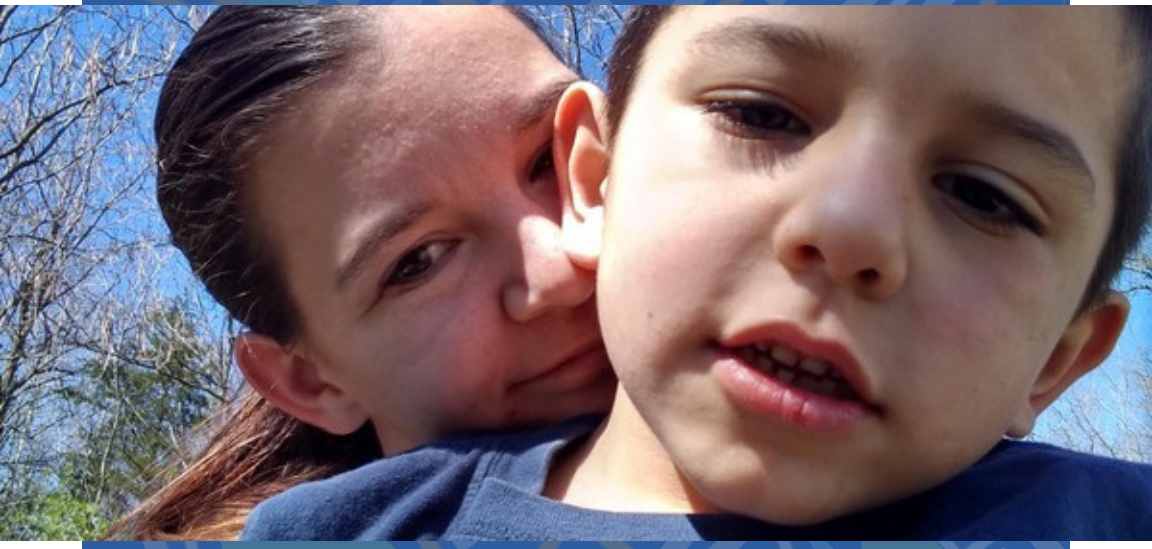
OR VISIT

HTTPS://SAFETYSLEEPER.COM/

Abram's NATION

MENTAL HEALTH

You cannot pour from an empty cup, and nobody hands caregivers a refill. Ask for help before you run out. These resources are a start.



FREE COURSE FOR CAREGIVERS

The Caregiver's Compass is a free virtual course where parents and caregivers come together to learn practical strategies for managing stress, strengthening communication, and supporting mental wellbeing. Each live session is guided by our licensed therapist and caregiver in a supportive, community-centered space. *Scan the QR code to visit our learning portal page to sign up for the next course.*



988 Suicide and Crisis Lifeline

The 988 Suicide and Crisis Lifeline provides free, confidential call, text, and chat support around the clock for people experiencing suicidal crisis or emotional distress.

Also covers: Behavioral Health

djaffar@vibrant.org

988lifeline.org

American Chronic Pain Association

American Chronic Pain Association provides peer support, education, and pain-management tools for people living with chronic pain and families managing pain connected to neurologic conditions.

Also covers: Trauma and Grief

ACPA@theacpa.org

913-991-4740

acpanow.com

Anxiety & Depression Association of America

An ADAA article explains how anxiety and depression can occur alongside chronic neurological conditions and summarizes how cognitive behavioral therapy may help address related emotional symptoms.

Also covers: Behavioral Health

lbram@adaa.org

240-485-1016

adaa.org/learn-from-us/from-the-experts/blog-posts/consumer/treating-psychological-and-physical-cognitive

Association for Child and Adolescent Mental Health (ACAMH) Resources

The Association for Child and Adolescent Mental Health shares research reviews, clinical guidance, podcasts, and learning resources about child mental health and neurodevelopmental conditions for practitioners and families.

Also covers: Behavioral Health

martin.pratt@acamh.org

acamh.org

The Neuro Care Bridge

STANDING ON THE BRIDGE
BETWEEN DIAGNOSIS AND DAILY LIFE

Helping bridge the space between diagnosis and daily life for families navigating neurological and neurodevelopmental care.



The Neuro Care Bridge exists to make complex medical experiences more understandable, accessible, and human beyond the hospital setting through education, advocacy, writing, resources, and community-centered initiatives.

www.gabriellewardcollier.org

Because families deserve support that continues beyond diagnosis and discharge.

For families, caregivers, clinicians, students, and advocates navigating neurological and neurodevelopmental care across every stage.

SCAN ME!

Cancer Support Community

Cancer Support Community offers a navigation helpline, MyLifeLine online community, virtual programs, and professionally led support through more than 200 Cancer Support Community and Gilda's Club locations.

Also covers: Transition of Care • Trauma and Grief

lireland@cancersupportcommunity.org

cancersupportcommunity.org **888-793-9355**

Caregiver Action Network

Caregiver Action Network offers education, peer support, and a help desk for caregivers managing chronic illness, disability, complex care, or behavioral-health needs across the lifespan.

info@caregiveraction.org **855-227-3640**

caregiveraction.org

Child Mind Institute

Child Mind Institute provides expert information, care guidance, videos, and family resources addressing children's mental health, behavior, learning differences, developmental concerns, and common parenting questions.

Also covers: Behavioral Health • Early Intervention & Education

info@childmind.org

childmind.org

Crisis Text Line

Crisis Text Line provides free, confidential, 24-hour text-based crisis support in the United States by texting HOME to 741741; it connects people experiencing emotional distress with trained crisis counselors.

Also covers: Behavioral Health

info@crisistextline.org

crisistextline.org

El Futuro

El Futuro provides Spanish-language, culturally responsive mental health and substance-use services, including care for children and adolescents with ADHD, behavioral concerns, trauma, or co-occurring needs.

Also covers: Behavioral Health

mhondermann@elfuturo-nc.org

elfuturo-nc.org

Family Caregiver Alliance

Family Caregiver Alliance provides education, service navigation, support, and policy information for caregivers of adults with chronic conditions or disabilities, including national and state resources.

info@caregiver.org

caregiver.org

415-434-3388
800-445-8106

Imerman Angels

Imerman Angels provides free one-to-one cancer support by matching patients, survivors, previvors, and caregivers with trained mentors sharing similar diagnoses or experiences, including Spanish-language service.

Also covers: Transition of Care • Trauma and Grief

info@imermanangels.org

imermanangels.org

International OCD Foundation: OCD in Kids

International OCD Foundation provides plain-language information about pediatric obsessive-compulsive disorder, evidence-based treatment, school support, and finding help for children, teens, parents, educators, and clinicians seeking appropriate care.

info@iocdf.org

kids.iocdf.org

Mental Health America

Mental Health America provides screening tools, educational information, policy and advocacy resources, and community programs focused on mental health and early intervention for people seeking mental-health information or screening.

Also covers: Behavioral Health

info@mhanational.org

mhanational.org

Mental Health News Education

Mental Health News Education publishes Autism Spectrum News and Behavioral Health News, sharing science-based information, advocacy, services, and community perspectives about autism and mental health.

Also covers: Transition of Care

dminot@mhnews.org

mhne.org

NAMI

NAMI provides mental-health education, support programs, local affiliate connections, and a national HelpLine for people with mental-health conditions and families seeking information outside a crisis.

Also covers: Behavioral Health

info@nami.org

800-950-6264

nami.org

National Alliance for Caregiving

National Alliance for Caregiving publishes national caregiver research, open data, guidebooks, advocacy tools, and condition-specific resources while convening coalitions that strengthen family caregiver policy and practice.

Also covers: Navigating Insurance • Transition of Care

info@caregiving.org

202-918-1013

caregiving.org

Connection and Care: Dementia

Information provided by Kaitlin Baum, RN, as part of our Courage in Care series

Advice for caregivers of children with dementia, like Lafora disease.

Takeaways

1

Importance of Routine

- Routine draws on **procedural memory**
- Helps maintain independence
- Keep simple daily routines
- Establish a **consistent** bedtime



2

Simple Communication

- Offer simple choices
- Break tasks into **small steps**
- Validate **emotions**
- Behaviors are not personal, they are a form of **communication**



3

Purposeful Activities

- Connect to activities they like, **even if modified**
- Music and reading support neural pathways
- Focus on activities that build **connection**
- This helps preserve identity and confidence



4

Join Your Child's Reality

- **Embrace** the imagined reality
- Don't correct errors in their memory
- Lean into things that bring joy
- Respond as if it's the **first** time you're hearing it



5

Move at Your Child's Pace

- Match **current** cognitive and processing speed
- Stay patient when asking a question
- Allow the day to be **slow**
- Encourage **participation** to promote confidence and preserve their control



Courage in Care

Lafora Caregiver Series

View more resources & trainings at https://chelseashope.org/courage-in-care/

National Institute of Mental Health

National Institute of Mental Health provides federal information about child and adolescent mental health, including symptoms, treatment, research, crisis resources, and ways to find appropriate help.

Also covers: Mental Health

nimhinfo@nih.gov

nimh.nih.gov/health/topics/child-and-adolescent-mental-health

Parent to Parent USA

Parent to Parent USA supports a national network of programs that match caregivers of people with disabilities or special healthcare needs with trained peer supporters.

Also covers: Behavioral Health

info@p2pusa.org

p2pusa.org

Raregivers

Raregivers supports rare-disease caregivers through emotional wellness education, peer connection, retreats, and community programs addressing the long-term mental and emotional effects of caregiving and family wellbeing.

Also covers: Trauma and Grief

info@angelaidcares.org

415-662-8450

raregivers.global

Rosalynn Carter Institute for Caregivers

Rosalynn Carter Institute for Caregivers provides dementia education, military caregiver coaching, stress-management tools, crisis connections, and evidence-based programs strengthening caregivers' health, resilience, and problem-solving across conditions and communities.

Also covers: Navigating Insurance • Transition of Care

info@rosalynncarter.org

rosalynncarter.org

Sibling Support Project

Sibshops are recreational peer-support programs for school-age siblings of children with disabilities or health conditions; the Sibling Support Project provides facilitator training and a directory of local programs.

info@siblingsupport.org

425-362-6421

siblingsupport.org/sibshops



TRAUMA & GRIEF

Some losses are sudden. Some come slowly, over years of appointments and hard news. Both are grief. Both deserve care.





WILLOW & WIND: *A GRIEF COMMUNITY*

Child Neurology FOUNDATION
Creating a Community of Support

WILLOW & WIND:

A CNF Grief Support Community

Grief is not meant to be carried alone. Support can make a meaningful difference in how families navigate loss. For those in the child neurology community, grief can take many forms: child loss, anticipatory grief, and the milestones that changed or never came. ***Willow & Wind*** *offers a supportive space for families to process, connect, and find resources, at their own pace, and in their own way.*

What we offer:

Guided Grief Course

A FREE structured, therapist-led course designed to help families move through grief with support and understanding.

Private Online Community

A private, compassionate space to connect with others who understand & share experiences.

"The Courage to Live" Podcast

Real conversations & shared stories from families & advocates across the community.

Education & Resources

Information around SUDEP, seizure detection, and other important topics to help families feel informed and supported.

Bereavement Resources for Families

The New York Life Foundation provides downloadable bereavement materials for children, caregivers, schools, and community organizations, including age-appropriate guides and activities for supporting grieving children.

NYLFoundation@NewYorkLife.com **800-225-5695**

newyorklife.com/foundation/bereavement-support/for-families

Center for Pediatric Traumatic Stress

Center for Pediatric Traumatic Stress provides evidence-based training, screening tools, and family resources addressing pediatric medical traumatic stress and trauma-informed healthcare for caregivers and professionals.

CPTS@chop.edu

healthcaretoolbox.org

Comfort Zone Camp

Comfort Zone Camp offers free bereavement camps where children who have lost a parent, sibling, or primary caregiver can connect with peers and trained adult mentors.

Also covers: Mental Health

info@comfortzonecamp.org

comfortzonecamp.org

Compassionate Friends

Compassionate Friends is a self-help organization offering friendship, understanding, and hope to bereaved families that have experienced the death of a child, grandchild, or sibling.

nationaloffice@compassionatefriends.org

compassionatefriends.org **877-969-0010**

Dougy Center

Dougy Center provides grief education, peer support resources, and training for children, teens, young adults, families, and professionals navigating death, dying, loss, and bereavement experiences.

help@dougy.org

dougy.org/grief-support-resources

Eluna / Camp Erin

Eluna's Camp Erin network provides free bereavement camps for children and teens, combining peer connection, grief activities, and opportunities to remember someone who died in supportive settings.

Also covers: Mental Health

info@elunanetwork.org

elunanetwork.org

Experience Camps

Experience Camps offers free grief-support camps and year-round programs for children and teens who have experienced the death of a parent, sibling, or primary caregiver.

ashley.laughlin@experiencecamps.org

experiencecamps.org

Faith's Lodge

Faith's Lodge provides retreat experiences for families coping with a child's serious illness or death, offering space for rest, remembrance, and connection with other families.

Also covers: Mental Health

info@faithslodge.org

faithslodge.org

HealGrief

HealGrief's Actively Moving Forward program connects grieving young adults with peer-led communities, education, and support that honor their losses and help them navigate life after death.

Admin@HealGrief.org

healgrief.org/actively-moving-forward

MISS Foundation

MISS Foundation provides counseling, support groups, peer connection, advocacy, and education for families grieving the death of a child, including pregnancy loss and traumatic death.

Also covers: Mental Health

info@missfoundation.org

888-455-6477

missfoundation.org

National Alliance for Children's Grief

National Alliance for Children's Grief supports professionals and communities serving grieving children through education, practice standards, networking, advocacy, and a searchable directory of bereavement programs.

deirdra.flavin@nacg.org

866-432-1542

nacg.org

Riley Children's Health

Riley Grief Services provides grief and bereavement support for children and caregivers connected to Riley Children's Health, including counseling, support groups, workshops, remembrance activities, and educational materials.

rileygrief@iuhealth.org

317-963-0829

rileychildrens.org/support-services/grief-bereavement-services

Sudden Unexplained Death in Childhood Foundation (SUDC)

SUDC Foundation supports families and professionals after sudden unexplained death in childhood through bereavement resources, awareness, research funding, family services, and information for medical examiners.

DanielleLCSW@sudc.org

sudc.org

The Comfort Cub

The Comfort Cub provides weighted therapeutic bears and grief support to people and families experiencing pregnancy, infant, or child loss, including resources for healthcare professionals.

info@thecomfortcub.org

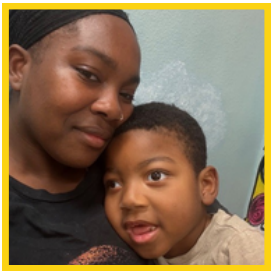
thecomfortcub.org



FINANCIAL SUPPORT

Many families skip care because of cost. Before you do, look here. Programs exist for medicine, travel, equipment, and the bills in between.





CNF'S HARNETT GRANT

The Harnett Mini-Grant was founded by Mr. Michael Harnett in January 2014 as a memorial to his nephew, Brendan Michael Harnett, who was diagnosed with infantile spasms and passed away before his first birthday. Each year during Infantile Spasms Awareness Week (early December), one $1,000 mini-grant is awarded to a child with infantile spasms and their caregivers to cover the cost of medical devices, treatments, therapies, or other services not covered by insurance. To apply, visit our Harnett grant page in November. To donate in a loved one's honor, please visit our donation page.

GRANTS & SCHOLARSHIPS

DONATE TO CNF

Accessia Health

Accessia Health provides eligible patients with financial assistance for insurance premiums, medication copayments, travel, and other costs connected with managing chronic or rare health conditions.

Also covers: Navigating Insurance

info@accessiahealth.org **800-366-7741**

accessiahealth.org

Acorns to Oak Trees

Acorns to Oak Trees helps families of children with serious illnesses or disabilities meet urgent financial and resource needs while managing complex medical care and related expenses.

season@acorns2oak.com

acorns2oak.com

Air Care Alliance

Air Care Alliance connects people needing medical transportation with volunteer pilot organizations that may provide free flights for treatment, diagnosis, follow-up care, or other qualifying needs.

mail@aircarealliance.org

aircarealliance.org

ARCH National Respite Locator

ARCH National Respite Network provides respite information, state program links, caregiver resources, and a searchable locator helping families identify respite services available in their communities.

Also covers: Transition of Care

sjsummers@archrespite.org

archrespite.org

CancerCare

CancerCare's oncology social workers provide free counseling, support groups, education workshops, resource navigation, specialized family programs, and limited financial or copayment help by phone and online.

Also covers: Mental Health • Transition of Care • Trauma and Grief

info@cancercare.org

800-813-4673

cancercare.org

Challenged Athletes Foundation

Challenged Athletes Foundation provides grants, adaptive sports equipment, coaching, camps, and community opportunities helping people with physical disabilities participate in sports and active lifestyles in their communities.

Also covers: Mental Health • Transition of Care

info@challengedathletes.org

challengedathletes.org

Colton's Cause Foundation

Colton's Cause Foundation provides financial assistance for eligible children and young adults with complex disabilities, including help with nursing care, mobility equipment, therapy, and home accessibility modifications.

Also covers: Transition of Care

coltonscausefoundation@gmail.co
m

coltonscause.org

Computers for the Blind

Computers for the Blind provides affordable refurbished computers with accessible software, training, and technical support for people who are blind or have low vision throughout the United States.

Also covers: Transition of Care

info@computersfortheblind.org

computersfortheblind.org

Corporate Angel Network

Corporate Angel Network arranges free flights to treatment for eligible cancer patients by matching travelers with available seats on corporate aircraft throughout the United States.

Also covers: Navigating Insurance

info@corpangelnetwork.org

corpangelnetwork.org

Different Needz Foundation

Different Needz Foundation provides grants to eligible individuals with developmental disabilities for medical equipment, therapy, adaptive devices, or other services not fully covered elsewhere through its grant program.

info@differentneedzfoundation.org

differentneedzfoundation.org

Digitunity

Digitunity works with nonprofit organizations and technology partners to expand computer ownership, device access, and digital participation for people and communities experiencing technology gaps across the United States.

Also covers: Transition of Care

info@digitunity.org

digitunity.org

Eliana's Light

Eliana's Light supports families of children with complex medical needs through practical assistance, wellness resources, care packages, and community connections addressing emotional, financial, and daily-care challenges.

Also covers: Mental Health • Navigating Insurance • Trauma and Grief

info@elianaslight.org

elianaslight.org

Family Reach

Family Reach helps people facing cancer manage everyday costs through financial coaching, personalized navigation, local resource searches, educational tools, and limited grants for qualifying expenses.

Also covers: Navigating Insurance

info@familyreach.org

familyreach.org

Friends of Karen

Friends of Karen provides emotional, financial, and practical support for families caring for a child with cancer or another life-threatening illness, including siblings and household needs.

Also covers: Trauma and Grief

lesliebellissimo@friendsofkaren.org **914-277-4547**

friendsofkaren.org

Friends of Man

Friends of Man accepts applications from referring professionals for mobility equipment, prosthetics, hearing aids, home modifications, medical equipment, assistive technology, and other essential needs through its grant program.

info@friendsofman.org

friendsofman.org

Giving Angels Foundation

Giving Angels Foundation assists eligible lower-income families of children with physical disabilities by funding medical equipment, therapy, and other items that can improve daily life.

info@givingangelsfoundation.org

givingangelsfoundation.org

Good Days

Good Days helps qualifying patients with treatment copays, insurance premiums, diagnostic testing, and travel arrangements, including transportation and lodging coordinated by trained care navigators nationwide.

Also covers: Navigating Insurance

info@mygooddays.org **877-968-7233**

mygooddays.org

HealthWell Foundation

HealthWell Foundation provides eligible insured patients with assistance for medication copayments, insurance premiums, deductibles, selected treatment-related costs, and certain travel expenses through available disease-specific funds.

Also covers: Navigating Insurance

info@healthwellfoundation.org **800-675-8416**

healthwellfoundation.org

Help Hope Live

Help Hope Live helps people with serious medical conditions organize community-based fundraising for uncovered medical expenses, equipment, treatment-related travel, housing modifications, and other qualifying needs.

Also covers: Behavioral Health

smullen@helphopelive.org **800-642-8399**

helphopelive.org

June Jessee Memorial Foundation

The June Jessee Memorial Foundation's financial-resource page lists grants and assistance programs for children with complex neurologic conditions, including help with medical care, equipment, respite, therapies, and other needs.

karlita@junejessee.org

junejessee.org/resources/financial

MEC Disabilities

MEC Disabilities provides adaptive equipment and related assistance to children with disabilities whose families need help obtaining items that support mobility, communication, access, or daily activities.

info@mecdisabilities.org

mecdisabilities.org

Mercy Medical Angels

Mercy Medical Angels arranges free medical transportation through volunteer flights, commercial airfare, ground transportation, rideshare, or gas assistance for eligible patients traveling to care across the United States.

info@mercymedical.org

888-675-1405

mercymedical.org

Miracle Flights

Miracle Flights provides free commercial air travel for eligible children ages 17 and younger who must travel within the United States for specialized medical care.

info@miracleflights.org

800-359-1711

miracleflights.org

Modest Needs

Modest Needs provides short-term grants for eligible workers and families facing emergency expenses that could threaten their housing, employment, or ability to remain self-sufficient during a temporary crisis.

general.questions@modestneeds.org

modestneeds.org

National Disability Institute

National Disability Institute provides financial education, benefits information, tax resources, employment tools, and guidance designed to strengthen the financial well-being of people with disabilities and their families.

Also covers: Transition of Care

info@ndi-inc.org **202-296-2040**

nationaldisabilityinstitute.org

NeedyMeds

NeedyMeds connects families and healthcare professionals with information about medication assistance programs, low-cost clinics, discount programs, and other resources that may reduce healthcare expenses for families and caregivers.

outreach@needymeds.org

needymeds.org

Oracle Health Foundation

Oracle Health Foundation provides pediatric grants for eligible healthcare expenses, including treatment, therapy, medical equipment, assistive technology, and limited travel or lodging connected with a child's care.

oraclehealthfoundation_ww@oracle.com

oraclehealthfoundation.org

Patient Advocate Foundation

Patient Advocate Foundation provides no-cost case management and financial-navigation services for people with chronic, life-threatening, or debilitating conditions; services may include insurance appeals, access-to-care help, and referrals to financial programs.

Also covers: Navigating Insurance

info@patientadvocate.org **800-532-5274**

patientadvocate.org

Patient AirLift Services / SkyHope

Patient AirLift Services, operating as SkyHope, coordinates free volunteer flights for eligible people traveling for medical care, disaster response, humanitarian needs, or other qualifying missions.

info@skyhope.org

skyhope.org

Ragan's Hope

Ragan's Hope provides practical and emotional support for families of children facing catastrophic illness or injury, including meals, transportation, household help, care coordination, and community assistance.

Also covers: Trauma and Grief

info@raganshope.com

raganshope.org

Ronald McDonald House Charities

Ronald McDonald House Charities provides lodging and family-centered programs near children's hospitals, helping families remain close while a child receives medical care away from home.

Also covers: Trauma and Grief

info@rmhc.org

630-623-7048

rmhc.org

Small Steps in Speech

Small Steps in Speech provides grants for speech therapy and communication devices for eligible children whose families cannot fully cover these expenses through insurance or other funding.

Also covers: Early Intervention & Education

info@smallstepsinspeech.org

smallstepsinspeech.org

Special Needs Navigator

Special Needs Navigator offers paid, plain-language guidance about SSI, Medicaid, disability benefits, long-term planning, and transition services for families and professionals navigating public supports and eligibility.

Also covers: Navigating Insurance • Transition of Care

eric@specialneedsnavigator.us

specialneedsnavigator.us

The Assistance Fund

The Assistance Fund operates more than 100 disease-specific programs helping eligible patients pay medication copayments, coinsurance, deductibles, premiums, and other approved health-related expenses for treatment.

Also covers: Navigating Insurance

communications@tafcares.org

855-845-3663

tafcares.org

The Parker Lee Project

The Parker Lee Project supplies medical equipment and everyday care items to families of children with medical needs when insurance or other programs do not cover them.

info@theparkerleeproject.org

theparkerleeproject.org

Triage Cancer Financial Resources

Triage Cancer provides plain-language education and tools about medical bills, employment, disability benefits, insurance, and financial planning for people and families managing cancer or serious illness.

Also covers: Navigating Insurance

info@TriageCancer.org

triagecancer.org/cancer-finances

U.S. Department of Health and Human Services

The Temporary Assistance for Needy Families program provides federal funding to states and territories for time-limited cash assistance and related services that support eligible households with children.

info.ofa@acf.hhs.gov

202-401-5457

acf.gov/ofa/programs/temporary-assistance-needy-families-tanf

UnitedHealthcare Children's Foundation

UnitedHealthcare Children's Foundation provides medical grants for eligible children whose commercially insured healthcare expenses are not covered or are only partially covered by their plan.

uhccfcustomerservice@uhc.com

uhccf.org

Variety – The Children's Charity

Variety – The Children's Charity supports eligible children through mobility equipment, adaptive bicycles, communication devices, and other programs delivered through participating Variety chapters across the United States.

Also covers: Early Intervention & Education

info@usvariety.org

usvariety.org

Wheel to Walk Foundation

Wheel to Walk Foundation provides grants for eligible children and young adults to obtain medical equipment or services not fully covered by insurance or other funding sources.

info@wheeltowalk.com

wheeltowalk.com

NAVIGATING INSURANCE

Insurance can be confusing. You are not behind, and you are not alone. These resources walk you through it one step at a time.



Centers for Medicare & Medicaid Services

Centers for Medicare and Medicaid Services offers Coverage to Care materials explaining health coverage, provider selection, appointment preparation, costs, prescriptions, and preventive or primary-care benefits.

CoverageToCare@cms.hhs.gov **800-633-4227**

cms.gov/priorities/health-equity/c2c/navigate-your-coverage

Charles B. Wang Community Health Center Special Needs Program

Charles B. Wang Community Health Center provides bilingual clinical care, developmental screening, care coordination, social work, parent-peer support, and workshops for children with developmental disabilities.

Also covers: Transition of Care

parentpeerleader@cbwchc.org

cbwchc.org/community-health/special-needs-program

Disability Rights Education and Defense Fund

Disability Rights Education and Defense Fund advances disability civil rights through legal advocacy, public policy, healthcare access work, special education resources, training, and parent information services.

Also covers: Transition of Care

info@dredf.org

dredf.org

Family Voices

Family Voices provides family-to-family support and advocacy for caregivers navigating healthcare, behavioral or mental health services, insurance coverage, and complex systems for children with health needs.

Also covers: Behavioral Health

partnership@familyvoices.org **888-835-5669**

familyvoices.org

Find Coverage for Your Family

InsureKidsNow.gov helps caregivers identify and apply for state Medicaid or Children's Health Insurance Program coverage for eligible children and teens who need affordable healthcare for their families.

Also covers: Financial Support

ConnectingKids@cms.hhs.gov
877-543-7669
insurekidsnow.gov/coverage

Healthcare.gov

HealthCare.gov explains how to request an internal appeal or independent external review when a health plan denies a claim, refuses prior authorization, or ends covered services.

Champion@cms.hhs.gov
800-318-2596
appeals 855-231-1751
healthcare.gov/appeal-insurance-company-decision

National Association of Free and Charitable Clinics

National Association of Free and Charitable Clinics maintains a national network and searchable directory helping uninsured and underinsured people locate free or charitable healthcare services in their communities.

info@nafcclinics.org
nafcclinics.org

National Center for Medical-Legal Partnership

National Center for Medical-Legal Partnership helps healthcare organizations integrate legal services addressing insurance, benefits, housing, education, employment, immigration, and other concerns that can influence health.

ncmlp@gwu.edu
medical-legalpartnership.org

National Disability Rights Network

National Disability Rights Network represents the nationwide Protection and Advocacy system, offering information and connections to agencies that protect the legal rights of people with disabilities.

Also covers: Transition of Care

info@ndrn.org

202-408-9514

ndrn.org

Native American Disability Law Center

Native American Disability Law Center provides advocacy, legal information, and rights-protection services for Native Americans with disabilities living within its service area in the Southwest.

Also covers: Transition of Care

info@nativedisabilitylaw.org

nativedisabilitylaw.org



EARLY INTERVENTION & EDUCATION

Small steps early can make a big difference later. These resources help you find services near you and get them started.



Academy of Physical Therapy Pediatrics

APTA Pediatrics provides clinical resources, education, research, professional groups, and family information supporting pediatric physical therapy from infancy through adolescence and the transition to adulthood.

Also covers: Transition of Care

info@pediatricapta.org **571-534-3993**

pediatricapta.org

Advocating 4 Kids

Advocating 4 Kids provides special-education advocacy, training, and family support, with particular attention to children whose disabilities or behavioral needs are not being adequately addressed at school.

Also covers: Behavioral Health

adv4kids@gmail.com

adv4kidsinc.org

American Occupational Therapy Association

The American Occupational Therapy Association provides public information, professional standards, education, and resources supporting occupational therapy services that help people participate in daily activities across the lifespan.

customerservice@aota.org

aota.org

Boston Children's Hospital

Boston Children's Hospital explains Massachusetts early-intervention services for children from birth through age three who have developmental delays or conditions that may affect their development.

earlyintervention@childrens.harvard.edu

childrenshospital.org/services/early-intervention

CommunicationFIRST

CommunicationFIRST protects the rights of people with speech-related disabilities through policy advocacy, public education, research priorities, legal work, and resources created with communication-device users and their families.

Also covers: Transition of Care

info@communicationfirst.org

communicationfirst.org

Community Parent Resource Centers

Community Parent Resource Centers connect underserved families of children with disabilities to parent training, special-education information, advocacy support, and disability resources available within their communities.

CPIR@spanadvocacy.org

973-642-8100

parentcenterhub.org

Council of Parent Attorneys and Advocates

Council of Parent Attorneys and Advocates supports families, advocates, and attorneys through training, referrals, legal resources, and information about special education rights and dispute resolution.

Also covers: Navigating Insurance • Transition of Care

admin@copaa.org

copaa.org

Division for Early Childhood of the Council for Exceptional Children

The Division for Early Childhood provides professional standards, recommended practices, family resources, training, and policy information supporting early intervention and early-childhood special education services nationwide.

dec@dec-sped.org

dec-sped.org

Early Childhood Technical Assistance Center

Early Childhood Technical Assistance Center provides federal resources on IDEA Part C, early intervention, preschool special education, implementation practices, family participation, and systems improvement for educators and providers.

denise.bennett@unc.edu

ectacenter.org

Easterseals Children's Services

Easterseals Children's Services provides early intervention, therapy, education, family support, and developmental services for children and young adults through participating local Easterseals affiliates and communities nationwide.

relefane@easterseals.com

easterseals.com/get-support/areas-of-support/children-services

Eye to Eye

Eye to Eye provides mentoring and school-based programs that help students with learning differences and ADHD build self-advocacy skills, explore strengths, and connect with peers.

Also covers: Mental Health • Transition of Care

info@eyetoeyenational.org

eyetoeyenational.org

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act is a federal law supporting eligible children with disabilities through early intervention, special education, related services, and educational protections.

Also covers: Transition of Care

IDEA@ed.gov

202-245-7459

sites.ed.gov/idea

IRIS Center

IRIS Center provides free, evidence-based training modules, case studies, activities, and classroom resources for educators and families supporting students with disabilities and diverse learning needs.

iris@vanderbilt.edu

iris.peabody.vanderbilt.edu

Matrix Parent Network and Resource Center

Matrix Parent Network and Resource Center provides special-education guidance, parent training, peer support, and advocacy resources for families of children and young adults with disabilities.

julie@marincil.org

matrixparents.org

National Center for Learning Disabilities

The National Center for Learning Disabilities summarizes research on factors associated with well-being for young adults with learning disabilities, including daily-living skills, disability rights, identity, healthcare access, and financial stability.

Also covers: Mental Health • Transition of Care

media-inquiries@ncld.org **301-966-2234**

ncld.org/centering-well-being-in-the-transition-to-adulthood

National Fair Learning Initiative

IEPNotes is a secure online platform from the National Fair Learning Initiative that helps caregivers, educators, advocates, and professionals organize records, communications, services, and progress data related to special education.

contact@iepnotes.com

iepnotes.com/nfli/home

Aeroflow Urology

Never buy another pull-on again!

www.aeroflowurology.com/cnf





Check your child's eligibility!

*Free medical-grade diapers, pull-ons, bladder control pads, wipes, and more for your child through insurance!

Monthly Shipments

20K+ 4.9 Star Google Reviews

Eligibility & Coverage Requirements Apply

PACER Center

PACER Center provides special-education information, assistive-technology resources, transition guidance, workshops, and advocacy support for families of children and young adults with disabilities across school and adult transitions.

Also covers: Transition of Care

pacer@pacer.org

pacer.org

Parent Alliance for Students with Exceptional Needs

Parent Alliance for Students with Exceptional Needs provides families with a resource library, advocacy tools, and support for navigating special education and promoting children's school success.

info@pasen.org

pasen.org/resource-library

TASH

TASH advocates for disability rights, inclusive education, employment, self-determination, and community living while providing policy information and practical resources for families, professionals, and self-advocates across disability communities.

Also covers: Transition of Care

dtaylor@tash.org

tash.org

The Arc@School

The Arc@School provides special-education advocacy training, rights information, and a directory of state agencies, parent centers, protection and advocacy programs, and Arc chapters for students with disabilities and caregivers.

Also covers: Transition of Care

info@thearc.org

800-433-5255

thearc.org/our-initiatives/education

The Neuro Care Bridge

The Neuro Care Bridge, a Gabrielle Ward Collier Foundation program, connects families navigating neurologic conditions with plain-language education, care guidance, advocacy resources, and community support.

Also covers: Transition of Care

gablward@umich.edu

gabriellewardcollier.org

Understood.org

Understood provides free, expert-informed information, tools, and practical strategies for people with learning and thinking differences, including ADHD and dyslexia, and those supporting them at home and school.

Also covers: Behavioral Health • Mental Health

partnerships@understood.org

646-757-3100

understood.org

United States Society for Augmentative and Alternative Communication

The United States Society for Augmentative and Alternative Communication offers webinars, research, member connections, speaker resources, and information for people who use AAC and those supporting them.

Also covers: Transition of Care

info@ussaac.org

ussaac.org

ZERO TO THREE

ZERO TO THREE provides research-based information about infant and toddler development, early relationships, mental health, early learning, parenting, and family support for caregivers and professionals.

Also covers: Behavioral Health

gdavis@zerotothree.org

zerotothree.org

TRANSITION OF CARE

Transition covers more than doctors. Insurance, school, legal decisions, and independence all change at once. These resources cover each piece.



LIFESPAN CARE

Today, the move to adult care can leave families to navigate guardianship, benefits, and new providers largely on their own. Lifespan Care is closing that gap, so the momentum built in childhood continues into adult life instead of starting over.

Lifespan Care is CNF's effort to fix this at the root. Instead of every clinic and every family solving the transition from scratch, CNF is building one shared standard for how a young patient moves from pediatric to adult care. It is a clear, repeatable process any clinic can follow, and CNF is working to spread it nationwide.

The Lifespan Care Coalition is the vehicle for that work: the way CNF builds the standard and carries it from one clinic to the next.

Centers of Excellence define what good transition of care looks like. CNF recognizes clinics already doing this work well and holds them to a clear benchmark: who owns the handoff, how a young patient's readiness is assessed and documented, and how adult providers are prepared to take them on.

For a family, this means the move to adult care doesn't have to be something you face alone. For a clinician, it means you don't have to build a transition program from scratch. You can adopt a standard that already works.

To learn more, go to https://www.childneurologyfoundation.org/transitions/.







American College of Physicians

The American College of Physicians' Pediatric to Adult Care Transitions Initiative provides condition-specific toolkits and guidance to support the transfer of young adults from pediatric to adult healthcare.

help@acponline.org
800-227-1915
215-351-2600
acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative

Center for Transition to Adult Health Care for Youth with Disabilities

The Center for Transition to Adult Health Care provides accessible tools helping youth with intellectual and developmental disabilities lead their move from pediatric to adult healthcare.

jshorr@thenationalalliance.org
movingtoadulthc.org

Chinese Parents Association for the Disabled

Chinese Parents Association for the Disabled provides parent training, peer mentoring, recreation, advocacy, and family support for Chinese-speaking households that include children or adults with disabilities.

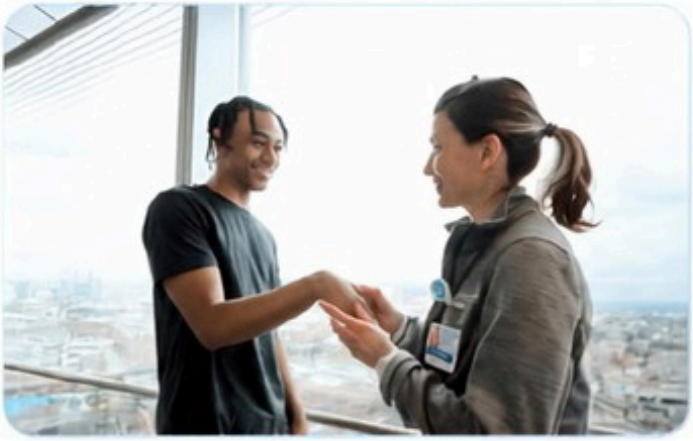
info@cpad.org
cpad.org/programs-and-services/about-us

Commonwealth of Massachusetts

Massachusetts provides healthcare professionals with practical transition guidance and links for helping youth with special healthcare needs prepare for adult care, self-management, insurance, and community services.

dalila.hyry-dermith@mass.gov
800-882-1435
mass.gov/info-details/health-transition-tips-and-resources-for-healthcare-providers

Children's Hospital of Philadelphia™



Children's Hospital of Philadelphia Transition Resources

https://www.chop.edu/transition-adulthood-resource

CHOP offers guides to help teens and families prepare for the transition to adult healthcare, insurance, and independent living. We also provide condition-specific resources and support for planning for life after high school.

Patients, Families, Clinicians, and Caregivers can all benefit from this resource!

Georgia Department of Public Health

The Georgia Department of Public Health provides healthcare-transition guidance for professionals supporting youth with special healthcare needs; the information addresses planning, care coordination, and preparation for adult healthcare.

childrens.medical@dph.ga.gov

dph.georgia.gov/child-health/preparing-teens-move-adult-care/hct-providers

Got Transition

Got Transition provides tools and guidance for young people, families, clinicians, and health systems preparing for the move from pediatric to adult healthcare and greater independence.

jshorr@thenationalalliance.org

202-769-0486

gottransition.org

Institute for Community Inclusion

Institute for Community Inclusion advances employment, education, and community participation for people with disabilities through research, training, consultation, technical assistance, and practical resources for families and professionals.

ici@umb.edu

communityinclusion.org

Ives Torres Foundation

Ives Torres Foundation provides Spanish-language workshops, family support, advocacy education, technology training, and inclusion activities helping people with intellectual and developmental disabilities navigate school, services, and adulthood.

info@ivestorresfoundation.org

ivestorresfoundation.org

Juvenile Law Center

Juvenile Law Center advocates for youth in foster-care and justice systems, with transition resources supporting young people with disabilities as they prepare for adulthood and independent living.

kotto@jlc.org

jlc.org/improving-transition-adulthood-youth-disabilities-foster-care

National Association of State Boards of Education (NASBE)

This NASBE article describes evidence-based transition practices and policy actions that state boards of education can use to improve education, employment, and independent-living outcomes for students with disabilities.

renee.lang@nasbe.org **703-684-4000**

nasbe.org/supporting-students-with-disabilities-in-transitioning-to-adulthood

National Black Disability Coalition

National Black Disability Coalition promotes leadership, policy advocacy, community education, and civic participation addressing the experiences and priorities of Black people with disabilities across the United States.

Also covers: Mental Health • Navigating Insurance

info@blackdisability.org

blackdisability.org

National Center on Health, Physical Activity and Disability (NCHPAD)

NCHPAD provides customized exercise, physical activity, and behavioral play guidance for children and adults with disabilities, their families, caregivers, healthcare professionals, and community organizations supporting inclusive health.

Also covers: Behavioral Health

nchpad@uab.edu **866-866-8896**

nchpad.org

PM&R Knowledge Now

PM&R KnowledgeNow provides a clinician-focused review of transition planning for people with childhood-onset disabilities, including assessment, healthcare transfer, education, employment, independent living, and community participation.

knowledgeNOW@aapmr.org **847-737-6000**

now.aapmr.org/transition-to-adulthood-for-persons-with-childhood-onset-disabilities

RespectAbility

RespectAbility advances disability inclusion through advocacy, leadership development, entertainment and media representation, employment initiatives, and educational resources for disabled people and community partners across multiple sectors.

Also covers: Mental Health

info@respectability.org

respectability.org

Rutgers Health

The Boggs Center's two-page transition timeline identifies age-based actions and planning milestones related to education, employment, healthcare, benefits, legal decision-making, and adult services for youth with developmental disabilities and caregivers.

bethany.chase@rutgers.edu **732-235-9316**

boggscenter.rwjms.rutgers.edu/documents/BOGGS/Publications/Transition/TransitionTimeline-ENG.pdf

Self Advocates Becoming Empowered

Self Advocates Becoming Empowered is a national self-advocacy organization led by people with intellectual and developmental disabilities, offering leadership training, policy advocacy, and educational resources.

Also covers: Mental Health

sabeusa@gmail.com

sabeusa.org

Sibling Leadership Network

Sibling Leadership Network provides information, peer connection, leadership development, state chapters, and advocacy opportunities for siblings of people with disabilities across childhood, adulthood, and later life.

Also covers: Mental Health

chapter.inquiries@siblingleadership.org

siblingleadership.org

TransCen

TransCen provides employment services, transition programs, training, and technical assistance that help youth and adults with disabilities prepare for work and participate in their communities.

info@transcen.org

transcen.org

Transition to Adulthood

Exceptional Children's Assistance Center provides transition-to-adulthood tools for North Carolina youth with disabilities and their caregivers, covering education, employment, independent living, healthcare, benefits, and self-advocacy.

bvoll@ecacmail.org **800-962-6817**

ecac-parentcenter.org/transition-to-adulthood

Youth Transition Services

The U.S. Department of Labor provides information and resources to help youth with disabilities prepare for employment, education, independent living, and the transition into adulthood.

odepemail@dol.gov **866-633-7365**

dol.gov/agencies/odep/program-areas/individuals/youth/transition/federal-partners **202-693-7880**

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ACRONYM GLOSSARY

ACRONYM	MEANING
AAC	Augmentative and Alternative Communication
ADHD	Attention-Deficit/Hyperactivity Disorder
BIPOC	Black, Indigenous, and People of Color
CHIP	Children's Health Insurance Program
CNF	Child Neurology Foundation
DEE	Developmental and Epileptic Encephalopathy
DNA	Deoxyribonucleic Acid
ETV	Endoscopic Third Ventriculostomy
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
NIH	National Institutes of Health
OCD	Obsessive Compulsive Disorder
SNAP	Supplemental Nutrition Assistance Program
SSI	Supplemental Security Income
SUDEP	Sudden Unexpected Death in Epilepsy

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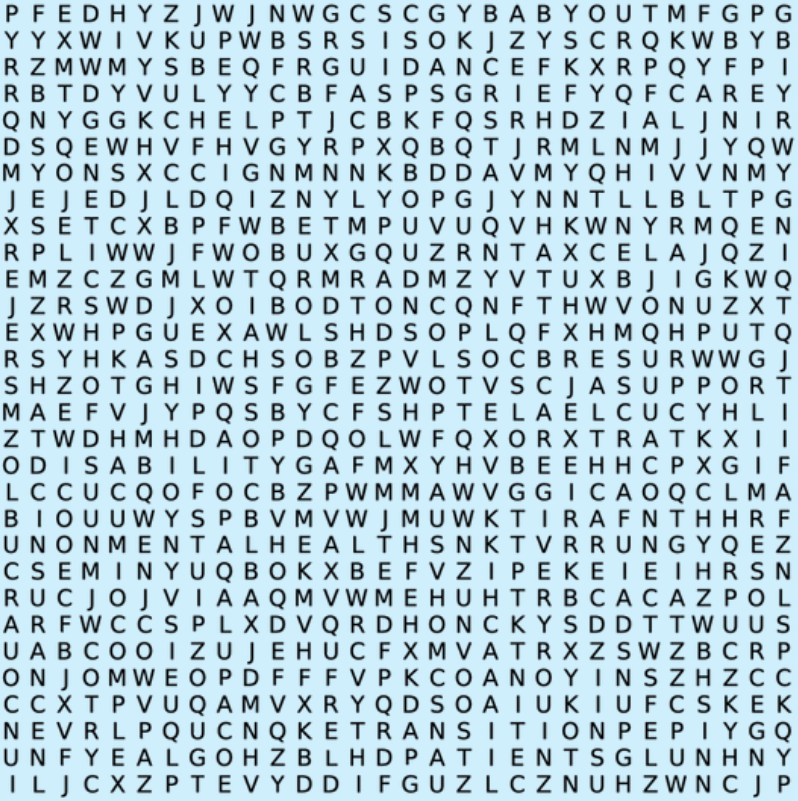


Kori Motes
Marketing & Outreach Coordinator

CNF is a 501(c)3 nonprofit organization committed to serving as a collaborative center of education and support for children and families living with neurologic conditions.

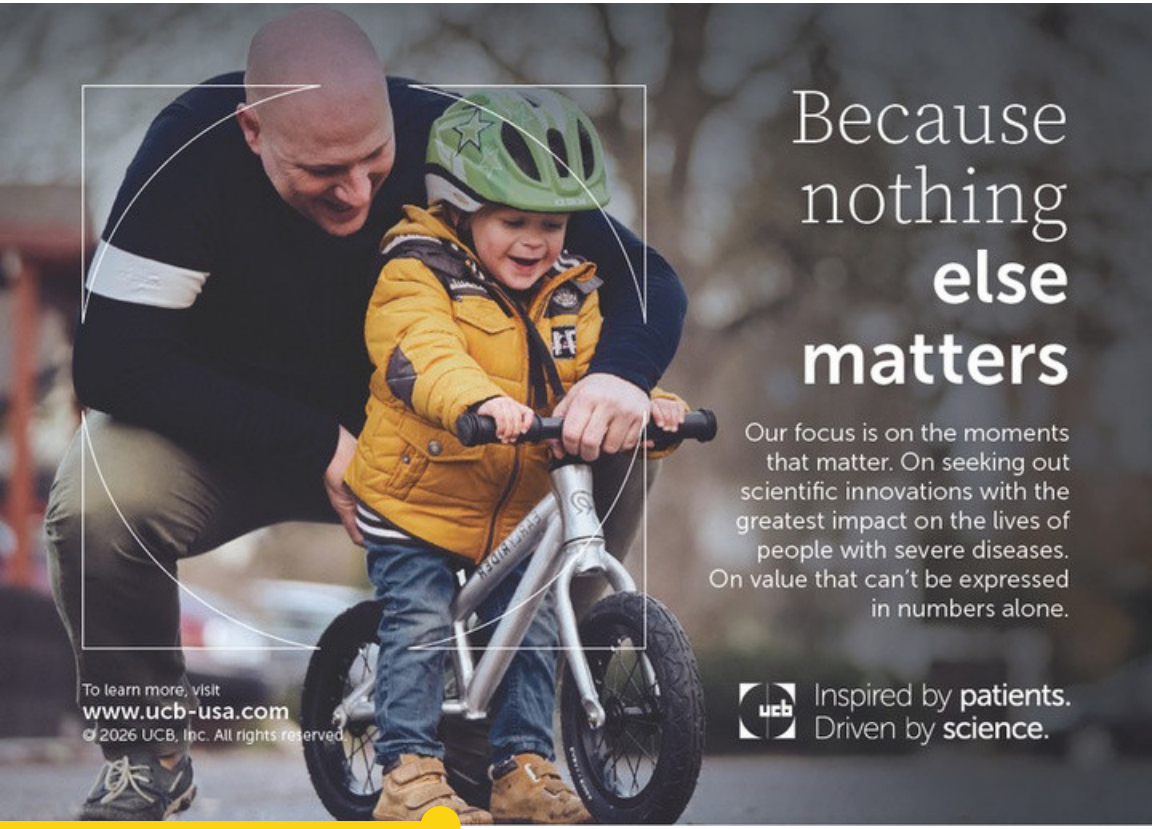
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WORD SEARCH



mentalhealth
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neurology
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insurance
community
resource
love
guidance
support
patient
care
complex
connect
genetic
brain

THOUGHTS & CONNECTIONS


Because nothing else matters
Our focus is on the moments that matter. On seeking out scientific innovations with the greatest impact on the lives of people with severe diseases. On value that can't be expressed in numbers alone.
To learn more, visit
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Driven by science.



A heartfelt thank you to the collaborating sponsors whose support helped make this resource book a reality:









The Child Neurology Foundation exists to expand access and strengthen support for those living with pediatric-onset neurologic conditions, and the families and clinicians who walk alongside them. **We believe every family deserves clear information, and every stage of care deserves the same level of support.**

Know of an organization, program, or service that could be helpful to include?

SUGGEST A RESOURCE!