

# QUICK GUIDE

June 2023

## FINANCIAL AND MEDICAL RESOURCES FOR FAMILIES



Raising a child with complex medical needs can be expensive. You may have to pay for doctor's visits, hospital stays, medications, and more. While you are struggling to care for your child, you should not have to struggle to pay the bills. This guide contains a list of resources to help ease financial strain and improve your family's overall quality of life.

You can find these and many other resources on [The \(Almost\) Everything List](#) which will be updated regularly.

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Before you start:

- Talk to your child's doctor or hospital social worker. The hospital may be able to connect you to charity programs affiliated with the hospital. Perhaps they can provide vouchers for parking or hotel rooms. Your child may qualify for a clinical trial. Most hospitals have a payment plan option if your bills are unmanageable.
- Contact your state or local [social service agencies](#) to find out about helpful programs in your area.
- Look through this excellent resource tool, the Patient Advocate Foundation's [National Financial Resource Directory](#).

*Please note that we are providing this list for informational purposes only. We cannot verify any of these programs; check out any organization carefully before sharing personal information.*

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## **PESA's FINANCIAL RESOURCES:**

The Pediatric Epilepsy Surgery Alliance's [Dreams for Danny Surgical Evaluation Travel Scholarship](#) provides up to \$1,000 in approved travel funds for scholarship awardees to pursue a surgical evaluation at a Level 4 pediatric epilepsy center located in the U.S. at least 50 miles from the child's place of residence. This scholarship aims to alleviate the financial burden associated with travel expenses, enabling families to access specialized evaluation centers.

The [Neurology Social Services Network](#) is a partnership with Child Neurology Foundation and Unite Us. By entering your needs on the intake form, you can be matched with needed resources and services near you (note that services are unavailable in some areas).

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## **EMERGENCY FINANCIAL NEEDS**

[Aubrey's Warriors Foundation](#) is a non-profit organization whose primary goal is to assist families with emergency funding for transportation assistance, medical treatment, therapies, and rehabilitative equipment.

ChildCare.gov [Services for Children with Disabilities](#) provides links to state parent training and information centers (PTI) and community parent resource centers (CPRC) which offer support and training to parents of children with disabilities. These centers can help connect you to local financial and medical resources.

[Community Action Agency](#) staff can connect you with any available resources, financial or otherwise, that are available in your [area](#).

[Help Hope Live](#) is a charitable organization that provides one-on-one fundraising help, a customizable Campaign Page, bill pay support, and additional benefits based on their 501c3 nonprofit status at no charge. Plus the funds go through them, so it doesn't impact benefits. They have helped people pay for a wide range of expenses, including out-of-pocket costs for: medications, durable medical equipment, home health care, wheelchair-accessibility modifications, physical therapy, innovative treatments, medical travel and temporary relocation, even emergency living assistance.

Modest Needs makes “Self-Sufficiency Grants” that assist working individuals and families who live just above the poverty level and may be ineligible for conventional social assistance but are one or two paychecks away from financial catastrophe.

NeedHelpPayingBills.com lists many sources of financial assistance; see their state listings to find out what is available in your state.

The Salvation Army can provide rental and housing assistance, utility help, food, shelter, and more. You can find your nearest Salvation Army center here.

Temporary Assistance for Needy Families (TANF) is temporary financial assistance for low-income parents to care for their children.

The United Way can provide emergency support on many levels. Call 2-1-1 to be connected with services and resources, or visit 211.org.

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## FEDERAL BENEFITS

It's important to know whether your child qualifies for the following federal benefits: Medicaid and CHIP (Children's Health Insurance Program) can help with medical bills if you do not have health insurance.

- Medicaid is a joint federal/state program that helps with medical costs for some people with limited income. If you make too much money to qualify for Medicaid based on your income, your state may disregard your income if you have a child with a qualifying disability. This is called a waiver. Check to see if there is a waiver program in your state. (Some state waiver programs have long waiting lists, so it's essential to get on the waiting list as soon as possible). If you or your child are eligible to receive Medicaid, there may be emergency services available or other supports and services.
- The Children's Health Insurance Program (CHIP) provides health insurance to children whose families cannot afford private insurance but make too much money to qualify for Medicaid. Contact your state Medicaid/CHIP agency or visit InsureKidsNow.gov.

Medicare: many people with disabilities are eligible for Medicare; if your child is over 18 and receives SSI, they can receive Medicare.

Supplemental Security Income (SSI) is available for children with health conditions and disabilities such as cerebral palsy, blindness, deafness, down syndrome, intellectual disability, muscular dystrophy, HIV, infants with low birth weight, or babies/toddlers who are failing to thrive, and more. This program provides a monthly income for the individual.

Social Security Disability Insurance (SSDI): People who become disabled before age 22 can receive Social Security Disability Insurance (SSDI) if:

- one of their parents is currently receiving Social Security benefits or is deceased,
- but worked enough to qualify for Social Security.

These SSDI “child” benefits can continue to be provided throughout adulthood as long as they meet income restrictions.

Supplemental Nutrition Assistance Program (SNAP) provides food benefits for those who meet household eligibility requirements.

Temporary Assistance for Needy Families (TANF) is temporary financial assistance for low-income parents to care for their children.

See also:

- [Government Programs for Children with Disabilities](#), Special Needs Alliance
- [2023 Update: How to Find Public Benefits Programs to Support Autistic Adults in Any State \(PLAN/AANE\)](#)This webinar teaches autistic adults in any state how to find public federal and state support programs that provide free or low-cost services to help them reach their immediate and longer term needs and goals. Eligibility requirements and availability of these services vary significantly by state. This webinar will address accessing support services that are specifically allocated for autistic individuals who do not have a diagnosis of intellectual disability. Download the PDF of the webinar slides [here](#).
- [Benefits For Children With Disabilities](#), Social Security Administration
- [Epilepsy and Social Security Disability Benefits](#) (private attorney website, but has useful information)
- [Federal Grants Wire – federal grants, government grants, and loans](#)
- [Tips on Applying for Social Security with Epilepsy | Disability Benefits Help](#)
- [Social Security Disability Insurance \(SSDI\)](#): People who become disabled before age 22 can receive Social Security Disability Insurance (SSDI) if one of their parents is currently receiving Social Security benefits or is deceased, but worked enough to

qualify for Social Security. These SSDI “child” benefits can continue to be provided throughout adulthood as long as they meet income restrictions.

- [Supplemental Nutrition Assistance Program \(SNAP\)](#) provides food benefits for those who meet household eligibility requirements.
  - [Supplemental Security Income \(SSI\) is available for children](#) with health conditions and disabilities such as cerebral palsy, blindness, deafness, down syndrome, intellectual disability, muscular dystrophy, HIV, infants with low birth weight, or babies/toddlers who are failing to thrive, and more. This program provides a monthly income for the individual.
  - [Supplemental Security Income: What Happens to My SSI When I Turn 18?](#)
  - [Understanding SSI - Living Arrangements](#)
  - [Understanding Supplemental Security Income SSI Eligibility Requirements](#)
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## **GRANTS & SCHOLARSHIPS FOR MEDICAL & THERAPY EXPENSES, EQUIPMENT, AND CAMPS**

*Note that some of these grants are disability-specific.*

[ACT Today!](#) provides grants for children with autism for Applied Behavior Analysis Therapy, speech and occupational therapy, biomedical testing, supplements, assistive technologies (such as iPad or communication apps), safety equipment (safety fencing, GPS tracking devices, or autism service dogs), social skills groups, special needs summer camps, and more.

[Alyssa V. Phillips Foundation](#) provides financial support to those impacted by cerebral palsy to access therapy and equipment.

[ASDF Social Skills Camp](#) partners with autism organizations that offer social skills summer camps and provides scholarships for families who need financial assistance to send their children to camp.

[The Association of Blind Citizens](#) operates an [Assistive Technology Fund](#), which provides funds to cover up to half of the cost of adaptive devices or software.

CARE Family Grant Program helps children with autism or suspected autism by providing autism diagnosis/evaluation, medication, therapy (including speech, OT, and ABA), and autism-focused summer camps. Funds are paid directly to the vendor or service provider to pay for tuition, supplements, medication, medical evaluation, testing, therapies, etc.

The Child Neurology Foundation's Digital Access Program provides laptops and hotspots to families with a child living with a neurologic condition to ensure connectivity and access to essential services. These resources ensure that families can stay connected for various purposes, including telehealth visits, school-related activities, learning games, and more. Parents and caregivers can also use the provided laptops and hotspots for job-related activities, staying in touch with family and friends, and other essential tasks.

Danny Did Foundation provides grants for intervention devices for children and adults with epilepsy.

#### Disabled Children's Fund

Easter Seals provides grant funding for technology programs and services, including assistive technology and augmentative communication systems.

The Epilepsy Foundation offers financial assistance programs to help individuals with epilepsy manage the costs associated with their condition. They provide grants and scholarships for medication and treatment-related expenses and educational scholarships for students with epilepsy. Visit their website at [www.epilepsy.com](http://www.epilepsy.com) to learn more about their available programs and application processes.

Friends of Disabled Adults and Children provides durable medical equipment (DME) such as wheelchairs and hospital beds at little or no cost to individuals with disabilities and their families.

Friends of Man provides children in need with grants for mobility equipment, prosthetics, glasses, dentures, hearing aids, and more.

Fund it Forward provides funding for needed medical devices or equipment (such as augmentative communication devices, bath and feeding chairs, enclosed beds, sensory equipment) for any person who has a diagnosed disability or medical condition.

#### Funding & Grants For Children With Disabilities – United Spinal Association

The Glenn Garcelon Foundation provides need-based grants up to \$1,000 for all patients living with a primary brain tumor.

[Give A Voice program](#) provides communication devices to individuals with autism who are non-verbal or minimally verbal and whose communication challenges put them at increased risk of injury or harm (The National Autism Association)

[Giving Angels Foundation](#) awards grants for life-changing equipment, medical supplies, essential family bills, specialized camps, and therapeutic toys for a child with a physical disability from a lower-income family.

[Grants | especialneeds](#) – EverythingSpecialNeeds.org

[Grant Search Engines](#)

[GRANTS.GOV](#)

[HealthWell Foundation Pediatric Assistance Fund](#) is a non-profit organization that provides financial assistance to individuals who cannot afford their medical expenses. They offer grants to eligible individuals to assist with the cost of epilepsy medications, insurance premiums, and other healthcare-related expenses. This fund assists children 18 years old or younger living with chronic or life-altering conditions that their families are struggling to treat due to cost.

[Help Hope Live](#) is a charitable organization that provides one-on-one fundraising help, a customizable Campaign Page, bill pay support, and additional benefits based on their 501c3 nonprofit status at no charge. Plus the funds go through them, so it doesn't impact benefits. They have helped people pay for a wide range of expenses, including out-of-pocket costs for: medications, durable medical equipment, home health care, wheelchair-accessibility modifications, physical therapy, innovative treatments, medical travel and temporary relocation, even emergency living assistance.

[JoshProvides](#) provides grants to people with epilepsy who need them – for Seizure Monitoring Devices, Transportation, Medication, and Seizure Dogs (limited). Grants are available to people with epilepsy across the entire United States, and applications are reviewed and money is distributed (as available) weekly.

[Kiddie Pool](#)

[Kiddos' Clubhouse Foundation](#)

[Kindred Kids](#) (Wisconsin)

[Laughing At My Nightmare, Inc.](#) works to improve the quality of life for people living with disabilities by providing free adaptive and medical equipment and assistive technology to people in need.



The LGS Foundation's mission is to improve the lives of those affected by Lennox-Gastaut Syndrome (LGS) through research, family support programs, and education. Their Elevate Patient Assistance Program assists individuals with LGS to help pay for durable medical equipment not covered through insurance or other programs. These funds can cover helmets, wheelchairs, orthotics, cooling vests, weighted blankets, adaptive bikes, communication equipment, or seizure alert devices (provided in partnership with Danny Did Foundation).

#### Maggie Welby Foundation

Mission4Maureen assists brain tumor patients and their families by paying bills such as rent, mortgage, utilities, car payments, insurance, taxes, medical bills, credit cards, loans, and more.

Modest Needs Foundation provides emergency grants to those at risk of slipping into poverty and for whom no other source of immediate help is available.

The M.O.R.G.A.N. Project stands for Making Opportunities Reality Granting Assistance Nationwide. Morgan's Legacy Gift provides "tools" not considered medically necessary by insurance and Medicaid but significantly impacts the parent's ability to be the safest caregiver and best advocate for their child that they can be.

The National Autism Association's Give A Voice program provides communication devices to individuals with autism who are non-verbal or minimally verbal and whose communication challenges put them at increased risk of injury or harm.

Oracle Health Foundation provides funding for children whose families can't afford medical care, equipment, vehicle modifications, or displacement related to care.

The Ray Tye Medical Aid Foundation funds in-hospital life-saving medical treatment and surgeries for those who do not have medical insurance or other available financial resources.

Small Steps in Speech provides grants on behalf of children with speech and language disorders for therapies, treatments, communicative devices, and other services to improve their communication skills.

Sunshine Foundation answers the dreams of ill, physically disabled, or abused children. Dream requests may include a family trip to Disney World or other Orlando theme parks, a celebrity meet and greet, a family trip, a shopping spree, or adaptive medical or therapeutic equipment.

The UnitedHealthcare Children's Foundation (UHCCF) provides medical grants to children under age 16 to help them access health-related services not covered (or not fully covered) by their family's commercial health insurance plan. Families can receive up to \$5,000 annually per child (\$10,000 lifetime maximum per child) and do not need to have insurance through UnitedHealthcare to be eligible.

Variety: The Children's Charity has three programs (all grants can go to individual children or the organization providing the service or equipment):

- Variety's Care Program delivers medical equipment and services. Care grants may cover cochlear implants, hearing tests and aids; orthodontics and braces; feeding systems and specialized nutrition; oxygen, suction, and insulin pumps; nebulizers and ventilators; vision care like eye tests and corrective equipment; sensory equipment; prosthetics and orthotics; respite care; electrical stimulation devices and seizure alarms; and more.
- Variety's Freedom Program delivers equipment and services for mobility, independence, and social inclusion. Freedom grants may cover wheelchairs, adaptive bicycles, and trikes; assistance animals; hoists and lifts; modified vehicle access; standing and walking assistance like gait trainers, walkers, standing frames, and positioning systems; specialized car seating, shower, and toilet chairs, and more.
- Variety's Future Program provides communication equipment and services, education, and self-esteem. Future grants may cover communication technology and devices; scholarships in education, the arts, and music or sports; sports wheelchairs; adaptive sports programs; camps and retreats; early literacy programs and learning aids; after school programs; performance groups for disabled children; outings, parties, experiences; and more.

Wheelchairs 4 Kids provides wheelchairs, home & vehicle modifications, and other assistive and therapeutic devices for children with limited mobility.

## **FUNDING FOR SEIZURE DOGS**

- Assistance Dog United Campaign
- BestFriends.org
- Chelsea Hutchison Foundation: Seizure-Response Dogs for those with Epilepsy

## FUNDING TO ATTEND CONFERENCES

- The Chelsea Hutchison Foundation is accepting nominations for all-expense paid trips to Epilepsy Awareness Expo and Day at Disneyland, October 30-November 4, 2023. If you have an immediate family member who has an epilepsy diagnosis and could benefit, please see their [nomination form](#) and read the instructions and qualifiers for submitting your nomination.
  - [Fundraising: Finding the Funds to Attend Parent Conferences](#) (FamilyConnect)
  - The [Hemispherectomy Foundation](#) provides funding for individuals who have had epilepsy surgery to attend the [Pediatric Epilepsy Surgery Alliance's](#) bi-annual [Family Conference](#). Contact [scholarship@hemifoundation.org](mailto:scholarship@hemifoundation.org).
  - [How to Obtain Conference Funding through the IEP Process](#) (PRISMS)
  - [Morgan's Legacy Gift](#) – offers a limited number of families financial assistance to help offset the cost to attend family oriented, disease-specific medical support group conferences for the first time in order to network with other families in the same situation.
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## HEALTH INSURANCE

The [Children's Health Insurance Program \(CHIP\)](#) provides health insurance to children whose families cannot afford private insurance but make too much money to qualify for Medicaid. Contact your [state Medicaid/CHIP agency](#) or visit [InsureKidsNow.gov](http://InsureKidsNow.gov).

[Kidswaivers.org](http://Kidswaivers.org) a compilation of information about Medicaid waivers, Katie Beckett or TEFRA programs, and other programs for children with disabilities or medical needs.

[Medicaid](#) and CHIP (Children's Health Insurance Program) can help with medical bills if you do not have health insurance.

[Medicaid](#) is a joint federal/state program that helps with medical costs for some people with limited income. If you make too much money to qualify for Medicaid based on your income, your state may disregard your income if you have a child with a qualifying disability. This is called a waiver.

[Medicaidwaiver.org](http://Medicaidwaiver.org): Check to see if there is a [waiver program](#) in your state. (Some state waiver programs have long waiting lists, so it's essential to get on the waiting list as soon

as possible). If you or your child are eligible to receive Medicaid, there may be emergency services available or other supports and services.

Medicare: many people with disabilities are eligible for Medicare; if your child is over 18 and receives SSI, they can receive Medicare.

Patient Advocate Foundation “We provide patient services, eliminating obstacles in access to quality healthcare.”

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## **PATIENT ASSISTANCE PROGRAMS**

Patient Assistance Programs offer certain drugs at a discount or for free to people who cannot afford them. The program can deliver medicines to people’s homes, doctor’s offices, or pharmacies. All major drug companies have these programs. You may have to apply at each company. There are nonprofit patient groups to help you learn how to get discounted medication or other help.

On their websites, you can:

- check if you can get help with your child’s medication
- find out which company makes the drug
- print applications and instructions
- find forums for patient support

Nonprofit and government groups can help you understand Patient Assistance Programs. Here are some resources to help you get started:

- [Epilepsy Foundation’s 24/7 Helpline](#)
- [Epilepsy Foundation’s Patient Assistance page](#)
- [Epilepsy Foundation’s Prescription Drug Assistance Programs](#)
- [Epilepsy Foundation’s Resource page](#)
- [FamilyWize Community Service Partnership](#)
- [The Medicare Prescription Drug Assistance Programs](#)
- [Medicine Assistance Tool \(MAT\)](#)
- [NeedyMeds.Org](#) - an online resource that provides information on various patient assistance programs, discount coupons, and resources to help individuals afford

their medications. They offer a comprehensive database of available programs and guide eligibility criteria and application processes.

- [Partnership For Prescription Assistance](#)
  - [PatientAssistance.Com](#)
  - [Patient Assistance Programs \(The Brain Recovery Project/Pediatric Epilepsy Surgery Alliance\)](#)
  - [Pfizer RxPathways](#)
  - [RxAssist](#)
  - [RxHope](#)
  - [Rx Outreach](#)
  - [Veterans Affairs Veteran's Benefits](#)
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## RESPIRE SUPPORTS & WISH ORGANIZATIONS

[ARCH National Respite Network and Resource Center](#) helps families locate respite and crisis care services in their communities.

[Believe In Tomorrow Children's Foundation](#) provides hospital and respite housing services to critically ill children and their families.

[Children's Wish Foundation](#) allows families a respite from hospital or treatment life.

[Give Kids The World Village \(Florida\)](#) –The process to be granted a vacation to Give Kids The World Village begins with a [wish granting organization](#).

[Kids Wish Network](#)

[Make-A-Wish Foundation](#)

[Ronald McDonald House Charities](#) is a network of local Chapters that has been making children happier and healthier by keeping families close during hospital stays.

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## TRANSPORTATION AND MEDICAL TRAVEL HELP

The **Pediatric Epilepsy Surgery Alliance's** [Dreams for Danny Surgical Evaluation Travel Scholarship](#) provides up to \$1,000 in approved travel funds for scholarship awardees to pursue a surgical evaluation at a Level 4 pediatric epilepsy center located in the U.S. at least 50 miles from the child's place of residence. This scholarship aims to alleviate the financial burden associated with travel expenses, enabling families to access specialized evaluation centers.

### [Angel Flights](#)

[Air Care Alliance](#) is a Volunteer Pilot Organization (VPO) that helps patients in need access distant medical care or supportive services by arranging free flights through volunteer pilots who fly their private aircraft and pay for the flight expenses.

[Air Charity Network](#) provides free air transportation to specialized health care facilities or distant destinations due to family, community, or national crisis. Air Charity Network also coordinates flights to fly organ transplant candidates, people involved in clinical trials, chemotherapy or other repetitive treatment, victims of abuse seeking relocation, families receiving help from Ronald McDonald Houses, Shriners Hospitals, or other charities, disabled or sick children to special summer camp programs, and for many other humanitarian reasons.

[Children's Flight of Hope \(CFOH\)](#) provides air transportation for young patients and their families who need access to specialized medical care that might otherwise be out of reach. Often, the organization will reserve tickets on commercial airlines for the child and one adult companion to travel for treatment. On limited occasions, their resources allow for private flights for a child who is medically unable to travel on a commercial airline.

[Footprints in the Sky](#) provides flights for patients to medical facilities throughout the United States for routine, critical or life-saving care and who cannot use commercial airline service or other means of transportation because of financial constraints and medical issues.

[Grants for Travel Expenses](#) (Kaufman Children's Center)

[Help Hope Live](#) is a charitable organization that provides one-on-one fundraising help, a customizable Campaign Page, bill pay support, and additional benefits based on their 501c3 nonprofit status at no charge. Plus the funds go through them, so it doesn't impact benefits. They have helped people pay for a wide range of expenses, including out-of-pocket costs for: medications, durable medical equipment, home health care, wheelchair-accessibility modifications, physical therapy, innovative treatments, medical travel and temporary relocation, even emergency living assistance.

[Mercy Medical Angels](#) provides medical transportation to vital healthcare via assistance for transportation on the ground (with gas cards, bus, or train tickets) or in the air (with flights flown by volunteer pilots or on commercial airlines).

[Miracle Flights](#) provides free flights to those in need of life-changing medical care not found in their local communities.

[Operation Liftoff](#) provides air transportation for children with a life-threatening illness for a treatment trip.

[Ride Share for People with Epilepsy](#) – people with epilepsy and their caregivers are eligible to receive a \$50 Uber ride share voucher (Epilepsy Foundation)

[Southwest Airlines Medical Transportation Grant Program](#) provides complimentary roundtrip tickets to participating nonprofit hospitals and medical transportation organizations.

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## ADDITIONAL RESOURCES

- [11 Grants for Parents with a Disabled Child](#)
- [22 free things, services, and grants for kids with special needs](#)
- [Autism Grants for Families](#), Autism Speaks
- [Benefits For Children With Disabilities](#), Social Security Administration
- [The Complete List of Free Things and Grants for Kids with Special Needs](#)
- [Federal Grants Wire - federal grants, government grants, and loans.](#)
- [Financial Assistance Resources](#), Autism Speaks
- [Financial Help for Special Needs Children & Their Families](#), Debt.org
- [Financial Management During Crisis \(for Parents\)](#) - Nemours KidsHealth
- [FREE Stuff for Kids with Disabilities \(or Special Needs\)](#)
- [Funding & Grants For Children With Disabilities - United Spinal Association](#)
- [Grants | especialneeds](#) - EverythingSpecialNeeds.org
- [Grants for Travel Expenses](#)
- [Grant Search Engines](#)
- [GRANTS.GOV](#)
- [Government Programs for Children with Disabilities](#), Special Needs Alliance
- [Health Insurance Marketplace](#) offers health, vision, and dental insurance for you and your family.
- [HealthCare.gov](#) helps you find insurance options, compare care, learn about preventive services, and more.
- [Help for Special Needs Families: Grants, Programs and Services](#)
- [InsureKidsNow.gov](#)
- The Patient Advocate Foundation [National Financial Resource Directory](#) provides national and regional resources dedicated to improve access to quality care and decrease the financial burden of medical treatment.
- USA.gov maintains information on a variety of government and other assistance:
  - [Government Benefits, Grants, and Loans](#)
  - [Financial Assistance and Support Services for People with Disabilities](#)

*Questions? Corrections? Suggestions?*

*Email us at [info@epilepsysurgeryalliance.org](mailto:info@epilepsysurgeryalliance.org)*





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