

GENERAL RESOURCES - NATIONAL

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GENERAL RESOURCES - NATIONAL

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

Aaron's Tracheostomy Page

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

Web: 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/>

Allsup

Provides Social Security Disability Insurance representation for a fee. Website includes SSDI guidelines.

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

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.

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

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

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

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Web: www.thearc.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."

Web: www.babysfirsttest.org/

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/

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

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

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

Bubel Aiken Foundation

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

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

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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 an 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

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

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

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

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

Children's Wish Foundation International

8615 Roswell Rd.

Atlanta, GA 30350-7526 Phone: (800) 323-9474 www.childrenswish.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

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

Web: 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>

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

Crystal's Special Care

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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

DailyCareCalls

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

Phone: 1-877-777-7219

Email: 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

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

Eli's Angels

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

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PO Box 423
Eastlake, CO 80614-0423
Phone: 1.800.497.5219
Email: ekurtz03@comcast.net
Web: 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

Families USA

Healthcare advocacy network
1201 New York Ave
Suite 1100
Washington, DC 20005
202-628-3030
Fax: 202 347-2417

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Email: info@familiesusa.org
Web: www.familiesusa.org

Family Village

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

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 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
Web: 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]

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Fax: (336) 292-0536 [8am - 8pm EST every day]
Web: www.fodsupport.org

Free Gas USA Inc.

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
Web: 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

Web: 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

GovBenefits.gov

Locate federal and state benefits you might be eligible for.

Web: www.govbenefits.gov

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

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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

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

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

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.”

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/

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

Web site: <http://www.ifond.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/>

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.

111 East 59th 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

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

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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

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

Email: 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 provides 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/

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

Toll free: 800-572-1717

Email: mda@mdausa.org

Web: 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

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devices, braces and social outings. Support is available 24/7. MDFF 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.mdff.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

Web: 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

National Dissemination Center for Children with Disabilities (NICHCY)

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

Web: 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.

10400 Connecticut Avenue, Suite #500

Kensington, MD 20895-3944

Phone: 301-942-6430 or 800-896-3650

Email: info@nfcacares.org

Web: www.nfcacares.org

National Health Information Center (NHIC)

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“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/

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
Web: 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
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

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.” Numerous website links included.

Web: <http://www.needhelppayingbills.com/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

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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 Donations

Organ/body donations

In addition, there are two other NIH-sponsored banks in Baltimore, Maryland:

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

http://www.ndriresource.org/Donor_Programs/Tissue_Banks/112/ 800-222-NDR1 (6374)

Brain and Tissue Bank for Developmental Disorders (FL)

University of Miami

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 Dr. Nyhan)

Autism: brain tissue donation program at 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, Data: www.atpportal.org

The following is a new mito bio-bank/repository at the Mayo Clinic:
<http://mayoresearch.mayo.edu/mitochondrial-disease-biobank/> .

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

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

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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

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.

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.*

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

Web: www.patientadvocate.org

The resource guide website section: 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.

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

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>

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.

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.”

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.

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

Web: www.songsoflove.org

Special Needs Alliance

Disclaimer:

Inclusion of particular professionals, services, products, or organizations does not imply endorsement by UMDF.

“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

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

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

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

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

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

Internet: www.wellspouse.org

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> .

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,](#)

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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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