

# GENERAL RESOURCES - NATIONAL

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**GENERAL RESOURCES - NATIONAL**

Note: the following resources are listed in alphabetical order and not by category.

**4 Paws for Ability**

Their “mission is to place quality service dogs with children with disabilities and veterans who have lost use of limbs or hearing; help with animal rescue, and educate the public regarding use of service dogs in public places.”

Address: 253 Dayton Ave., Xenia, Ohio 45385

Email: [karen@4pawsforability.org](mailto:karen@4pawsforability.org)

Phone: 937-374-0385

Website: [www.4pawsforability.org](http://www.4pawsforability.org)

**Aaron's Tracheostomy Page**

Information on the nuances of pediatric trach care that may be helpful for many disabilities

Email: [tracheostomy@bissells.com](mailto:tracheostomy@bissells.com)

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UMDF.

Website: [www.tracheostomy.com](http://www.tracheostomy.com)

### **Adolescent Health Transition Project**

A resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities” as they transition from pediatric to adult health care.

Phone: 206-685.-350

Website: [www.depts.washington.edu/healthtr](http://www.depts.washington.edu/healthtr)

### **AdvoConnection**

Find patient advocates, health navigators and coaches, care and case managers, insurance navigators, and other professionals in your state. Some may charge a fee for services.

Email: [info@aphadvocates.org](mailto:info@aphadvocates.org)

Website: [www.advoconnection.com](http://www.advoconnection.com)

### **Allsup Medicare Advisor**

Whether you’re enrolling for the first time or reconsidering your current Medicare plan, Allsup Medicare Advisor offers personal assistance to help you find the plan that provides the coverage you need.

Phone: 866-521-7655

Website: [www.truehelp.com/healthcare-assistance/healthcare-assistance-for-individuals/medicare-advisor](http://www.truehelp.com/healthcare-assistance/healthcare-assistance-for-individuals/medicare-advisor)

### **Allsup SSDI**

Provides free online Social Security Disability Insurance assessment with empower® by Allsup and SSDI representation.

Website: [www.allsup.com/a-better-way-to-apply-for-ssdi](http://www.allsup.com/a-better-way-to-apply-for-ssdi)

### **Alzheimer’s Association**

Works on a global, national and local level to enhance care and support for all those affected by Alzheimer’s and related dementias. Per UMDF regional coordinator, Margaret Moore, they are willing to offer support to patients with dementias related to mitochondrial disease.

Phone 800-272-3900 / tdd: 866-403-3073

Website: [www.alz.org](http://www.alz.org)

### **American Association on Health and Disability**

AAHD is dedicated to the advancement of theory, knowledge and practice in the prevention of secondary disabling conditions and promotion of health and wellness for people with disabilities. Among other programs, includes emergency preparedness information by state, and college scholarship program.

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Phone: 301-545-6140  
Website: [www.aahd.us](http://www.aahd.us)

### **American Cancer Society**

At the American Cancer Society, we're on a mission to free the world from cancer. Until we do, we'll be funding and conducting research, sharing expert information, supporting patients, and spreading the word about prevention. All so you can live longer — and better.

Phone: 800-227-2345  
Website: [www.cancer.org](http://www.cancer.org)

### **Association of Gastrointestinal Motility Disorders, Inc (AGMD)**

Education, information, and support for patients suffering from digestive motility disorders. Includes cyclic vomiting and pseudo-obstruction disorders.

Email: [digestive.motility@gmail.com](mailto:digestive.motility@gmail.com)  
Phone: 781-275-1300  
Website: [www.agmd-gimotility.org](http://www.agmd-gimotility.org)

### **The Arc**

The Arc is the world's largest community based organization of and for people with intellectual and developmental disabilities. Works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community.

Phone: 800-433-5255  
Website: [www.thearc.org](http://www.thearc.org)

### **Aubrey Rose Foundation**

Our mission is to help families caring for children with life threatening illnesses with our focus being on the family unit. We strive to lift families from life's complexities during this difficult time by providing emotional and financial support. Helps families with financial need because of medical expenses of their children. Offers some educational scholarships to private high schools in Cincinnati/Northern KY/Southeast IN areas based on how children have made an impact on the people around them.

Email: [mnancy@aubreyrose.org](mailto:mnancy@aubreyrose.org)  
Phone: 513-265-5801  
Website: [www.aubreyrose.org](http://www.aubreyrose.org)

### **Baby's First Test**

Newborn screening education center for families and providers. This site provides information and resources about screening at the local, state, and national levels.

Website: [www.babysfirsttest.org](http://www.babysfirsttest.org)

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### **Baby Signs Program**

A program designed for early communication with babies before they can talk. Uses simple gestures to communicate. Programs in various locations and info on their website.

Phone: 916-606-6676

Website: [www.babysignstoo.com](http://www.babysignstoo.com)

### **Band-Aides & Blackboards**

A site about growing up with medical problems designed and arranged by Joan Fleitas, Ed.D., RN of Lehman College. Interactive sections for kids, teens, and adults (including teachers).

Website: [www.lehman.cuny.edu/faculty/jfleitas/bandaides/](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/)

### **Bobby's Books**

A program that uses books to help children and adults deal with difficult issues. Using children's literature as a springboard for conversations will give kids the chance to express their feelings and tell their own stories.

Email: [jtaylor@leadingageohio.org](mailto:jtaylor@leadingageohio.org)

Phone: 614-545-9028

Website: [www.bobbysbooks.org](http://www.bobbysbooks.org)

### **Bookshare**

Children with qualifying disabilities can have free access to over 57,000 talking e-books.

Phone: 650-352-0198

Website: [www.bookshare.org](http://www.bookshare.org)

### **Brave Kids**

Directory of medical services and resources for children with special needs. Includes special lodging information in various locations for families with a hospitalized child.

Website: [www.bravekids.org](http://www.bravekids.org)

### **Bridges4Kids**

Where to find help for a child anywhere in the U. S. Includes state and local agencies, and a variety of programs.

Email: [info@bridges4kids.org](mailto:info@bridges4kids.org)

Website: [www.bridges4kids.org](http://www.bridges4kids.org)

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### **Camphill Communities**

Residential facilities across North America that include “providing education, advocacy, therapeutic care and other services to support people with disabilities and helping them participate fully in the world as contributing citizens.”

Email: [erin@camphill.org](mailto:erin@camphill.org)

Phone: 484-228-1298

Website: [www.camphill.org](http://www.camphill.org)

### **Canine Companions for Independence**

CCI is a non-profit organization that places service, specialty, signal and social dogs into service so that a person (5 and older) with a disability can live independently.

Phone: 800-572-BARK (2275)

Website: [www.cci.org](http://www.cci.org)

### **Care.com**

Find a baby-sitter/nanny in your local area who is experienced with special needs children. Prescreened, detailed profiles provide experience, availability and specific services information.

Website: [www.care.com](http://www.care.com)

### **Caregiver Action Network**

Caregiver Action Network (CAN) is the nation’s leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age.

Email: [info@caregiveraction.org](mailto:info@caregiveraction.org)

Phone: 202-454-3970

Website: [www.caregiveraction.org](http://www.caregiveraction.org)

### **CaringBridge**

Free personalized websites that support and connect loved ones during critical illness, treatment and recovery.

Address: 2750 Blue Water Road, Suite 275 Eagan, MN 55121

Phone: 651-789-2300 - Customer Care

Phone: 651-452-7940

Website: [www.caringbridge.org](http://www.caringbridge.org)

### **Catalyst Center**

Provides information to help improve the coverage and financing of care for children and youth with special health care needs. Includes state-by-state information.

Email: [cyshcn@bu.edu](mailto:cyshcn@bu.edu)

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Phone: 617-638-1930

Website: [www.cahpp.org/project/the-catalyst-center](http://www.cahpp.org/project/the-catalyst-center)

### **Center for Parent Information & Resources**

Your central “Hub” of information and products created for the network of Parent Centers serving families of children with disabilities. All the materials found on the CPIR Hub have been created and archived for Parent Centers around the country to help them provide support and services to the families they serve

Email: [malizo@spannj.org](mailto:malizo@spannj.org)

Phone: 973-642-8100

Website: [www.parentcenterhub.org](http://www.parentcenterhub.org)

### **Challenged America Foundation**

The goal of the My Gym Challenged America Foundation is to provide equipment and services that enhance the quality of life and improve the physical, cognitive, emotional and social development of children who are physically or developmentally challenged and those coping with chronic illness.

Phone: 818-907-6966

Website: [www.challengedamerica.com](http://www.challengedamerica.com)

### **Cody’s Wheels of Hope**

Provides bicycles and riding toys for children with life-threatening diseases.

Phone: 814-460-8228

Website: [www.cwoh.org](http://www.cwoh.org)

### **Compassionate Friends**

National, independent, non-profit, self-help support organization offering friendship and understanding to families grieving the death of a child of any age, from any cause. There are no membership fees or dues, and bereaved family members are welcome.

Address: PO Box 3696, Oak Brook, IL 60522

Phone: 877-969-0010

Website: [www.compassionatefriends.org](http://www.compassionatefriends.org)

### **Complex Child e-magazine**

Complex Child is a monthly online magazine written primarily by parents of children with special healthcare needs and disabilities. It is intended to provide medical information, along with personal experiences, in simple language that other parents can understand. Articles are on a wide variety of topics ranging from basic information on medical conditions and treatments to advice on how to beat insurance company denials. Sources of information are generally cited in the articles.

Website: [www.complexchild.com](http://www.complexchild.com)

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### **Coolture**

Cooling vest. The Coolture garment is constructed of premium athletic fabrics that are designed to look good, feel good, and perform well.

Email: [luanne@coolture.net](mailto:luanne@coolture.net)

Phone: 716-281-0080

Website: [www.coolture.net](http://www.coolture.net)

### **Council of Parent Attorneys and Advocates**

COPAA's mission is to be a national voice for special education rights and to promote excellence in advocacy. Our primary goal is to secure high quality educational services for children with disabilities.

Address: PO Box 6767 Towson, MD 21285

Phone: 844-426-7224

Website: [www.copaa.org](http://www.copaa.org)

### **Dakota Medical Foundation**

Dedicated to measurably improving health and access to healthcare services, with a special emphasis on children.” While their grant programs are specific to residents of Cass County, ND and Clay County, MN, their website also provides information and step-by-step guidance for individuals who want to do a fundraiser. The mission of their Lend A Hand program is “to support and improve efforts to raise funds for individuals and families experiencing a medical crisis.

Phone: 701-271-0263

Website: [www.dakmed.org](http://www.dakmed.org)

### **Dysautonomia Information Network (DINET)**

DINET provides information and personal stories on several types of dysautonomia

Website: [www.dinet.org](http://www.dinet.org)

### **Easter Seals**

Provides services to children and adults with disabilities and other special needs, and support to their families. Includes adult services, childcare, and medical help for those who qualify. Over 450 local service centers.

Address: 141 W Jackson Blvd., 1400A Chicago, IL 60604

Email: [info@easterseals.com](mailto:info@easterseals.com)

Phone: 800-221-6827

Website: [www.easterseals.com](http://www.easterseals.com)

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### **Elk's Clubs**

Provides a variety of programs which vary from state to state. Each state has one major program. Included among the programs are in-home medical care, free dental clinic, camps, alternative schools, and many others. Search by state.

Address: BPO Elks of the USA 750 N. Lakeview Avenue Chicago, IL 60614-1889

Phone: 773-755-4700

Website: [www.elks.org](http://www.elks.org)

### **Epilepsy Foundation**

To work for children and adults affected by seizures through research, education, advocacy and service.

Address: 8301 Professional Place East, Suite 200 Landover, MD 20785-2353

Phone: 301-459-3700

Website: [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

### **Exceptional Parent: A Magazine**

Magazine that provides information, support, ideas, encouragement, and outreach for parents and families of children with disabilities and the professionals who work with them.

Website: [www.eparent.com](http://www.eparent.com)

### **Families USA**

Families USA, a leading national voice for health care consumers, is dedicated to the achievement of high-quality, affordable health care and improved health for all. We advance our mission through public policy analysis, advocacy, and collaboration with partners to promote a patient-and community-centered health system.

Address: 1225 New York Avenue NW Suite 800 Washington, DC 20005

Email: [info@familiesusa.org](mailto:info@familiesusa.org)

Phone: 202-628-3030

Website: [www.familiesusa.org](http://www.familiesusa.org)

### **Family Voices**

Aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care. Has state-by-state resources and health care information.

Address: P.O. Box 37188 Albuquerque, NM 8717

Phone: 505-872-4774 or 888-835-5669

Website: [www.familyvoices.org](http://www.familyvoices.org)

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### **First Hand Foundation**

First Hand Foundation is a public 501(c)(3) organization that provides funding for individual children—both domestically and globally—who need assistance with clinical necessities (such as surgery, medication and therapy), medical equipment and travel related to care.

Address: 2800 Rockcreek Parkway Kansas City, MO 64117

Email: [myfirsthand@cerner.com](mailto:myfirsthand@cerner.com)

Phone: 816- 201-1569

Website: [www.firsthandfoundation.org](http://www.firsthandfoundation.org)

### **FodSupport.org**

Resources and support for those with Fatty Oxidation Disorders. Includes nutritional and bereavement resources.

Address: PO Box 54 Okemos, MI 48805-0054

Email: [deb@fodsupport.org](mailto:deb@fodsupport.org)

Phone: 517-381-1940

Website: [www.fodsupport.org](http://www.fodsupport.org)

### **Genetic Alliance**

Genetic Alliance is an international coalition of individuals, professionals and genetic support organizations that work together to enhance the lives of those impacted by genetic conditions. A directory of support groups for a large number of disorders is available. Genetic Alliance has resources in areas including bioethics, disability, genetics, government agencies, grief and loss, insurance, public policy and publishes Also has “The [Advocacy ATLAS](#): Accessible Tools for Leadership and Advocacy Success, features over 250 tools and resources to help new and experienced advocates communicate their needs around services, support, and access.”

Email: [info@geneticalliance.org](mailto:info@geneticalliance.org)

Phone: 202-966-5557

Website: [www.geneticalliance.org](http://www.geneticalliance.org)

### **Global Genes**

Global Genes is one of the leading rare disease patient advocacy organizations in the world. The non-profit organization promotes the needs of the rare disease community under a unifying symbol of hope – the Blue Denim Genes Ribbon

Phone: 949-248-RARE (7273)

Website: [www.globalgenes.org](http://www.globalgenes.org)

### **Got Transition?**

National Health Care Transition Center. A national resource for health care professionals, families, youth, and state policy makers focusing on a young adult's transition from pediatric to adult health care. This site serves as the basis for an

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information exchange about health care transition, particularly as pertaining to youth with special health care needs.

Email: [info@GotTransition.org](mailto:info@GotTransition.org)

Phone: 202-223-1500

Website: [www.gottransition.org](http://www.gottransition.org)

### **GovBenefits.gov**

Locate federal and state benefits you might be eligible for.

Phone: 1-800-FED-INFO (1-800-333-4636),

Website: [www.benefits.gov](http://www.benefits.gov)

### **Gradient Gives Back Foundation**

A Minnesota-based non-profit organization that supports the Gradient Gives Back Community Outreach Program and devotes its resources to assisting Americans. The Foundation strives to help American families who are at risk of losing their homes. It also seeks to unite communities by inspiring Americans for the purpose of charitable giving.

Phone: 855-371-0328

Email: [info@gradientgivesback.com](mailto:info@gradientgivesback.com)

Website: [www.gradientgivesback.com](http://www.gradientgivesback.com)

### **Helping from Heaven, the Lexi Kazian Foundation**

Provides “education, therapy and playground equipment, therapy toys, resources and scholarships for families and therapists in need of financial assistance and/or community support.” Includes an Equipment Lending Library and financial support to families who have children with special needs.

Website: [www.helpingfromheaven.org](http://www.helpingfromheaven.org)

### **Hope, Inc.**

Provides mobility, educational and recreational opportunities for children who are physically and mentally challenged and their families.

Phone: 701-866-9002

Email: [adair@hopeinc.org](mailto:adair@hopeinc.org)

Website: [www.hopeinonline.org](http://www.hopeinonline.org)

### **Independent Living USA**

Non-residential centers across the country that assist individuals with disabilities to achieve their maximum potential within their families and communities.

Website: [www.ilusa.com/links/03-08centers1.htm#AZ](http://www.ilusa.com/links/03-08centers1.htm#AZ)

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### **Insure Kids Now, US Department of Health and Human Services**

Free or low-cost health insurance in each state for low-income families

Phone: 1-877-KIDS-NOW (1-877-543-7669)

Website: [www.insurekidsnow.gov](http://www.insurekidsnow.gov)

### **The International Foundation for Optic Nerve Disease**

Includes information on Leber's Hereditary Optic Neuropathy (LHON)

Email: [IFOND@aol.com](mailto:IFOND@aol.com)

Phone: 845-534-8606

Website: [www.ifond.org](http://www.ifond.org)

### **Invisible Disabilities Association**

Encourages, educates and connects people and organizations touched by illness, pain and disability around the globe. IDA's website, publications, seminars and awareness address all debilitating conditions that are often misunderstood. IDA also offers many resources to information about various illnesses, help with costs of medications, disability benefits and more.

Website: [www.invisibledisabilities.org](http://www.invisibledisabilities.org)

### **Jennifer Jaff Center**

The Jennifer Jaff Center, a respected national nonprofit for those suffering from chronic illness, has partnered with Patient Advocate Foundation to ensure its patient-focused services continue to be available to help those in need. The Jennifer Jaff Center and PAF have partnered to make available the Jennifer Jaff CareLine to assist patients diagnosed with Inflammatory Bowel Disease (IBD)

Phone: 844-244-1312

Website: [www.jenniferjaff.pafcareline.org](http://www.jenniferjaff.pafcareline.org)

### **Jonah and the Whale Foundation**

Educates parents in advocacy, and communicating with medical personnel. Also provides educational, medical, and support resources.

Website: [www.jtwf.org](http://www.jtwf.org)

### **Kids' Quest**

Created by the Center for Disease Control and Prevention, a government agency. This website helps kids learn about various disabilities and health.

Phone: 800-CDC-INFO (800-232-4636), TTY: 888-232-6348

Website: [www.cdc.gov/ncbddd/kids](http://www.cdc.gov/ncbddd/kids)

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### **Lighthouse, International**

“Dedicated to fighting vision loss through prevention, treatment, and empowerment.” Includes services, education, research, and advocacy. Has college scholarship program.

Phone: 800-284-4422 / TTY 711

Website: [www.lighthouseguild.org](http://www.lighthouseguild.org)

### **Lindsay Foundation**

Financial assistance for equipment, therapies and supplies not covered by insurance

Website: [www.facebook.com/TheLindsayFoundation](http://www.facebook.com/TheLindsayFoundation)

### **Lotsa Helping Hands**

Lotsa Helping Hands is a private, web-based caregiving coordination service that allows family, friends, neighbors, and colleagues to create a community to assist a family caregiver with the daily tasks that become a challenge during times of medical crisis, caregiver exhaustion, or when caring for an elderly parent.

E-mail: [info+contactus@lotsahelpinghands.com](mailto:info+contactus@lotsahelpinghands.com)

Website: [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

### **March of Dimes**

Works to improve the health of babies by preventing birth defects and infant mortality through programs of research, community services, education, and advocacy.

Website: [www.marchofdimes.com](http://www.marchofdimes.com)

### **Matthew Dudgeon Memorial Fund**

Raises monies and disburses funds to families caring for terminally or chronically ill children.

Website: [www.themattyfund.org](http://www.themattyfund.org)

### **Medicaid**

Medicaid in the United States is a joint federal and state program that helps with medical costs for some people with limited income and resources. Medicaid also offers benefits not normally covered by Medicare, like nursing home care and personal care services.

Phone: Toll-Free: 877-267-2323

Phone: TTY Toll-Free: 866-226-1819

Website: [www.medicaid.gov](http://www.medicaid.gov)

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## **Medicaid Appeals Process, published by the Kaiser Family Foundation – A Guide**

Website: [www.kff.org/medicaid/issue-brief/a-guide-to-the-medicaid-appeals-process](http://www.kff.org/medicaid/issue-brief/a-guide-to-the-medicaid-appeals-process)

### **Medicare**

It provides health insurance for Americans aged 65 and older who have worked and paid into the system through the payroll tax. It also provides health insurance to younger people with some disability status as determined by the Social Security Administration, as well as people with end stage renal disease and amyotrophic lateral sclerosis.

Phone: 800-MEDICARE (1-800-633-4227)

Website: [www.medicare.gov](http://www.medicare.gov)

### **Michigan State University List of Grants for NonProfits**

A compilation of web pages and books of potential interest to nonprofit organizations seeking funding opportunities related to health. It also contains information about funders who provide assistance to individuals coping with catastrophic health problems.

Phone: 800-500-1554

Website: [www.staff.lib.msu.edu/harris23/grants/2health.htm](http://www.staff.lib.msu.edu/harris23/grants/2health.htm)

### **Modest Needs Foundation**

Provides modest financial assistance to low-income individuals/families for a specific need. We have designed our programs to help those who work hard and have nowhere else to go for assistance, as well as those who give back to our communities and country such as public school teachers, first responders, veterans returning from service abroad and active duty military members. Our aim is to support those who don't generally qualify to receive assistance from conventional agencies so that they don't find themselves losing everything because of a short-term crisis.

Phone: 844-667-3776

Website: [www.modestneeds.org](http://www.modestneeds.org)

### **Mommies of Miracles**

An "international peer-driven support group of mothers who have children of any age (infant-adult) with complex medical issues, rare or undiagnosed conditions, and/or developmental disabilities." Their mission "is to eliminate the isolation mothers of exceptional needs children experience on a daily basis by providing an extended network of resources, products & services, grief support, family matching, and hope."

Website: [www.mommiesofmiracles.com](http://www.mommiesofmiracles.com)

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### **M.O.R.G.A.N. Project**

Promotes “awareness and support of parents caring for their special-needs children, and to enhance the quality of life for these special families.” Includes small equipment grants and first-time attendance grants for related conferences.

Phone: 321-506-2707

Website: [www.themorganproject.org](http://www.themorganproject.org)

### **MUMS National Parent-to-Parent Network**

Mothers United for Moral Support is no longer a Parent-to-Parent matching organization, but will continue to provide information and resources.

MUMS will also continue to provide a listing of Hyperbaric Oxygen Therapy clinics that will treat off label conditions.

Website: [www.mums-network.org](http://www.mums-network.org)

### **Muscular Dystrophy Association**

MDA is leading the fight to free individuals — and the families who love them — from the harm of muscular dystrophy, ALS and related muscle-debilitating diseases that take away physical strength, independence and life. We use our collective strength to help kids and adults live longer and grow stronger by finding research breakthroughs across diseases, caring for individuals from day one and empowering families with services and support in hometowns across America.

Email: [mda@mdausa.org](mailto:mda@mdausa.org)

Phone: 800-572-1717

Website: [www.mdausa.org](http://www.mdausa.org)

### **Muscular Dystrophy Family and Friends Foundation (MDFF)**

The Foundation has only one mission; to provide adaptive equipment and emotional support to individuals and families affected by one of over forty neuromuscular diseases covered under our program. Some of the adaptive equipment provided by MDFF are wheelchairs, hospital beds, van lifts, ramps for family homes, shower chairs, bath chairs, lift systems, breathing machines, clinic services, communication devices, braces and social outings. Support is available 24/7. MDFF provides service to children and adults regardless of race or income level.

Phone: 317-615-9140

Website: [www.mdff.org](http://www.mdff.org)

### **National Association of Hospital Hospitality Houses**

The Healthcare Hospitality Network, Inc. (HHN) is a nationwide professional association of nearly 200 unique, nonprofit organizations that provide lodging and support services to patients, families and their loved ones who are receiving medical treatment far from their home communities.

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Phone: 800-542-9730  
Website: [www.hhnetwork.org](http://www.hhnetwork.org)

**National Association of Insurance Commissioners (NAIC)**

Locate insurance commissioners for all 50 states. Mission includes protecting the public interest and facilitating the “fair and equitable treatment of insurance consumers.”

Email: [help@naic.org](mailto:help@naic.org)  
Phone: 816-783-8500  
Website: [www.naic.org](http://www.naic.org)

**National Family Caregivers Association**

Caregiver Action Network (CAN) is the nation’s leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer’s disease.

Email: [info@caregiveraction.org](mailto:info@caregiveraction.org)  
Phone: 202-454-3970  
Web: [www.nfcacares.org](http://www.nfcacares.org)

**National Hospice and Palliative Care Organization/National Hospice Foundation**

Provides free referrals to the public for hospice listings across the United States and internationally. Distributes free packets of general information describing hospice services and the Medicare Hospice Benefit.

Phone: 703-837-1500  
Website: [www.nhpc.org](http://www.nhpc.org)

**The National Inclusion Project**

The National Inclusion Project serves to bridge the gap that exists between young people with disabilities and the world around them. Supports “communities and programs in creating awareness and opportunities for full inclusion...” Provides assistance and grants for inclusion, education, programs, training, and symposia.

Email: [contactus@inclusionproject.org](mailto:contactus@inclusionproject.org)  
Phone: 919-314-5540  
Website: [www.inclusionproject.org](http://www.inclusionproject.org)

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### **National Institutes of Health (NIH) Office of Rare Diseases (ORD)**

GARD is a program of the National Center for Advancing Translational Sciences (NCATS) to provide access to current, reliable, and easy to understand information about rare or genetic diseases in English or Spanish.

Phone: 888-205-2311 / TTY 888-205-3223

Website: [www.rarediseases.info.nih.gov](http://www.rarediseases.info.nih.gov)

### **National Organization for Rare Diseases (NORD)**

Is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 260 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. Mitochondrial disease information. Resource guide & medication assistance program.

Phone: 800-999-6673

Website: [www.rarediseases.org](http://www.rarediseases.org)

### **Need Help Paying Bills**

Find information on assistance programs, charity organizations, and other resources that will provide you with help paying your bills, mortgage and debt, show you how to save money, as well as provide some tips and ways to pay bills when money is tight.

Website: [www.needhelppayingbills.com](http://www.needhelppayingbills.com)

### **Newborn Screening resources and sites**

- Baby's First Test  
Website: [www.BabysFirstTest.org](http://www.BabysFirstTest.org)
- StepOne Newborn Screening  
Website: [www.perkinelmer.co.uk/genetics/index.html](http://www.perkinelmer.co.uk/genetics/index.html)

### **One Place for Special Needs**

Information network and social community that allows the disability community to share resources and make connections in their own neighborhood. And a place where those who actively work with those who have disabilities can let families learn about their products, programs and services. Includes Find-a-Friend program for kids.

Email: [info@oneplaceforspecialneeds.com](mailto:info@oneplaceforspecialneeds.com)

Website: [www.oneplaceforspecialneeds.com](http://www.oneplaceforspecialneeds.com)

### **Organ/Tissue Donations**

Please note: the UMDF is currently unaware of any US bio-bank that accepts full body donations for mitochondrial disease research.

- NAMDC – North American Mitochondrial Disease Consortium

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Phone: 212-305-1048

Website: [www.rarediseasesnetwork.org/cms/namdc](http://www.rarediseasesnetwork.org/cms/namdc)

- Mayo Clinic Mitochondrial disease bio-bank

Website: [www.mayoresearch.mayo.edu](http://www.mayoresearch.mayo.edu)

- NIH-sponsored banks:

- 1) Brain and Tissue Bank

Phone: 800-847-1539

Website: [www.medschool.umaryland.edu/BTBank](http://www.medschool.umaryland.edu/BTBank)

- 2) National Disease Research Interchange

Phone: (800) 222-NDRI (6374), ext. 243

Website: [www.ndriresource.org/for-donors-patients](http://www.ndriresource.org/for-donors-patients)

- 3) Brain endowment bank

Collects samples from patients with a variety of genetic and developmental disorders, patients with related disorders, and age-matched controls. The material is used by investigators studying diseases that affect normal brain. (Info from a mitochondrial disease specialist)

Website: [www.brainbank.med.miami.edu](http://www.brainbank.med.miami.edu)

- Coriell Institute for Medical Research

Coriell Biobank is regarded as the most diverse collection of cell lines and DNA available to the international research community.

Phone: 800-752-3805

Website: [www.coriell.org/1/Services/Biobanking](http://www.coriell.org/1/Services/Biobanking)

- Autism BrainNet

Autism BrainNet will enable the highest quality and most rigorous research into the causes of autism spectrum disorder and other related neurodevelopmental conditions. The postmortem brain resource will generate data that will contribute to the development of preventions and treatments to improve the quality of life of individuals with autism spectrum disorder.

Phone: 877-333-0999

Website: [www.autismbrainnet.org](http://www.autismbrainnet.org)

### **The Oley Foundation**

To enrich the lives of patients dependent on home intravenous nutrition (parenteral) and tube feeding (enteral) through education, advocacy, and networking

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Phone: 518-262-5079  
Website: [www.oley.org](http://www.oley.org)

### **Parent Education & Advocacy Leadership Center (PEAL)**

The PEAL Center is an organization of parents of children with disabilities and special health care needs who educate and guide: Parent Education & Advocacy Leadership (PEAL) Center serves families across Pennsylvania with offices in Pittsburgh and Philadelphia.

Email: [info@pealcenter.org](mailto:info@pealcenter.org)  
Phone: 866-950-1040 Toll Free  
Website: [www.pealcenter.org](http://www.pealcenter.org)

### **Parent Technical Assistance Center Network**

Parent Center Network is a family friendly blog sharing some of the most popular parental items and gift ideas for babies, kids right up to teens.

Email: [contact@parentcenternetwork.com](mailto:contact@parentcenternetwork.com)  
Website: [www.parentcenternetwork.org](http://www.parentcenternetwork.org)

### **Parent to Parent USA**

Parent to Parent programs provide emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained 'Support Parent.' Most statewide programs are "cross-disability, with many different physical and developmental disabilities being represented.

Email: [memberinfo@p2pusa.org](mailto:memberinfo@p2pusa.org)  
Phone: 855-238-8979  
Website: [www.p2pusa.org](http://www.p2pusa.org)

### **Patient Advocate Foundation**

Patient Advocate Foundation's Patient Services provides patients with arbitration, mediation and negotiation to settle issues with access to care, medical debt, and job retention related to their illness. .

Student Scholarship Program - The purpose of our scholarship program is to provide support to individuals that are legal residents of the United States of America, under the age of 25, who have been diagnosed with or treated for cancer, a chronic, or life threatening debilitating disease within the past five years.

Website: [www.patientadvocate.org/help.php?p=69](http://www.patientadvocate.org/help.php?p=69)

PAF has produced numerous publications and informational brochures to aid clarity and provide valuable information to patients. These publications are devoted to individual health related topics and target the most commonly misunderstood areas of the medical world.

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Website: [www.patientadvocate.org/resources.php?p=749](http://www.patientadvocate.org/resources.php?p=749)

Email: [Info@patientadvocate.org](mailto:Info@patientadvocate.org)

Phone: 800-532-5274

Web: [www.patientadvocate.org](http://www.patientadvocate.org)

### **PatientsLikeMe**

PatientsLikeMe is a health information sharing website for patients. Only here do patients like you have the opportunity to share both personal stories and health data about your conditions to help uncover great ideas and new knowledge.

By sharing information on our site, you can put your disease experiences in context and find answers to the questions you have. You can know detailed information about every medication, supplement, or device used to treat patients like you and learn about what works; connect easily with patients that have the same conditions, experiencing the same symptoms or using similar treatments; and learn from patients like you.

Email: [support@patientslikeme.com](mailto:support@patientslikeme.com)

Website: [www.patientslikeme.com](http://www.patientslikeme.com)

### **R & R Vans & Lifts, Inc**

Located in the Atlanta metro area, serving the Southeast and beyond. Has new and pre-owned vehicles to meet most financial situations. Also helps with finding grant and funding sources.

Phone: 866-605-1596

Website: [www.rrvan.com](http://www.rrvan.com)

### **Ronald McDonald Houses**

Our Ronald McDonald House program provides a 'home-away-from-home' for families so they can stay close by their hospitalized child at little or no cost.

Email: [info@rmhc.org](mailto:info@rmhc.org)

Phone: 630-623-7048

Website: [www.rmhc.org/home](http://www.rmhc.org/home)

### **RonWear**

A line of clothing for Chemo, Dialysis, Transfusion, and other Infusion patients with ports that keeps them warm and dignified while having easy access to their ports through hidden zippers in the chest, arms and groin areas. The outfit looks like a stylish jogging suit, allowing them to look and feel 'normal' while going through the process.

Email: [info@ronwear.com](mailto:info@ronwear.com)

Phone: 800-513-1458

Website: [www.ronwear.com](http://www.ronwear.com)

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### **SAMI**

SAMi is a sleep activity monitor for caregivers and individuals who need to watch carefully for unusual movements at night.

Email: [info@samialert.com](mailto:info@samialert.com)

Phone: 303 335-0051

Website: [www.samialert.com](http://www.samialert.com)

### **Save the Kid Fund INC**

Dedicated to improve the lives of children by providing them with opportunities they may not otherwise receive or by providing financial support for medical treatments, medications or adaptive equipment. To better the lives of children living in the State of Connecticut and Rhode Island, one child at a time, without regard to ethnic heritage or religious and political beliefs.

Email: [info@savethekid.org](mailto:info@savethekid.org)

Website: [www.savethekid.org](http://www.savethekid.org)

### **ShareNetwork.org**

Special Help and Respite Exchange Network, sharing services and equipment for those who have special needs Note: has a special "Wish, Dream, and Helping Groups" list for those under 18 years old and another for those over 18. Includes camps, make-a-wish type organizations (including some by state), and relief funds.

Website: [www.sharenetwork.org/wish.html](http://www.sharenetwork.org/wish.html)

### **Sibling Support Project**

The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns. Includes workshops.

Email: [info@siblingsupport.org](mailto:info@siblingsupport.org)

Phone: 206-297-6368

Website: [www.siblingsupport.org](http://www.siblingsupport.org)

### **Songs of Love Foundation**

Creates free, personalized, original songs to uplift children and teens currently facing tough medical, physical or emotional challenges. Each CD is professionally produced with lyrics containing the child's name and references to all of his or her favorite activities, things, people, and pets. Songs are written and performed in any language in the musical style that the child likes best (kids, pop, R&B, rap, rock, alternative, etc.), by many talented singer/songwriters.

Email [info@songsoflove.org](mailto:info@songsoflove.org)

Phone: 800-960-SONG (7664)

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Website: [www.songsoflove.org](http://www.songsoflove.org)

### **Special Needs Alliance**

Organization of attorneys dedicated to the practice of disability and public benefits law. Committed to helping individuals with disabilities, their families, and the professionals who represent them.

Phone: 877-572-8472

Website: [www.specialneedsalliance.com](http://www.specialneedsalliance.com)

### **Starlight Children's Foundation**

Helps seriously ill children and their families cope with their pain, fear and isolation through education, entertainment and family activities.

Website: [www.starlight.org](http://www.starlight.org)

### **Terrell Foundation**

To support higher education for a high school senior affected by neurologic diseases/brain injury through tuition to an institute for advanced learning. Offers one scholarship nationwide per year.

Website: [www.terrellfoundation.org](http://www.terrellfoundation.org)

### **Think College!**

Think College is a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability.

Website: [www.thinkcollege.net](http://www.thinkcollege.net)

### **Trust It or Trash It**

Free online tool from the Genetic Alliance that provides guidance for determining if online medical information is trustworthy.

Email: [info@geneticalliance.org](mailto:info@geneticalliance.org)

Website: [www.trustortrash.org](http://www.trustortrash.org)

### **United Mitochondrial Disease Foundation (UMDF)**

UMDF supports newly diagnosed patients with critical information on treatment and care. Our vast online viewing library provides countless topics on living with mitochondrial disease. When a patient or family member calls or emails the UMDF, we try to answer questions quickly. If there is a question we are unable to answer, we'll help you get the information you need. If your doctor needs information, we will point him or her to an expert in the mitochondrial medicine field for answers. And of course, we are here to listen in difficult times. UMDF connects patients to each other. UMDF Ambassadors across the nation provide patients and families with support in their state or region.

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Address: 8085 Saltsburg Road, Suite 201 Pittsburgh, PA 15239

Email: [info@umdf.org](mailto:info@umdf.org)

Phone: 888-317-UMDF

Website: [www.umdf.org](http://www.umdf.org)

### **United Cerebral Palsy**

UCP is the leading source of information on cerebral palsy and is a pivotal advocate for the rights of persons with any disability. As one of the largest health charities in America, UCP's mission is to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities. Note: “for people with CP and ‘related or similar conditions’ — wonderful source of general info — has a grant specifically to fund adapted sports & recreational equipment.” Kim McCrary

Phone: 800.872.5827

Website: [www.ucp.org](http://www.ucp.org)

### **United Cerebral Palsy, One-Stop Resource Guide**

There are a myriad of disability, health and human service programs in every state and community however they are not always easy to find. Whether you need healthcare, home modifications, or financial assistance—we can direct you to the organizations that can help.

Website: [www.ucp.org/resources/resource-guide](http://www.ucp.org/resources/resource-guide)

### **UnitedHealthcare Children’s Foundation**

Provides financial assistance toward the family's share of the cost of medical services not covered by insurance. (Must have commercial insurance.)

Email: [customerservice@uhccf.org](mailto:customerservice@uhccf.org)

Phone: 1 855-MY-UHCCF / 1 855-698-4223

Web: [www.uhccf.org](http://www.uhccf.org)

### **US Department of Labor, Office of Disability Employment Policy**

The Office of Disability Employment Policy (ODEP) is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities.

Email: [odep@dol.gov](mailto:odep@dol.gov)

Phone: 866-ODEP-DOL

Website: [www.dol.gov/odep](http://www.dol.gov/odep)

### **Waisman Center**

Dedicated to advancing knowledge about human development, developmental disabilities, and neurodegenerative diseases.

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Email: [info@waisman.wisc.edu](mailto:info@waisman.wisc.edu)  
Phone: 608.263.1656 / 608.263.3301  
Website: [www.waisman.wisc.edu](http://www.waisman.wisc.edu)

### **We Connect Now**

We Connect Now is dedicated to uniting people interested in rights and issues affecting people with disabilities, with particular emphasis on college students and access to higher education and employment issues. One of the goals of this site is to help college students with disabilities to succeed in their studies by getting the information and support they need, both through resources, links, blogs latest news, studying existing laws and regulation and through personal contacts.

Website: [www.weconnectnow.wordpress.com](http://www.weconnectnow.wordpress.com)

### **Well Spouse Association**

Advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner. We offer peer to peer support and educate health care professionals and the general public about the special challenges and unique issues "well" spouses face every day.

Email: [info@wellspouse.org](mailto:info@wellspouse.org)  
Phone: 800-838-0879 732-577-8899  
Website: [www.wellspouse.org](http://www.wellspouse.org)

### **Wrightslaw**

Accurate, reliable information about special education law, education law, and advocacy for children with disabilities. They also have a free online newsletter called

Website: [www.wrightslaw.com/subscribe.htm](http://www.wrightslaw.com/subscribe.htm) - The Special Ed Advocate Newsletter  
Website: [www.wrightslaw.com](http://www.wrightslaw.com)

### **Wrightslaw Yellow Pages for Kids**

Find educational consultants, psychologists, educational diagnosticians, health care providers, academic therapists, tutors, speech language therapists, occupational therapists, coaches, advocates, and attorneys for children with disabilities. You will also find special education schools, learning centers, treatment programs, parent groups, respite care, community centers, grassroots organizations, and government programs for children with disabilities. By state.

Website: <http://www.yellowpagesforkids.com/help/ptis.htm>

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