

# **GENERAL RESOURCES - NATIONAL**

**Disclaimer:**

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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.”

253 Dayton Ave.

Xenia, Ohio 45385

Phone: (937) 374-0385

Email: [Info@4PawsForAbility.org](mailto:Info@4PawsForAbility.org)

Website: <http://4pawsforability.org/>

### **Aaron's Tracheostomy Page**

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

Web: [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.

Web: <http://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.

<http://www.advoconnection.com/>

### **Allsup**

Provides Social Security Disability Insurance representation for a fee, but does not charge the fee up-front. Website includes SSDI guidelines. Also provides a Medicare Plan Selection service.

<http://www.allsup.com/>

<http://www.allsup.com/about-ssdi/ssdi-guidelines-by-disability/general-guidelines.aspx>

### **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.

<http://www.alz.org/>

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

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“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.

Website: <http://aahd.us/>

### **American Cancer Society**

<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.

AGMD International Corporate Headquarters

12 Roberts Dr

Bedford, MA 01730

Phone: 781-275-1300

Fax: 781-275-1304

Web: [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.”

The Arc of the United States

1010 Wayne Ave., Suite 650

Silver Spring, MD 20910

Phone: 301-565-3842

Fax: 301-565-5342

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

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

### **Aubrey Rose Foundation**

3862 Race Road

Cincinnati, OH 45211

“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.

Website: <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.”

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

### **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.

Website: <http://www.babysignsprogram.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).

Web: [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.”

[http://www.bobbysbooks.org/aws/BB/pt/sp/home\\_page](http://www.bobbysbooks.org/aws/BB/pt/sp/home_page)

### **Bookshare**

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

Website: <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.

Web: [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.

Web: <http://www.bridges4kids.org/HelpForKids-US.html>

### **Bright Beacon**

Provides “a safe haven for parents of children with medical needs to meet, discuss their children, their children's medical needs, and perhaps even their own personal stories,”

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

Web: <http://www.brightbeacon.org/>

### **Bubel Aiken Foundation**

#### **Disclaimer:**

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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.

8601 Six Forks Road, Suite 400

Raleigh, NC 27615

Tel 919-882-2152

Fax 919-882-2155

Email: [contactus@bubelaiken.org](mailto:contactus@bubelaiken.org)

Web: <http://www.inclusionproject.org/>

### **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.”

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

Camphill Association of North America

Attn: Ruth Oslund, President

351 W. 19th Street

North Vancouver B.C. V7M1X7

Canada

Phone: 604-987-3407

E-mail: [info@camphill.org](mailto:info@camphill.org)

Camphill Foundation

285 Hungry Hollow Road

Chestnut Ridge, NY 10977

Phone: 845-517-2776

Fax: 845-517-2779

E-mail: [info@camphillfdn.org](mailto:info@camphillfdn.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.

Audrina Wilhelm or Dan O'Brien

4989 Street Rt. 37 East Indianapolis, IN

Delaware, OH 43015

Phone: (740) 548-4447 (317) 251-8813

### **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**

#### **Disclaimer:**

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“Education, peer support, and resources for family caregivers.”

<http://caregiveraction.org/>

### **CaringBridge**

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

Website: <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.

Website: <http://hdwg.org/catalyst/>

### **Challenged America Foundation**

Has grant program, up to \$500, to provide equipment and services to physically and developmentally challenged children, ages 18 and under.

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

### **The Child King Foundation**

“Administers funds and disburses grants to organizations, charities and individuals that assist those with intellectual disabilities.”

PO Box 808

Hull, MA 02045

Email: [mail@TheChildKing.com](mailto:mail@TheChildKing.com)

Web: <http://www.childkingfoundation.org/>

### **Children’s R.A.R.E. Disease Network**

“An online community where children with rare diseases, their families, and the organizations that support them will have the opportunity to communicate, collaborate, become educated and tap existing resources,” Includes state resources, blogging, networking, parent advocacy, disease database.

24701 La Plaza

Suite 201

Dana Point, CA 92629

Web: <http://www.crdnetwork.org/>

### **Cody’s Wheels of Hope**

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

PO Box 8735

Erie, PA 16505

Phone: (814) 460-8228 or (814) 460-9102

Web: <http://www.cwoh.org/>

### **Compassionate Friends**

#### **Disclaimer:**

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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.

P.O. Box 3696

Oak Brook, IL 60522-3696

630-990-0010

877-969-0010

Email: [nationaloffice@compassionatefriends.org](mailto:nationaloffice@compassionatefriends.org)

Web: [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.

Web: <http://www.complexchild.com/index.html>

### **Coolture**

Cooling vest

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

<http://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.”

P.O. Box 6767

Towson, Maryland 21285

PH: 410-372-0208

Fax: 410-372-0209

Web: [www.copaa.net](http://www.copaa.net)

### **Crystal’s Special Care**

Created by a mother with two special-needs children, this website offers products to help a special-needs child learn to read, and two types of personalized books: one to explain the child’s disability to a classroom; and a different one to give the child’s school teacher a better understanding of how to care for the child.

N. Augusta, SC 29841

864-323-7902

[shonshad30@yahoo.com](mailto:shonshad30@yahoo.com)

### **DailyCareCalls**

#### **Disclaimer:**

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For peace of mind, provides daily phone calls to a loved one. Fee.

**Phone:** 1-877-777-7219

**Email:** [CustomerService@DailyCareCalls.com](mailto:CustomerService@DailyCareCalls.com)

### **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.”

Website: <http://www.dakmed.org/lendahand/> , fundraiser suggestions are at <http://www.dakmed.org/lendahand/plan-an-event/toolkit/>

### **Disabled Children’s Relief Fund**

Provides modest financial assistance for equipment, therapy, and surgery.

Disabled Children's Relief Fund

P.O. Box 89

Freeport, New York 11520

TEL: 516-377-1605

FAX: 516-377-3978

Web: [www.dcrf.com](http://www.dcrf.com)

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

Has a mito/dysautonomia article in their Spring 2003 newsletter.

PO Box 147

Slayton, MN 56172

Email: [staff@dinet.org](mailto:staff@dinet.org)

Web: [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.

230 Monroe Street, Suite 1800

Chicago, IL 60606

Fax: 312-726-1494

Phone: 800-221-6827 (toll free)

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

### **Eli’s Angels**

Sends a gift to children with Leigh’s and other mitochondrial disorders.

PO Box 423

Eastlake, CO 80614-0423

Phone: 1.800.497.5219

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Email: [ekurtz03@comcast.net](mailto:ekurtz03@comcast.net)  
Web: [http://home.comcast.net/~elis\\_angels/](http://home.comcast.net/~elis_angels/)

### **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.

Website: <http://www.elks.org/states/>

BPO Elks of the USA  
2750 N. Lakeview Avenue  
Chicago, IL 60614-1889

### **Epilepsy Foundation**

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

4351 Garden City Drive  
Landover, MD 20785  
Phone: 800-332-1000

Web: <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.

Subscription Customer Service and New Orders  
E-mail Whitney Sheehan or call Toll Free (800) 372-7368  
Publishing & Editorial Office  
EP Global Communications, Inc.  
416 Main Street  
Johnstown, PA 15901  
Phone: (814) 361-3860 or (800) 372-7368  
Fax: (814) 361-3861  
Web: [www.eparent.com](http://www.eparent.com)

### **Families USA**

Healthcare advocacy network  
1201 New York Ave  
Suite 1100  
Washington, DC 20005  
202-628-3030  
Fax: 202 347-2417  
Email: [info@familiesusa.org](mailto:info@familiesusa.org)  
Web: [www.familiesusa.org](http://www.familiesusa.org)

### **Family Village**

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A global community that integrates information, resources, and communication opportunities for individuals with cognitive and other disabilities, their families and their providers. Family Village includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature.

Waisman Center

University of Wisconsin-Madison

1500 Highland Avenue

Madison, WI 53705-2280

Web: [www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

### **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.

Website: <http://www.familyvoices.org/>

### **First Hand Foundation**

“Helps the families of children [all over the world] with health problems address the financial aspects of their child’s healthcare.” For those who qualify, First Hand helps with clinical expenses, medical equipment, and relocation during treatment.

First Hand Foundation

c/o Cerner Corporation

2800 Rockcreek Parkway

Kansas City, MO 64117

Attn: Mary Nelson

Phone: 816-201-1569

Fax: 816-571-1569

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

Web: [http://globalhand.org/en/browse/yellow\\_pages/15/all/organisation/22081](http://globalhand.org/en/browse/yellow_pages/15/all/organisation/22081)

### **FodSupport.org**

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

Deb Lee Gould, MEd

Director, FOD Family Support Group

MCAD Parent and Grief Consultant

1559 New Garden Rd, 2E

Greensboro, NC 27410

Phone: (336) 547-8682 [8am - 8pm EST every day]

Fax: (336) 292-0536 [8am - 8pm EST every day]

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

### **Free Gas USA Inc.**

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Gasoline assistance program. Provides gas-assistance grants to poverty-stricken applicants to drive to work, medical appointments, school, grocery shopping, etc. Must meet salary requirements.

P.O. Box 2632

Kalamazoo, Michigan 49003-2632

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

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

### **GeneTests**

“Medical genetics information resource”

Disease reviews, genetics testing lab directory, clinics, educational materials

9725 Third Avenue NE

Suite 602

Seattle, WA 98115

Phone: 206-616-4033

Fax: 206-221-4679

Email: [genetests@genetests.org](mailto:genetests@genetests.org)

Web: [www.geneclinics.org](http://www.geneclinics.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 the Newsletter Alert.

4301 Connecticut Ave, NW, #404

Washington, DC 20008

Phone: (800) 336-4363

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

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.”

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

<http://www.gottransition.org/>

### **GovBenefits.gov**

Locate federal and state benefits you might be eligible for.

Web: [www.govbenefits.gov](http://www.govbenefits.gov)

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### **Gradient Gives Back Foundation**

Has program that assists financially struggling families with mortgage/rent payments and financial planning.

Website: <http://www.gradientgivesback.com/>

and [http://www.needhelppayingbills.com/html/gradient\\_gives\\_back\\_community\\_.html](http://www.needhelppayingbills.com/html/gradient_gives_back_community_.html)

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

Website: <http://kff.org/medicaid/issue-brief/a-guide-to-the-medicaid-appeals-process/>

### **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.

105 Townline Rd, Ste 132

Vernon Hills, IL 60061

Phone: 847-624-LEXI

Website: <http://helpingfromheaven.org/about-us.html>

### **Hope, Inc.**

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

803 22nd Ave

South Moorhead, MN 56560

Phone: 866-225-4673 (toll free)

Fax: 701-772-5284

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

Web: <http://www.hopeinonline.org/>

### **Hope for Support**

Lists numerous disability resources for children, such as: service dogs, wish organizations, equipment, sports, and “fun stuff.”

Website: <http://www.hopeforsupport.com/>

### **Hugs and Hope** for sick children

Sick children can join this club and receive “happy mail” (cards and gifts) from volunteers.

P.O. Box 56

Harshaw, WI 54529

Email: [ejupdates@yahoo.com](mailto:ejupdates@yahoo.com)

Web: <http://www.hugsandhope.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.”

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Web: <http://www.ilusa.com/links/03-08centers1.htm#AZ>

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

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

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

**The International Foundation for Optic Nerve Disease**

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

P. O. Box 777, Cornwall NY 12518, USA.

TEL/FAX (845) 534 7250

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

Web site: <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."

<http://www.invisibledisabilities.org/>

**Jennifer Jaff Center**

Helps with the following: "File health insurance appeals (80% success rate), Negotiate reasonable accommodations at work and school, Help chronically ill employees assert their rights under the Family and Medical Leave Act, Provide resources and information on insurance, prescription drug assistance programs, health care reform, and more."

<http://www.thejenniferjaffcenter.org/>

**Jonah and the Whale Foundation**

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

PO Box 981

Mars, PA 16046

Phone: 1-877-49-JONAH (56624)

Web: <http://www.jtwf.org/>

**KIDSEnabled Magazine**

Online resource with informative articles and blog, as well as a resource directory and community calendar for the Atlanta area. The articles are universal to any location.

<http://www.kidsenabled.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.

Web: <http://www.cdc.gov/ncbddd/kids/index.html>

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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.

111 East 59<sup>th</sup> St

New York, NY 10022-1202

Phone: 800-829-0500

Web: <http://www.lighthouse.org/>

### **Lindsay Foundation**

Financial assistance for equipment, therapies and supplies not covered by insurance  
<http://www.lindsayfoundation.org/>

### **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.”

Web: <http://www.lotsahelpinghands.com/caregiving/home/>

### **March of Dimes Birth Defects Foundation**

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

1275 Mamaroneck Avenue

White Plains, NY 10605

Phone: 914-428-7100

Toll free: 888-663-4637

Email: [askus@marchofdimes.com](mailto:askus@marchofdimes.com)

Web: [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: <http://www.themattyfund.org/>

### **Medicare, Medicaid and Medicaid Waiver Programs**

<http://www.geocities.com/HotSprings/Villa/1029/medicaid.html>

List of waiver-covered services by state:

<http://cms.hhs.gov/medicaid/1915c/regular.pdf>

<http://cms.hhs.gov/medicaid/1915c/model.pdf>

### **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

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funders who provide assistance to individuals coping with catastrophic health problems.”

Web: <http://staff.lib.msu.edu/harris23/grants/2health.htm>

### **Modest Needs Foundation**

Provides modest financial assistance to low-income individuals/families for a specific need.

Web: [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: <http://www.mommiesofmiracles.com>

### **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.

Robert & Kristen Malfara, co-founders

3830 S. Hwy. A-1-A

Suite C4, #153

Melbourne Beach, FL 32951

Web: [http://themorganproject.org/about\\_us.html](http://themorganproject.org/about_us.html)

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

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

“MUMS is a national Parent-to-Parent organization for parents or care providers of a child with any disability, syndrome, chromosomal abnormality or health condition. MUMS providers support to parents by matching them with other parents whose children have the same or similar condition.” They publish a newsletter allowing families to share and speak out about issues affecting their lives.

150 Custer Court

Green Bay, WI 54301-1243

Phone: (920) 336-5333 or (877) 336-5333 (parents only)

Web: [www.netnet.net/mums/](http://www.netnet.net/mums/)

### **Muscular Dystrophy Association**

The Association's comprehensive service program includes medical examinations, flu shots, support groups, MDA summer camps for youngsters and assistance with purchase of wheelchairs and leg braces (up to \$2,000).

3300 East Sunrise Drive

Tucson, AZ 85718-3208

Phone: 520-529-2000

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Toll free: 800-572-1717  
Email: [mda@mdausa.org](mailto:mda@mdausa.org)  
Web: [www.mdausa.org](http://www.mdausa.org)

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

“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 MDF 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. MDF provides service to children and adults regardless of race or income level.

2330 N. Meridian Street  
Indianapolis, IN 46208-5730  
Phone: (317) 923-6333 or (800) 544-1213  
Web: [www.mdf.org](http://www.mdf.org)

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

“Non-profit organization serving facilities that provide lodging and other supportive services to patients and their families when confronted with medical emergencies.”

PO Box 1439 Gresham, OR 97030  
Phone: 1.800.542.9730  
Email: [Helpinghomes@nahhh.org](mailto:Helpinghomes@nahhh.org)  
Web: [www.nahhh.org](http://www.nahhh.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.”

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

### **National Dissemination Center for Children with Disabilities (NICHY)**

Federal information source for disabilities, special education law, No Child Left Behind, educational practices, IEP resources, state resources (information also in Spanish).

P.O. Box 1492  
Washington, DC 20013  
Phone: (800) 695-0285 · v/tty  
Fax: (202) 884-8441  
Email: [nichcy@aed.org](mailto:nichcy@aed.org)  
Web: [www.nichcy.org](http://www.nichcy.org)

### **National Family Caregivers Association**

Grassroots organization dedicated to supporting and improving the lives of America’s family caregivers. Created to educate, support, empower, and advocate for the millions of Americans who care for their ill, aged, or disabled loved ones.

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10400 Connecticut Avenue, Suite #500  
Kensington, MD 20895-3944  
Phone: 301-942-6430 or 800-896-3650  
Email: [info@nfcacares.org](mailto:info@nfcacares.org)  
Web: [www.nfcacares.org](http://www.nfcacares.org)

**National Health Information Center (NHIC)**

“Puts health professionals and consumers who have health questions in touch with those organizations that are best able to provide answers.” Established by US Dept. of Health & Human Services. Web: [www.health.gov/nhic/](http://www.health.gov/nhic/)

**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.

1700 Diagonal Road, Suite #625  
Alexandria, VA 22314  
Phone: 703-837-1500  
Helpline: 800-658-8898  
Email: [Nhpco\\_info@nhpco.org](mailto:Nhpco_info@nhpco.org)  
Web: [www.nhpco.org](http://www.nhpco.org)

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

“Provides information about ORD-sponsored biomedical research, scientific conferences, rare and genetic diseases.”

6100 Executive Boulevard  
Room 3B01, MSC 7518  
Bethesda, Maryland 20892-7518  
Phone: (301) 402-4336 (voice)  
Fax: (301) 480-9655 (fax)  
Email: [ord@od.nih.gov](mailto:ord@od.nih.gov)  
Web: <http://rarediseases.info.nih.gov/>

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

Mitochondrial disease information. Resource guide & medication assistance program.

55 Kenosia Avenue  
PO Box 1968  
Danbury, CT 06813-1968  
Phone: (203) 744-0100  
Tollfree: (800) 999-6673 (voicemail only)  
Fax: (203)798-2291  
Web: [www.rarediseases.org](http://www.rarediseases.org)

**Need Help Paying Bills**

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“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.” Numerous website links included.

Web: <http://www.needhelppayingbills.com/index.html>

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

- **Baylor Research Institute**  
Institute of Metabolic Disease  
Dallas, TX  
Phone: 214-820-4533  
Web: [www.BaylorHealth.com](http://www.BaylorHealth.com)
- **Baby’s First Test**  
Web: [www.BabysFirstTest.org](http://www.BabysFirstTest.org)
- **StepOne Newborn Screening**  
Phone: 866-463-6436  
Web: [www.perkinelmergenetics.com](http://www.perkinelmergenetics.com)

### **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.

Web: <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

<http://rarediseasesnetwork.epi.usf.edu/NAMDC/about/contact.htm>

The following is a mito bio-bank/repository at the Mayo Clinic:

<http://mayoresearch.mayo.edu/mitochondrial-disease-biobank/> .

Two NIH-sponsored banks:

1) in Baltimore, Maryland:

<http://medschool.umaryland.edu/BTBank/gintro.html> (410)-706-1755 (800)-847-1539

2) and in Philadelphia

[http://www.ndriresource.org/Donor\\_Programs/Tissue\\_Banks/112/](http://www.ndriresource.org/Donor_Programs/Tissue_Banks/112/) 800-222-NDR1 (6374)

Brain and Tissue Bank for Developmental Disorders (FL)  
University of Miami

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Tel: 800-59BRAIN (592-7246)

Fax: 305-243-6970

<http://braindonation.org/> 1-800-59-BRAIN

Description: 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)

Coriell Institute for Medical Research

<http://www.coriell.org/research-services/biobanking>

Autism: brain tissue donation program at [www.MemoriesofHope.org](http://www.MemoriesofHope.org) if any members want autism research done at the same time. We do post-mortem home visits to establish autism diagnosis and have a number of projects going on. Jane Pickett, Ph.D., Autism Tissue Program (ATP), ATP Director of Brain Resources & Data, Autism Speaks, 5119 Alejo St, San Diego CA 92124, 877-333-0999, Fax: 858-694-0748, Web: [www.MemoriesofHope.org](http://www.MemoriesofHope.org), Data: [www.atpportal.org](http://www.atpportal.org)

### **The Oley Foundation**

“Helping people whose daily survival depends on home intravenous or tube-fed nutrition.” Networking, resources and support information.

214 Hun Memorial, A-28

Albany Medical Center

Albany, NY 12208-3478

Phone: 1-800-776-OLEY (Toll Free In USA & Canada)

1-518-262-5079 (Outside USA)

Fax: 1-518-262-5528

E-mail: [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu)

Web: <http://www.oley.org/>

### **Parent Education & Advocacy Leadership Center**

Although this site is specific to residents of Western & Central Pennsylvania, it includes helpful resources such as free online courses to help navigate the special education system, advocate for a loved one, and find a job despite a disability. Other resources and links to additional organizations are included.

1119 Penn Avenue, Suite 400

Pittsburgh, PA 15222

Phone: 1-866-950-1040

Website: <http://www.pealcenter.org/>

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

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

National organization divided into regional centers that provide innovative technical assistance, up-to-date information, high quality resources and materials, and IEP assistance for children with disabilities and their families.

Website: <http://www.parentcenternetwork.org/>

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### **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.”

Website: <http://www.p2pusa.org/>. Contact information for each of the 35 states involved is provided on the website.

### **Patchwork Peddlers**

Attractively designed pads and belts for G and J tubes, and trachs. Made from colorfully decorated materials.

<http://www.patchworkpeddler.com/>

### **Patient Advocate Foundation**

National non-profit organization that serves “as an active liaison between patients and their insurers, employees and /or creditors to resolve insurance, job retention, and/or debt crisis matters relative to their diagnosis, through casemanagers, doctors, and attorneys. The foundation seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment, and preservation of their financial stability.” *Some college scholarships available at*

<http://www.patientadvocate.org/help.php?p=69> .

Also included on this website is “The National Underinsured Resource Guide” which is intended to help those who are underinsured locate resources and alternative options for coverage.

421 Butler Farm Road

Hampton, VA 23666

Phone: 800-532-5274

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

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

The resource guide website section: [patientadvocate.org/help4u.php](http://patientadvocate.org/help4u.php)

### **PatientsLikeMe.com**

“Committed to providing a better, more effective way to capture valuable results and share them with patients, healthcare professionals, and industry organizations that are trying to treat the disease.” They have “created a platform for collecting and sharing real world, outcome-based patient data and are establishing data-sharing partnerships with doctors, pharmaceutical and medical device companies, research organizations, and non-profits.” Patients can input their own progress data and compare it to others with similar disorders and/or are on similar treatments.

<http://www.patientslikeme.com/>

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### **QuitSmokingCommunity**

Great resource to help quit smoking and raises awareness of the consequences of smoking and helps communities become smoke-free.

<https://QuitSmokingCommunity.org>

### **R.A.R.E. Space**

["The site will educate and connect users about critical resources, innovations in research, standards of care as well as best practices in treating rare diseases and disorders. Creating a community filled with medical professionals, policy advocates, researchers and parents catalyzes a free exchange of information, increasing the general knowledge quotient of every stakeholder."](http://www.medpedia.com/communities/274-RareSpace)

<http://www.medpedia.com/communities/274-RareSpace>

### **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.

Website: <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."

Web: <http://rmhc.org/what-we-do/ronald-mcdonald-house/> Click on their *chapter* link for nationwide locations.

### **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."

RonWear

P.O.Box 22482

Beachwood, Oh 44122-0482

Phone: 800-513-1458

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

### **SAMI, the sleep activity monitor**

"A night vision camera used to monitor and record abnormal sleep movements."

Web: <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."

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290 Geer Rd  
Lebanon, CT 06249  
Web: <http://savethekid.org/home.html>

### **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 at <http://www.sharenetwork.org/wish.html>.

Includes camps, make-a-wish type organizations (including some by state), and relief funds.

### **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.

<http://www.siblingsupport.org/>

### **Songs of Love Foundation**

“Dedicated to creating personalized songs for chronically and terminally ill children and young adults.” The songs are free.

PO Box 750809

Forest Hills, NY 11375

Phone: 718-441-4588

Toll Free: 1-800-960-SONG (7664)

Fax: 718-441-7372

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

Web: [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.”

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

Newsletter: <http://www.specialneedsalliance.org/the-voice/4/8>

### **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: <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: <http://www.terrellfoundation.org/>

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### **Think College!**

College Options for People with Intellectual Disabilities

<http://www.thinkcollege.net/>

### **Title V CSHCN Programs** (by state)

Federally funded health and support services listed by state for children with special health care needs.

Web: <http://cshcnleaders.ichp.edu/titlevdirectory/directory.htm>

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

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

Website: <http://www.trustortrash.org/>

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

8085 Saltsburg Road, Suite 201

Pittsburgh, PA 15239

Phone: 412-793-8077

Fax: 412-793-6477

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

Website: <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

United Cerebral Palsy

1660 L Street, NW, Suite 700

Washington, DC 20036-5602

Phone: (800) USA-5-UCP or (202) 776-0406

TTY: (202) 973-7197

Fax: (202) 776-0414

E-mail: [national@ucp.org](mailto:national@ucp.org)

Web: <http://www.ucp.org>

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

Provides contact information for disability resources in every state.

[http://www.ucp.org/ucp\\_generaldoc.cfm/1/3/43/43-43/5807](http://www.ucp.org/ucp_generaldoc.cfm/1/3/43/43-43/5807)

### **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.)

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MN012-S286  
PO BOX 41  
Minneapolis, MN 55440-0041  
1-800-328-5979 - Ask for extension 24459 or  
(952) 992-4459 (Voice mail line only)  
Web: [www.uhccf.org](http://www.uhccf.org)

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

Web: <http://www.dol.gov/odep/>

**Visual Impairment Information Page**

<http://home.comcast.net/~visioninformation/>

Includes definitions, training, and organizations.

**We Connect Now**

“Dedicated to uniting college students with disabilities in access to higher education and employment issues.” Also in Spanish.

<http://weconnectnow.wordpress.com/>

**We Move/Life in Motion**

“the Internet’s most comprehensive resource for movement disorder information and the hub of movement disorder activities on the web.”

Website: <http://www.wemove.org/>

**Well Spouse Association**

Focuses on “the needs of spouses caring for a chronically ill and/or disabled husband, wife, or partner.”

63 West Main Street, Suite H

Freehold, NJ 07728

800-838-0879 732-577-8899

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

Internet: [www.wellspouse.org](http://www.wellspouse.org)

**Wheelforce**

Facebook page

“Our mission is to serve the disabled community by providing information, interviews with inspiring people, and by fostering a community to allow those affected by disability to lead happier, more productive, and more fulfilling lives.”

<https://www.facebook.com/wheelforces>

**Wrightslaw**

“Accurate, reliable information about special education law, education law, and advocacy for children with disabilities.”

Website: <http://www.wrightslaw.com/>

They also have a free online newsletter called *The Special Ed Advocate Newsletter* at <http://www.wrightslaw.com/subscribe.htm> .

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**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.

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

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