Neurological Disorders
Directory of Health Information Resources

Office of Communications and Public Liaison
National Institute of Neurological Disorders and Stroke
National Institutes of Health
U.S. Department of Health and Human Services
Bethesda, Maryland

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Contact information for the organizations listed in this guide is accurate as of March 2019. If you are unable to reach a particular organization because of a change in phone number or address, please check our website at www.ninds.nih.gov or contact the National Institute of Neurological Disorders and Stroke, National Institutes of Health, Bethesda, MD 20892, and we will assist you.

This guide is not intended to be a comprehensive listing of all voluntary health agencies in the United States, nor does inclusion of any particular agency imply endorsement by the National Institutes of Health or the Department of Health and Human Services. Our intent is to provide information useful to individuals nationally, and for this reason we have not included many local groups that offer valuable assistance to individuals and their families in individual states or cities.
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I. Voluntary Health Organizations

Acoustic Neuroma
*(See also Neurofibromatosis)*

Acoustic Neuroma Association
600 Peachtree Parkway, Suite 108
Cumming, GA 30041
770-205-8211
www.anausa.org

Provides information and support to patients diagnosed with or treated for acoustic neuroma or other benign tumors affecting the cranial nerves.

IRSA (International RadioSurgery Association)
2960 Green Street
P.O. Box 5186
Harrisburg, PA 17110
717-260-9808
www.irsa.org

Patient organization that provides educational information and guidelines on stereotactic radiosurgery for brain tumors, arteriovenous malformations, and neurological pain and movement disorders.

Agenesis of the Corpus Callosum

National Organization for Disorders of the Corpus Callosum
PMB 363
18032-C Lemon Drive
Yorba Linda, CA 92886
714-747-0063
www.nodcc.org

Works to enhance the quality of life and promote opportunities for individuals with disorders of the corpus callosum and to raise the profile, understanding, and acceptance of these disorders through research, education, advocacy, and networking.
Aicardi Syndrome

Aicardi Syndrome Foundation
P.O. Box 3202
St. Charles, IL 60174
800-374-8518
http://ouraicardilife.org

Information gathering and sharing resource for professional and healthcare personnel and Aicardi syndrome families. Sponsors a biennial conference.

Alzheimer’s Disease

Alzheimer’s Association
225 North Michigan Avenue, Floor 17
Chicago, IL 60601-7633
312-335-8700
800-272-3900
TDD 312-335-5886
www.alz.org

National voluntary health organization committed to finding a cure for Alzheimer’s and helping those affected by the disease.

Alzheimer’s Drug Discovery Foundation
57 West 57th Street, Suite 904
New York, NY 10019
212-901-8000
www.alzdiscovery.org

Public charity whose sole mission is to rapidly accelerate the discovery and development of drugs to prevent, treat, and cure Alzheimer’s disease, related dementias, and cognitive aging.
Alzheimer’s Disease Education and Referral Center (ADEAR)
National Institute on Aging
Building 31, Room 5C27
31 Center Drive, MSC 2292
Bethesda, MD 20892
800-438-4380
www.nia.nih.gov/alzheimers

The ADEAR Center, a service of the National Institute on Aging, offers current research-based information on Alzheimer’s disease.

Alzheimer’s Foundation of America
322 Eighth Avenue, 7th Floor
New York, NY 10001
866-232-3484
https://alzfdn.org

Works to provide optimal care and services to individuals confronting dementia and to their caregivers and families through member organizations dedicated to improving quality of life.

Association for Frontotemporal Degeneration
Radnor Station Building #2, Suite 320
290 King of Prussia Road
Radnor, PA 19087
267-514-7221
866-507-7222
www.theaftd.org

Nonprofit organization that promotes and funds research into finding the cause and cure for frontotemporal dementias (FTD). Provides information, education, and support to those affected by FTD and their caregivers; and sponsors professional health education programs related to FTD.
BrightFocus Foundation
22512 Gateway Center Drive
Clarksburg, MD 20871
800-437-2423
www.brightfocus.org/alzheimers/

Nonprofit charitable organization dedicated to saving mind and sight by funding innovative research worldwide and by promoting better health through education.

John Douglas French Alzheimer’s Foundation
1191 Brookmere Road
Pasadena, CA 91105-3301
www.jdfaf.org

Provides seed money for novel and innovative Alzheimer’s research at major California universities that otherwise would not be funded through pharmaceutical or governmental grants. Unsolicited applications and/or letters of inquiry not accepted.

See also Lewy Body Dementia Association, page 40.

Amyotrophic Lateral Sclerosis

The ALS Association
1275 K Street, N.W., Suite 250
Washington, DC 20005
202-407-8580
800-732-4747
www.alsa.org

Nonprofit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis. Funds research and sponsors advocacy programs, a network of chapters, and certified centers and clinics located nationwide.
ALS Therapy Development Institute
300 Technology Square, Suite 400
Cambridge, MA 02139
617-441-7200
www.als.net

Nonprofit biotechnology company dedicated to discovering and developing treatments for ALS, with a focus on a concentrated drug discovery program for ALS.

Les Turner ALS Foundation
5550 West Touhy Avenue, Suite 302
Skokie, IL 60077-3254
847-679-3311
http://lesturnerals.org

Advances scientific research into the causes, treatments and prevention of ALS, provides people living with ALS, their families and caregivers exceptional clinical care and support services, and increases awareness and education of ALS.

Project ALS
801 Riverside Drive, Suite 6G
New York, NY 10032
212-420-7382
855-900-2257
www.projectals.org

Nonprofit organization that raises awareness and funds toward treatments and a cure for amyotrophic lateral sclerosis.

See also Muscular Dystrophy Association, page 49.

Aneurysm
(See Stroke)
Angelman Syndrome

Angelman Syndrome Foundation
75 Executive Drive, Suite 327
Aurora, IL 60504
800-432-6435
www.angelman.org

Works to advance awareness and treatment of Angelman syndrome through education and information, research, and support.

Aphasia
(See also Stroke)

American Speech-Language-Hearing Association
2200 Research Boulevard
Rockville, MD 20850
301-296-5700
800-638-8255
www.asha.org

Professional, scientific, and credentialing association for audiologists, speech-language pathologists, and speech, language, and hearing scientists. Offers public information about a wide range of speech, language, and hearing disabilities in both children and adults.

National Aphasia Association
P.O. Box 87
Scarsdale, NY 10583
800-922-4622
www.aphasia.org

Promotes the care, welfare, and rehabilitation of people with aphasia through public education and support of research. Offers printed materials, a toll-free information hotline, a newsletter, and a listing of support groups.

Arachnoiditis
(See Pain)
Arteriovenous Malformation
(See Birthmarks and Cavernous Malformation)

See also International RadioSurgery Association, page 1.

Ataxia

National Ataxia Foundation
600 Highway 169 South, Suite 1725
Minneapolis, MN 55426
763-553-0020
https://ataxia.org

Encourages and supports research into the hereditary and sporadic ataxias, a group of chronic and progressive neurological disorders affecting coordination. Sponsors chapters and support groups throughout the U.S.A. and Canada. Publishes a quarterly newsletter and educational literature on the various forms of ataxia.

See also Friedreich’s Ataxia Research Alliance, page 30 and Muscular Dystrophy Association, page 49.

Ataxia-Telangiectasia
(See also Ataxia)

Ataxia Telangiectasia (A-T) Children’s Project
5300 W. Hillsboro Blvd., Suite 105
Coconut Creek, FL 33073
954-481-6611
800-543-5728
www.atcp.org

Nonprofit organization that raises funds to support and coordinate biomedical research projects, scientific conferences, and a clinical center aimed at finding a cure for ataxia-telangiectasia, a lethal childhood genetic disease.
Atrial Fibrillation
(See Stroke)

Attention Deficit/Hyperactivity Disorder

CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder
4601 Presidents Drive, Suite 300
Lanham, MD 20706
301-306-7070
800-233-4050
https://chadd.org

Works to improve the lives of people affected by attention-deficit/hyperactivity disorder (AD/HD) through collaborative leadership, advocacy, research, education, and support and offers the National Resource Center on AD/HD at www.help4adhd.org.

Learning Disabilities Association of America
4156 Library Road
Pittsburgh, PA 15234-1349
412-341-1515
www.ldameric.org

Dedicated to improving the lives of children and adults nationwide with learning and attention issues.
Autism

Association for Science in Autism Treatment
P.O. Box 1447
Hoboken, NJ 07030
www.asatonline.org

Not-for-profit organization of parents and professionals committed to adopting higher standards of accountability for and improving the education, treatment, and care of all individuals with autism.

Autism National Committee
3 Bedford Green
South Burlington, VT 05403
http://autcom.org

Works to protect and advance the human and civil rights of all persons with autism, pervasive developmental disorder, and related differences of communication and behavior.

Autism Research Institute
4182 Adams Avenue
San Diego, CA 92116
833-281-7165
www.autism.com

Conducts research and disseminates research-based information on the cause, prevention, and treatment of autism and related disorders.

Autism Science Foundation
106 West 32nd Street, Suite #182
New York, NY 10001
949-810-9100
www.autismsciencefoundation.org

Supports autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. Also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism.
Promotes lifelong access and opportunities for persons within the autism spectrum of disorders and their families through advocacy, public awareness, education, and research programs. Its research Foundation raises and provides funds to support biomedical and applied research to address unanswered questions about autism.

Autism Speaks
1 East 33rd Street, Fourth Floor
New York, NY 10016
646-385-8523
www.autismspeaks.org

Nonprofit organization dedicated to finding the causes, prevention, effective treatment and, ultimately, a cure for autism spectrum disorders. Provides research grants and fellowships and sponsors scientific conferences.

Coalition for Safe Minds
10807 Falls Road, Suite 1416
Brooklandville, MD 21022
202-780-9821
https://www.safeminds.org

Nonprofit organization dedicated to ending the autism epidemic by advancing environmental research and effective treatment.

MAAP Autism Spectrum Coalition
P.O. Box 524
Crown Point, IN 4630
219-662-1311
www.aspergersyndrome.org

Provides information, advice, and networking to families of individuals affected by the more advanced autism spectrum disorders, including autism, Asperger syndrome, and pervasive developmental disorder. Publishes a quarterly newsletter.

See also Birth Defect Research for Children, Inc., page 13.
Autoimmune Disorders

American Autoimmune Related Diseases Association
22100 Gratiot Avenue
Eastpointe, MI 48021
586-776-3900
www.aarda.org

National organization that works to alleviate suffering and the socioeconomic impact of autoimmunity. Dedicated to the eradication of autoimmune diseases through fostering and facilitating collaboration in the areas of education, research, and patient services.

See also Multiple Sclerosis, page 45 and Myasthenia Gravis, page 50.

Back Pain
(See Pain)

Barth Syndrome

Barth Syndrome Foundation, Inc.
2005 Palmer Avenue, #1033
Larchmont, NY 10538
914-303-6323
www.barthsyndrome.org

Supports families and individuals affected by Barth syndrome through education, awareness, and research grant programs. Works with physicians to improve diagnosis and treatment and stimulates scientific advances ultimately in pursuit of a cure.
Batten Disease

Batten Disease Support and Research Association
2780 Airport Drive, Suite 342
Columbus, OH 43219
800-448-4570
https://bdsra.org

Dedicated to funding research, providing family support services, raising awareness, and advocating on behalf of those with Batten disease and their families and caregivers. The largest support and research organization dedicated to Batten disease in North America.

Nathan’s Battle Foundation
459 State Road 135 South
Greenwood, IN 46142
317-888-7396
www.nathansbattle.com

Foundation established to aid in the development of therapies for late infantile Batten disease.

Behcet’s Disease

American Behcet’s Disease Association
P.O. Box 80576
Rochester, MI 48308
800-723-4238
www.behcets.com

Nonprofit information and support resource. Provides information to the medical community and works to decrease isolation and stress for people with Behcet’s disease and their family members.
Birth Defects

Birth Defect Research for Children, Inc.
976 Lake Baldwin Lane, Suite 104
Orlando, FL 32814
407-895-0802
www.birthdefects.org

Nonprofit organization that offers parents and expectant parents information about specific birth defects, their causes and treatments, support group referrals, and parent matching services. Provides information about environmental exposures that may be associated with birth defects. Sponsors the National Birth Defect Registry, a research project that collects data on birth defects and prenatal/preconceptual exposures of mothers and fathers.

Children’s Craniofacial Association
13140 Coit Road, Suite 517
Dallas, TX 75240
800-535-3643
214-570-9099
www.ccakids.org

Nonprofit organization dedicated to improving the quality of life for people with facial differences and their families.

March of Dimes
1550 Crystal Drive, Suite 1300
Arlington, VA 22202
888-663-4637
www.marchofdimes.com
www.nacersano.org (Spanish)

Works to improve the health of babies by preventing birth defects and infant mortality through programs of research, community services, education, and advocacy.
Pediatric Brain Foundation
(formerly Children’s Neurobiological Solutions)
2144 E. Republic Road, Building B, Suite 202
Springfield, MO 65804
417-887-4242
www.pediatricbrainfoundation.org
Facilitates science for and educates parents of children with neurological conditions, as well as educated public officials on the critical importance of funding pediatric neurological research.

Birthmarks
(See also Sturge-Weber Syndrome)

Vascular Birthmarks Foundation
P.O. Box 106
Latham, NY 12110
877-823-4646
http://birthmark.org
Provides support and resources for children and adults born with hemangioma, port wine stains, and other vascular birthmark disorders. Offers a newsletter and referrals to clinics.

Blepharospasm
(See also Dystonia)

Benign Essential Blepharospasm Research Foundation
P.O. Box 12468
Beaumont, TX 77726-2468
409-832-0788
www.blepharospasm.org
Works to promote and carry on the search for the cause of and a cure for benign essential blepharospasm and other related disorders and infirmities of the facial musculature.
Brachial Plexus Injuries/Erb’s Palsy

United Brachial Plexus Network
31 William Road
Reading, MA 01867
781-315-6161
https://ubpn.org

Nonprofit organization devoted to providing information, support, and leadership for families and those concerned with brachial plexus injuries worldwide. Publishes a magazine called Outreach Newsletter for families and those concerned with brachial plexus injuries.

Brain Tumor

Accelerate Brain Cancer Cure, Inc. (ABC2)
1717 Rhode Island Avenue, NW, Suite 700
Washington, DC 20036
202-419-3140
www.abc2.org

Focused on investing in research aimed at finding the fastest possible route to a cure for brain cancer.

American Brain Tumor Association
8550 W. Bryn Mawr Avenue, Suite 550
Chicago, IL 60631
773-577-8750
800-886-2282
www.abta.org

Nonprofit organization that funds researchers working toward breakthroughs in brain tumor diagnosis, treatment, and care. Offers comprehensive resources that serve the complex supportive care needs of brain tumor patients and caregivers.
American Cancer Society
National Home Office
250 Williams Street, NW
Atlanta, GA 30303-1002
800-227-2345
www.cancer.org

Nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

Childhood Brain Tumor Foundation
20312 Watkins Meadow Drive
Germantown, MD 20876
301-515-2900
877-217-4166
www.childhoodbraintumor.org

Nonprofit organization that raises funds for scientific and clinical research to improve both prognosis and quality of life for those affected by pediatric brain tumors. Works to heighten public awareness and provides information and resources for families and patients.

Children’s Brain Tumor Foundation
1460 Broadway
New York, NY 10036
866-228-4673
http://cbtf.org

Works to improve the treatment, quality of life, and long-term outlook for children with brain and spinal cord tumors through research, support, education, and advocacy programs.

Cushing’s Support and Research Foundation
60 Robbins, #12
Plymouth, MA 02360
617-723-3674
http://csrf.net

Provides information and support for Cushing’s disease and Cushing’s syndrome patients and their families and works to increase awareness and educate the public.
Hope for Hypothalamic Hamartomas
P.O. Box 721
Waddell, AZ 85355
www.hopeforhh.org

Provides information and support to hypothalamic hamartoma patients, caregivers, and healthcare providers and promotes research toward early detection, improved treatments, living with HH, and a cure.

Musella Foundation for Brain Tumor Research and Information
1100 Peninsula Boulevard
Hewlett, NY 11557
516-295-4740
888-295-4740
www.virtualtrials.com

Nonprofit organization dedicated to improving the quality of life and survival times for brain tumor patients by providing information and raising money for brain tumor research.

National Brain Tumor Society
55 Chapel Street, Suite 200
Newton, MA 02458
617-924-9997
866-455-3214
www.braintumor.org

Nonprofit organization committed to finding a cure for brain tumors. Aggressively drives strategic research, advocates for public policies that meet the critical needs of the brain tumor community and provides trusted patient information.

Pediatric Brain Tumor Foundation
302 Ridgefield Court
Asheville, NC 28806
828-665-6891
800-253-6530
www.curethekids.org

The world’s largest non-governmental funder of research into one of the deadliest forms of childhood cancer. Programs also include free educational resources, college scholarships for brain tumor survivors, and mission-focused awareness events.
Pituitary Network Association
P.O. Box 1958
Thousand Oaks, CA 91358
805-499-9973
https://pituitary.org

International nonprofit organization for patients with pituitary disorders, their families, loved ones, and the physicians and healthcare providers who treat them.

The Preuss Foundation, Inc.
2223 Avenida de la Playa, Suite 220
La Jolla, CA 92037
858-454-0200
www.thepreussfoundation.org

Provides forums for basic brain tumor researchers in an effort to increase communication and collaboration.

See also International RadioSurgery Association, page 1.

Canavan Disease

Canavan Disease Research
P.O. Box 5823
Buffalo Grove, IL 60089
800-833-2194
www.canavanresearch.org

Nonprofit organization that funds research, works to raise public awareness, and offers services in support of families affected by Canavan disease.

Canavan Foundation
600 West 111th Street, 8A
New York, NY 10024
866-907-1847
www.canavanfoundation.org

Works to educate the target population about genetic screening available for Canavan disease and other Jewish genetic diseases, and supports research to find a treatment and cure for Canavan disease.
Canavan Research Foundation
88 Route 37
New Fairfield, CT 06812
203-240-2326
www.canavan.org

All-volunteer nonprofit organization that funds research leading to treatments and/or a cure for diseases of the brain. Offers information and sponsors parent support programs.

See also National Tay-Sachs and Allied Diseases Association, page 71 and United Leukodystrophy Foundation, page 39.

Cavernous Malformation
(See also Arteriovenous Malformation)

Angioma Alliance
161 Jefferson Drive
Palmyra, VA 22963
866-432-5226
www.angiomaalliance.org

Nonprofit charitable organization created by people affected by cavernous angiomas. Provides education and support and promotes research.

Nevus Outreach, Inc.
600 SE Delaware Avenue, Suite 200
Bartlesville, OK 74003
918-331-0595
www.nevus.org

Nonprofit organization dedicated to improving awareness and providing support for people affected by congenital pigmented nevi, and finding a cure.

Cerebral Palsy

Cerebral Palsy Foundation
3 Columbus Circle, 15th Floor
New York, NY 10019
212-520-1686
http://yourcpf.org

Provides grants for research and training on causes and prevention of cerebral palsy and on improving the quality of life of persons with cerebral palsy.
Pathways.org
150 North Michigan Avenue, #2100
Chicago, IL 60601
800-955-2445
www.pathways.org

National nonprofit organization dedicated to raising awareness about the value of early detection, early therapy, and inclusion for infants and children with movement differences.

United Cerebral Palsy (UCP)
1825 K Street, NW, Suite 600
Washington, DC 20006
202-776-0406
800-872-5827
www.ucp.org

Works to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities, through our commitment to the principles of independence, inclusion and self-determination.

Charcot-Marie-Tooth Disorder
(See also Peripheral Neuropathy)

Charcot-Marie-Tooth Association (CMTA)
P.O. Box 105
Glenolden, PA 19036
610-499-9264
800-606-2682
www.cmtausa.org

Provides education and support to persons with Charcot-Marie-Tooth disorders, their families, and the health professionals who treat them.
Hereditary Neuropathy Foundation
401 Park Avenue South, 10th Floor
New York, NY 10016
212-722-8396
855-435-7268
www.hnf-cure.org
Nonprofit organization that raises awareness, funds innovative research, and offers medical information and emotional support for those with Charcot-Marie-Tooth disorder and their families and caregivers.

Chiari Malformation
(See also Spina Bifida and Syringomyelia)

Chiari and Syringomyelia Foundation
29 Crest Loop
Staten Island, NY 10312
718-966-2593
www.csinfo.org
Nonprofit organization committed to disseminating accurate and current information about treatments for and best practices surrounding the management of Chiari malformation, syringomyelia, and related disorders.

Coffin-Lowry Syndrome

Coffin-Lowry Syndrome Foundation
675 Kalmia Place, NW
Issaquah, WA 98027
425-427-0939 (between 6 p.m. and 9 p.m. PST)
http://clsf.info
Clearinghouse for information on Coffin-Lowry syndrome (CLS). Provides a general forum for exchanging experiences, advice, and information with other CLS families. Works to facilitate referrals for newly diagnosed individuals and to encourage medical and behavioral research in order to improve methods of social integration of CLS individuals.

Complex Regional Pain Syndrome
(See Reflex Sympathetic Dystrophy Syndrome)
Creutzfeldt-Jakob Disease

Creutzfeldt-Jakob Disease Foundation, Inc.
3610 Market Street
Akron, OH 44333
800-659-1991
https://cjdfoundation.org

Provides education and support to families affected by CJD, educates the community at large about CJD, and advocates for continued and increased research funds aimed at finding a treatment and eventually a cure.

National Prion Disease Pathology Surveillance Center
Institute of Pathology
Case Western Reserve University
2085 Adelbert Road, Room 419
Cleveland, OH 44106
216-368-0587
www.cjdsurveillance.com

Acquires tissue samples and clinical information to help monitor the possible occurrence of variant CJD (vCJD) in the United States. Studies prion diseases in animals that potentially may transmit the disease to humans.

Dandy-Walker Syndrome
(See also Birth Defects and Hydrocephalus)

Dandy-Walker Alliance
10325 Kensington Parkway, Suite 384
Kensington, MD 20895
877-326-3992
www.dandy-walker.org

Nonprofit organization committed to educational and informational activities, programs and publications, and supporting non-partisan research and events to increase public awareness for Dandy-Walker. Supports all efforts to determine the cause(s) of, find the cure for, and to ameliorate the effects of Dandy-Walker.
Dizziness and Balance
(See Vestibular Disorders)

Down Syndrome

National Down Syndrome Society
8 E. 41st Street, 8th Floor
New York, NY 10017
800-221-4602
www.ndss.org

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance, and inclusion of people with Down syndrome.

Dysautonomia
(See also Genetic Disorders and Shy-Drager Syndrome)

Dysautonomia Foundation
315 West 39th Street, Suite 701
New York, NY 10018
212-279-1066
www.familialdysautonomia.org

Nonprofit organization that supports medical research and clinical care. Offers information and sponsors chapters nationwide and overseas.

Dysautonomia International
67 Woodlawn Avenue
East Moriches, NY 11940
www.dysautonomiainternational.org

Nonprofit organization that seeks to identify the causes and cures for all forms of dysautonomia and to enhance the quality of life of people currently living with these illnesses.
Dysautonomia Youth Network of America (DYNA)
1301 Greengate Court
Waldorf, MD 20601
301-705-6995
www.dynainc.org

Nonprofit support and outreach network dedicated to serving youth diagnosed with various dysautonomia conditions. Provides peer and educational support, serves as a member forum for parents and youth, and sponsors a summer conference.

Familial Dysautonomia Hope Foundation, Inc. (FD Hope)
121 South Estes Drive, Suite 205D
Chapel Hill, NC 27514
919-969-1414
www.fdhope.org

Nonprofit organization that works to expand and accelerate research toward a cure for familial dysautonomia and to improve the lives of children and adults challenged by the disease. Funds research programs, provides a support network for patients and families, and promotes education and awareness in the medical community and the public.

National Dysautonomia Research Foundation
P.O. Box 301
Red Wing, MN 55066-0301
651-327-0367
www.ndrf.org

Nonprofit foundation established to help those with any of the various forms of dysautonomia. Provides a support network for affected individuals and family members by providing information on the various forms of dysautonomia, as well as providing contacts to other organizations that may be of assistance.
Dystonia
(See also Blepharospasm, Spasmodic Dysphonia/Spasmodic Torticollis)

The Bachmann-Strauss Dystonia & Parkinson Foundation
P.O. Box 38016
Albany, NY 12203
212-509-0995
www.dystonia-parkinson.org

Nonprofit foundation that supports patients, family members, researchers, clinicians, and volunteers working in partnership to find better medical treatments and a cure for dystonia and Parkinson’s disease.

Dystonia Medical Research Foundation
1 East Wacker Drive, Suite 1730
Chicago, IL 60601-1905
312-755-0198
www.dystonia-foundation.org

Nonprofit medical research foundation that funds research, advances awareness, and provides education and support on dystonia.

Epilepsy

Antiepileptic Drug Pregnancy Registry
Massachusetts General Hospital
125 Nashua Street, Suite 8438
Boston, MA 02114
888-233-2334
www.aedpregnancyregistry.org

Registry designed to determine what therapies are associated with increased risk of harmful fetal effects. Participation is confidential.
Charlie Foundation for Keotogenic Therapies
515 Ocean Avenue, #602N
Santa Monica, CA 90403
310-393-2347
https://charliefoundation.org

Nonprofit organization that raises money for scientific research, education, and public awareness of diet therapies for epilepsy. Offers education, programs, and materials for caregivers, dietitians, and physicians, and hospitals.

Citizens United for Research in Epilepsy (CURE)
430 West Erie Street, Suite 210
Chicago, Illinois 60654
312-255-1801
800-231-2873
www.CUREepilepsy.org

With its mission to find a cure for epilepsy, CURE is the largest private funder of epilepsy research and has invested more than $18 million in 160 scientists and laboratories in 13 countries around the world.

Dravet Syndrome Foundation
P.O. Box 3026
Cherry Hill, NJ 08034
203-392-1950
www.dravetfoundation.org

Provides advocacy and awareness, education and information, patient and family support, and increased medical research, with the goal to improve treatment of Dravet Syndrome and other related genetic, febrile sodium channel epilepsies.
Epilepsy Foundation
8301 Professional Place West, Suite 230
Landover, MD 20785
301-459-3700
800-332-1000
www.epilepsy.com

National charitable organization dedicated to the welfare of individuals and families impacted by epilepsy and seizures. Works to prevent, control, and cure epilepsy through community services; public education; federal and local advocacy; and supporting research into new treatments and therapies.

LGS Foundation (Lennox-Gastaut Syndrome)
80 Orville Drive, Suite 100
Bohemia, NY 11716
718-374-3800
www.lgsfoundation.org

Not-for-profit organization dedicated to providing information about Lennox-Gastaut Syndrome, a rare and severe form of childhood onset epilepsy, while raising funds for research, programs, and services for individuals living with LGS, and their families.

RE Children’s Project
79 Christie Hill Road
Darien, CT 06820
917-971-2977

National organization devoted to increase awareness regarding Rasmussen’s Encephalitis (RE) for the primary purpose of supporting scientific research directed toward a cure.

See also Hope for Hypothalamic Hamartomas, page 17.
Fabry Disease
(See also Tay-Sachs Disease)

Fabry Support & Information Group
108 NE Second Street, Suite C
P.O. Box 510
Concordia, MO 64020-0510
660-463-1355
866-303-2279
www.fabry.org

Nonprofit support and information group that works to raise awareness of Fabry disease and its symptoms. Offers a variety of self-help, educational, and advocacy initiatives and programs in an effort to enhance identification, diagnosis, and treatment of Fabry disease.

National Fabry Disease Foundation
4301 Connecticut Avenue, NW, Suite 404
Washington, DC 20008-2369
800-651-9131
www.fabrydisease.org

The National Fabry Disease Foundation works to increase the level of effort devoted to assisting and supporting people with Fabry disease. Primary functions include education, improving disease recognition and diagnosis, assistance to individuals with the disease, supporting Fabry disease research, and advocacy.

Fibromyalgia

American Fibromyalgia Syndrome Association, Inc.
P.O. Box 32698
Tucson, AZ 85751
520-733-1570
www.afsafund.org

All-volunteer research-funding organization that encourages scientific research toward finding the cause of and cure for fibromyalgia syndrome.
Arthritis Foundation  
1355 Peachtree Street NE, Suite 600  
Atlanta GA 30309  
844-571-4357  
www.arthritis.org  

Volunteer-driven organization that works to improve lives through leadership in the prevention, control, and cure of arthritis and related diseases. Offers free brochures on various types of arthritis, treatment options, and management of daily activities.

National Fibromyalgia Association  
3857 Birch Street, Suite 312  
Newport Beach, CA 92660  
www.fmaware.org  

Nonprofit organization that develops and executes programs dedicated to improving the quality of life for people with fibromyalgia by increasing awareness of the disorder with the public, media, government, and medical communities.

National Fibromyalgia Partnership, Inc.  
P.O. Box 2355  
Centreville, VA 20122  
866-725-4404  
www.fmpartnership.org  

Non-profit, membership organization of patients and medical professionals offering information on fibromyalgia, including the journal Fibromyalgia Frontiers.

See also American Autoimmune Related Diseases Association, page 11.
Fragile X Disease
(See also Genetic Disorders)

FRAXA Research Foundation
10 Prince Place, Suite 203
Newburyport, MA 01950
978-462-1866
https://fragilex.org

Funds research and sponsors educational and support programs on Fragile X syndrome, the most common inherited cause of intellectual and developmental disabilities.

National Fragile X Foundation
1861 International Drive, Suite 200
McLean, VA 22102
800-688-8765
www.fragilex.org

Provides support, education, awareness, research, and legislative advocacy for all Fragile X-associated disorders including fragile X syndrome (FXS), fragile X-associated tremor/ataxia syndrome (FXTAS), and fragile X-associated primary ovarian insufficiency (FXPOI).

Friedreich’s Ataxia
(See also Ataxia)

Friedreich’s Ataxia Research Alliance
533 W. Uwchlan Avenue
Downingtown, PA 19335
484-879-6160
www.curefa.org

National nonprofit organization dedicated to the pursuit of educational, scientific, and research activities leading to treatments for Friedreich’s ataxia and the related sporadic ataxias.
Frontotemporal Dementia

Association for Frontotemporal Degeneration
Radnor Station Building 2, Suite 320
290 King of Prussia Road
Radnor, PA 19087
267-514-7221
866-507-7222
www.theaftd.org

Works to improve the quality of life for people affected by frontotemporal degeneration and drive research to a cure.

The Bluefield Project to Cure Frontotemporal Dementia
637 Carolina Street
San Francisco, CA 94107
www.bluefieldproject.org

Nonprofit organization that raises awareness of and increases support to accelerate and fund research directed toward curing frontotemporal dementia (FTD).

See also Alzheimer’s Disease, page 2.

Gaucher Disease
(See also Genetic Disorders and Tay-Sachs Disease)

Children’s Gaucher Research Fund
8110 Warren Court
Granite Bay, CA 95746-2123
916-797-3700
www.childrensgaucher.org

Nonprofit organization that supports research efforts on Types 2 and 3 Gaucher disease.
National Gaucher Foundation
5410 Edson Lane, Suite 220
Rockville, MD 20852
800-504-3189
www.gaucherdisease.org

Funds research for a cure and alternative treatments for Gaucher disease, provides educational, financial, support and mentor programs, and advocates for legislation affecting the Gaucher and rare disease community.

Genetic Disorders
(See also individual disorder headings)

Genetic and Rare Diseases Information Center
National Institutes of Health
National Human Genome Research Institute
P.O. Box 8126
Gaithersburg, MD 20898-8126
301-251-4925
888-205-2311
www.genome.gov/10000409/

Genetic Alliance
4301 Connecticut Avenue, NW, Suite 404
Washington, DC 20008-2369
202-966-5557
www.geneticalliance.org

International coalition representing 600 consumer and professional organizations. Supports individuals and families with genetic conditions, educates the public, and advocates for consumer-informed public policies.

Phelan-McDermid Syndrome Foundation
200 Capri Isles Boulevard, Suite 7F
Venice, Florida 34292
941-485-8000
www.pmsf.org

Leading non-profit organization in the world that offers family support, facilitates research, and raises awareness of the rare genetic condition caused by deletions of part of chromosome 22 22q13 and mutations of the SHANK3 gene.
Giant Axonal Neuropathy

Hannah’s Hope Fund
19 Blue Jay Way
Rexford, NY 12148
518-275-5359
www.hannahshopefund.org

Nonprofit charity whose mission is to raise funds to support the development of a treatment and cure for GAN, and to be the resource for doctors, scientists and families world-wide.

Glycogen Storage Diseases
(See also Metabolic Disorders)

Association for Glycogen Storage Disease
P.O. Box 896
Durant, IA 52747
563-514-4022
www.agsdus.org

International nonprofit organization that acts as a focus for individuals with glycogen storage diseases and their families. Works to foster communication between family members, professionals, and others for the purpose of support and information sharing.

ISMRD-International Advocates for Glycoprotein Storage Diseases
20880 Canyon View Drive
Saratoga, CA 95070
734-449-1190
www.ismrdd.org

Advocates for families worldwide affected by glycoprotein and related storage diseases by building partnerships with medicine, science, and industry and by providing a network of support and information.
Guillain-Barré Syndrome

GBS/CIDP Foundation International
375 East Elm Street, Suite 101
Conshohocken, PA 19428
866-224-3301

Voluntary nonprofit organization that provides education and support to patients and families with Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and their variants. Awards grants to researchers and offers informational materials to healthcare professionals.

Hallervorden-Spatz Syndrome
(See Neurodegeneration with Brain Iron Accumulation)

Headache

American Headache Society
19 Mantua Road
Mt. Royal, NJ 08061
856-423-0043
https://americanheadachesociety.org

Nonprofit patient-health professional partnership dedicated to advancing the treatment and management of headache and to raising public awareness of headache as a valid, biologically based illness.

Migraine Research Foundation
300 East 75th Street, Suite 3K
New York, NY 10021
212-249-5402
https://migraineresearchfoundation.org

Nonprofit organization dedicated to ending the debilitating pain of migraine by raising money to fund promising research into its causes and treatment.
National Headache Foundation
820 N. Orleans, Suite 201
Chicago, IL 60610
312-274-2650
888-643-5552
https://headaches.org

Nonprofit organization dedicated to enhancing the treatment of headache sufferers. Provides information and educational resources, supports headache research, and advocates for the understanding of headache as a legitimate neurobiological disease.

Head Injury
(See Trauma)

Hemangioma
(See Birthmarks)

Hemiplegia, Alternating (of Childhood)

Alternating Hemiplegia of Childhood Foundation (AHCF)
2000 Town Center, Suite 1900
Southfield, MI 48075
313-663-7772
http://ahckids.org

Voluntary nonprofit foundation established to support children with alternating hemiplegia and their parents. Supports research, raises funds, and offers a newsletter, brochures, and fact sheets to those interested in knowing more about alternating hemiplegia.
**Holoprosencephaly**

**Carter Centers for Brain Research in Holoprosencephaly and Related Brain Malformations**
c/o Texas Scottish Rite Hospital for Children
2222 Welborn Street
Dallas, TX 75219-3993
214-559-8411
www.hperesearch.org

Collaborative initiative created to gather, analyze, and share information about holoprosencephaly. Maintains an international registry and an ongoing holoprosencephaly database. Supports and conducts research and maintains a network of Centers of Excellence.

**Huntington’s Disease**

**Hereditary Disease Foundation**
601 West 168th Street, Suite 54
New York, NY 10032
212-928-2121
www.hd foundation.org

Nonprofit, basic science organization dedicated to the cure of genetic diseases.

**Huntington’s Disease Society of America**
505 Eighth Avenue, Suite 902
New York, NY 10018
212-242-1968
800-3454372
www.hdsa.org

Dedicated to finding a cure for Huntington’s disease while providing support and services for those living with the disease and their families.
Hydrocephalus

Hydrocephalus Association
4340 East West Highway, Suite 905
Bethesda, MD 20814
301-202-3811
888-598-3789
www.hydroassoc.org

Non-profit patient organization committed to eliminating the challenges of hydrocephalus by providing support, education, and advocacy programs for families and professionals while facilitating progressive research throughout the US and Canada.

Children’s Hydrocephalus Support Group, Inc.
P.O. Box 4236
Chesterfield, MO 63006-4236
636-532-8228
www.hydrosupport.org

Nonprofit organization that publishes a quarterly newsletter, provides referrals, sponsors meetings and conferences, and offers an information library of articles and tapes about hydrocephalus.

National Hydrocephalus Foundation
12413 Centralia Road
Lakewood, CA 90715-1653
562-924-6666
http://nhfonline.org

National nonprofit organization that offers information and support services for patients and their families. Provides professional and patient information and referrals to chapters and support groups, sponsors meetings and scientific workshops, and funds research.

Inclusion Body Myositis
(See Myositis)
Intracranial Hypertension Syndrome

Intracranial Hypertension Research Foundation
6517 Buena Vista Drive
Vancouver, WA 98661
360-693-4473
https://ihrfoundation.org

International non-profit sponsoring and funding medical research of idiopathic intracranial hypertension (pseudotumor cerebri) and secondary intracranial hypertension. Provides communication and educational tools for patients; sponsors educational training opportunities for physicians and scientists; operates the IH patient database Registry.

Joubert Syndrome

Joubert Syndrome & Related Disorders
Foundation
9 Dorenfeld Court
Petaluma, CA 94952
614-864-1362
http://jsrdf.org

Nonprofit organization that offers information and support to families worldwide. Sponsors a conference, publishes a quarterly newsletter, and works to increase public awareness.

Kennedy’s Disease
(See also Spinal Muscular Atrophy)

Kennedy’s Disease Association
P.O. Box 1105
Coarsegold, CA 93614
855-532-7762
https://kennedysdisease.org

Nonprofit resource that offers support and information about spinal bulbar muscular atrophy, or Kennedy’s disease. Works to increase awareness and to raise funds in support of research. Sponsors support groups.

Krabbe Disease
(See Leukodystrophy)
Leukodystrophy
(See also individual disorder headings)

Hunter’s Hope Foundation
21 Princeton Plaza, Suite 12
P.O. Box 643
Orchard Park, NY 14127
716-667-1200
www.huntershope.org

Funds research for improved treatments and a cure for Krabbel disease and the leukodystrophies, raising awareness, expanding newborn screening and supporting families affected by these dreadful diseases.

MLD Foundation
21345 Miles Drive
West Linn, OR 97068
503-656-4808
800-617-8387
www.mldfoundation.org

A 501 (3) nonprofit organization formed to serve families throughout the world affected by metachromatic leukodystrophy (MLD). Focuses on offering families resources, including support, practical care, family conferences, emerging therapies, and clinical trial updates.

United Leukodystrophy Foundation
224 North 2nd Street, Suite 2
DeKalb, IL 60115
815-748-3211
800-728-5483
https://ulf.org

Nonprofit voluntary health organization that promotes and supports research into causes, treatments, and prevention of the leukodystrophies. Provides information, assists in identifying sources of medical care, social services, and genetic counseling; builds a communication network among families; and acts as an information source for healthcare providers.

See also Myelin Project, page 50.
Lewy Body Dementia
(See also Alzheimer’s Disease and Parkinson’s Disease)

Lewy Body Dementia Association
912 Killian Hill Road, SW
Lilburn, GA 30047
404-935-6444
800-539-9767 (Caregiver link)
www.lbda.org

National nonprofit health organization dedicated to raising awareness of Lewy body dementias (LBD), promoting scientific advances, and supporting people with LBD, their families and caregivers.

Lowe Syndrome

Lowe Syndrome Association
P.O. Box 417
Chicago Ridge, IL 60415
216-630-7723
www.lowesyndrome.org

Provides information, fosters communication among families, and supports medical research on Lowe syndrome. Activities include conferences, a research grant program, a newsletter, and other publications.

Lysosomal Storage Diseases
(See also Metabolic Disorders)

Hide and Seek Foundation/SOAR
6475 East Pacific Coast Highway, Suite 466
Long Beach, CA 90803
844-762-7672
https://hideandseek.org

Nonprofit that raises awareness and supports research to find treatments and cures for lysosomal disorders.
Meningitis and Encephalitis

Meningitis Foundation of America, Inc.
P.O. Box 1818
El Mirage, AZ 85335
480-270-2652
https://musa.org

Helps support patients with meningitis and their families. Provides information to educate the public and medical professionals about early diagnosis and treatment. Also works for the development of vaccines and other means of treating and/or preventing meningitis.

National Meningitis Association
P.O. Box 60143
Ft. Myers, FL 33906
866-366-3662
www.nmausa.org

Nonprofit public charity that works to inform families, medical professionals, and others about the dangers of meningococcal meningitis and the benefits of vaccination.

HHV-6 Foundation
1482 East Valley Road, Suite 619
Santa Barbara, CA 93108
888-530-6726
https://hhv-6foundation.org

Nonprofit organization that encourages scientific exchange among scientists and provides pilot grants for promising scientific and clinical research related to human herpesvirus 6 (HHV-6).
Metabolic Disorders
(See also Genetic Disorders, individual disorder headings, and Mitochondrial Disorders)

Acid Malate Deficiency Association (AMDA)
P. O. Box 700248
San Antonio, TX 78270
210-494-6144
www.amda-pompe.org

National nonprofit that funds research and promotes public awareness of Pompe disease.

American Liver Foundation
39 Broadway Street, #2700
New York, NY 10006
212-668-1000
800-465-4837
https://liverfoundation.org

National nonprofit health agency dedicated to the prevention, treatment, and cure of hepatitis and all liver diseases through research, education, and advocacy.

Association for Creatine Deficiencies
6965 El Camino Real, Suite 105-598
Carlsbad, CA 92009
https://creatineinfo.org

Nonprofit organization whose mission is to eliminate the challenges of creatine deficiency syndromes through education, advocacy, and medical research.

Iron Disorders Institute
P. O. Box 4891
Greenville, SC 29608
888-565-4766
www.irondisorders.org

National public interest organization that aids in the prevention and treatment of disease caused when iron is out of balance in the human body. Offers a number of education, awareness, advocacy, and research programs.
Pediatric Neurotransmitter Disease Association
28 Prescott Place
Old Bethpage, NY 11804
www.pndassoc.org

National nonprofit organization dedicated to helping children and families who are affected by dopamine-related pediatric neurotransmitter diseases (PND) such as tyrosine hydroxylase deficiency. Supports the identification of new PND’s, better treatments, and ultimately a cure for those diseases that are already known.

See also Hide and Seek Foundation/SOAR, page 40, Mucolipidosis Type IV (ML4) Foundation, page 44, Muscular Dystrophy Association, page 49, National MPS Society, Inc., page 44, and United Mitochondrial Disease Foundation, page 43.

Mitochondrial Disorders
(See Metabolic Disorders)

MitoAction
P.O. Box 51474
Boston, MA 10005
888-648-6228
www.mitoaction.org

Works to improve quality of life for adults and children affected by mitochondrial disease through support, education, and advocacy initiatives and to raise awareness about mitochondrial disorders.

United Mitochondrial Disease Foundation
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239
412-793-8077
888-317-8633
www.umdf.org

Promotes research for cures and treatments of mitochondrial disorders and provides support for affected families. Represents adults and children alike and serves families with a variety of programs.
Moebius Syndrome  
(*See also Birth Defects*)

Moebius Syndrome Foundation  
P.O. Box 147  
Pilot Grove, MO 65276  
844-663-2487  
https://moebiussyndrome.com

Nonprofit organization that provides individuals and families with a support network, promotes public and professional education about the disorder, and promotes and funds research.

Movement Disorders  
(*See Ataxia, Parkinson’s Disease, and Tremor*)

Mucolipidosis  
(*See also Genetic Disorders and Metabolic Disorders*)

Mucolipidosis Type IV (ML4) Foundation  
1440 Spring Street, NW  
Atlanta, GA 30309  
877-654-5459  
ml4.org

Funds, promotes, and supports medical research dedicated to developing treatments and a cure for ML4, which causes mental retardation, motor delays, retinal degeneration, and limited lifespan.

Mucopolysaccharidosis  
(*See also Genetic Disorders and Metabolic Disorders*)

National MPS Society, Inc.  
P.O. Box 14686  
Durham, NC 27709-4686  
919-806-0101  
877-677-1001  
www.mpssociety.org

Dedicated to finding cures for mucopolysaccharidosis (MPS) and related diseases. Provides hope and support for affected individuals and their families by sponsoring research, advocacy, and awareness programs.
Multiple Sclerosis

Accelerated Cure Project for Multiple Sclerosis
460 Totten Pond Road, Suite 140
Waltham, MA 02451
781-487-0008
www.acceleratedcure.org

Nonprofit organization dedicated to accelerating research to cure MS. Initiatives include the ACP Repository of data and biospecimens; the MS Discovery Forum research news/information portal; the MS Patient-Powered Research Network, an online research community for people with MS; and the OPT-UP study (Optimizing Treatment-Understanding Progression).

Multiple Sclerosis Association of America
375 Kings Highway North
Cherry Hill, NJ 08034
800-532-7667
https://mymsaa.org

National nonprofit organization dedicated to enhancing the quality of life for those affected by multiple sclerosis. Provides ongoing support and direct services to patients and their families and works to promote a greater understanding of the needs and challenges of those who face physical obstacles.

Multiple Sclerosis Foundation
6520 North Andrews Avenue
Ft. Lauderdale, FL 33309-2130
954-776-6805
888-673-6287
http://msfocus.org

Dedicated to helping people with multiple sclerosis. Offers a wide array of free services including national toll-free support, educational programs, homecare, support groups, assistive technology, publications, a comprehensive website, and more programs to improve the quality of life for those affected by multiple sclerosis.
Myelin Repair Foundation
18809 Cox Avenue, Suite 190
Saratoga, CA 95070
408-871-2410
http://myelinrepair.org

Foundation dedicated to delivering treatments for multiple sclerosis, by supporting research aimed at gaining a deeper understanding of the natural process of myelination.

National Multiple Sclerosis Society
733 Third Avenue, 3rd Floor
New York, NY 10017
212-463-7787
800-344-4867
www.nationalmssociety.org

Mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS. Funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services for people with MS and their families.

See also American Autoimmune Related Diseases Association, page 11, and Myelin Project, page 50.

Multiple System Atrophy (Shy-Drager Syndrome)
(See also Dysautonomia)
DefeatMSA
29924 Jefferson Avenue
Saint Clair Shores, MI 48082
855-542-5672
https://defeatmsa.org/

National nonprofit organization that aspires to balance efforts to support patients, educate medical professionals, raise public awareness and nurture promising research about Multiple System Atrophy.

Multiple System Atrophy Coalition
9935-D Rea Road, #212
Charlotte, NC 28227
866-737-5999
www.multiple-system-atrophy.org

National support group that collects and disseminates information and promotes education and support for people affected by Shy-Drager syndrome or multiple system atrophy.

Muscular Dystrophy

Coalition to Cure Calpain 3
15 Compo Parkway
Westport, CT 06880
203-829-9656
http://www.curecalpain3.org/

Coalition to Cure Calpain 3 provides support for promising research into finding treatments or a cure for limb-girdle muscular dystrophy, type 2A/Calpainopathy (LGMD2A).
Cure CMD (Congenital Muscular Dystrophy)
19401 S. Vermont Avenue, Suite J100
Torrance, CA 90405
323-250-2399
http://curecmd.org/

Nonprofit group whose mission is to bring research, treatments and, in the future, a cure for the congenital muscular dystrophies. Works globally with dedicated parent, government, and research advocates; funds high potential research and clinical trials, with success being determined by clinical applications that improve the lives of those afflicted with CMDs.

FSH Society (Facioscapulohumeral Dystrophy)
450 Bedford Street
Lexington, MA 02420
781-301-6060
www.fshsociety.org

Helps patients and families through education and outreach via a newsletter, website, conferences and social media; funds scientific research leading to treatments, guided by a world-class Scientific Advisory Board; and advocates for increased government and industry funding for research and to encourage drug trials.

Jain Foundation
9725 Third Avenue NE
Suite 204
Seattle, WA 98115
425-882-1440
www.jain-foundation.org

Seeks to expedite development of a cure or therapy for Limb-girdle muscular dystrophy type 2B (LGMD2B) and Miyoshi Myopathy. Maintains a patient registry, funds and monitors research and progress, provides financial support to accelerate clinical trials, and encourages scientific collaboration.
Muscular Dystrophy Association
National Office
161 N. Clark, Suite 3550
Chicago, IL 60601
800-572-1717
www.mda.org

Voluntary health agency that fosters neuromuscular disease research and provides patient care funded almost entirely by individual private contributors. Addresses the muscular dystrophies, spinal muscular atrophy, ALS, Charcot-Marie-Tooth disease, myasthenia gravis, Friedreich’s ataxia, metabolic diseases of muscle, and inflammatory diseases of muscle, for a total of more than 40 neuromuscular diseases.

Myotonic Dystrophy Foundation
1004A O’Reilly Avenue
San Francisco, CA 94129
415-800-7777
866-968-6642
www.myotonic.org

Enhances the quality of life of people living with myotonic dystrophy and advances research focused on treatments and a cure. The world’s largest patient organization focused solely on myotonic dystrophy.

Parent Project Muscular Dystrophy (PPMD)
401 Hackensack Avenue, 9th floor
Hackensack, NJ 07601
201-250-8440
800-714-5437
www.parentprojectmd.org

Dedicated to ending Duchenne muscular dystrophy through accelerated research and advocacy. Demands optimal care for all young men and educates the global community.
Myasthenia Gravis

Myasthenia Gravis Foundation of America, Inc.
355 Lexington Avenue, 15th Floor
New York, NY 10017
212-297-2156
800-541-5454
www.myasthenia.org

Works to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy, and patient care.

See also American Autoimmune Related Diseases Association, page 11, and Muscular Dystrophy Association, page 49.

Myelin Disorders

Myelin Project
P.O. Box 39
Pacific Palisades, CA 90272-0039
310-459-1071
888-869-3546
www.myelin.org

Works to accelerate research on repair of myelin, the white matter insulating the nerves, which can be destroyed by hereditary metabolic disorders, such as the leukodystrophies, and acquired disorders, such as multiple sclerosis.

See also American Autoimmune Related Diseases Association, page 11, Muscular Dystrophy Association, page 49, and Myelin Repair Foundation, page 46
Myositis

The Myositis Association
1940 Duke Street, Suite 200
Alexandria, VA 22314
703-299-4850
800-821-7356
www.myositis.org

Works to improve the lives of those affected by inflammatory myopathies. Seeks out persons with inflammatory myopathies, provides a support network, acts as a resource for patients and the medical community, advocates for patients, and promotes research into the causes and treatment of these disorders.

See also American Autoimmune Related Diseases Association, page 11, Arthritis Foundation, page 29, and Muscular Dystrophy Association, page 49.

Narcolepsy

(See Sleep Disorders)

Neurodegeneration with Brain Iron Accumulation

NBIA Disorders Association
2082 Monaco Court
El Cajon, CA 92019-4235
619-588-2315
www.nbiadisorders.org

Supports individuals and their families affected by Neurodegeneration with Brain Iron Accumulation. There are currently 11 different rare, genetic, neurological disorders under the NBIA umbrella that share the common feature of iron accumulation in the brain, along with a progressive movement disorder.
Neurofibromatosis
(See also Acoustic Neuroma and Genetic Disorders)

Children’s Tumor Foundation
120 Wall Street, 16th Floor
New York, NY 10005
212-344-6633
www.ctf.org

Nonprofit medical foundation dedicated to improving the health and well-being of individuals and families affected by neurofibromatosis. Sponsors scientific research, promotes the development of clinical activities, develops public awareness programs, and provides support services and referrals for patients and families.

Neurofibromatosis Network
213 S. Wheaton Avenue
Wheaton, IL 60187
630-510-1115
800-942-6825
www.nfnetwork.org

Dedicated to finding treatments and a cure for neurofibromatosis by promoting scientific research, improving clinical care, providing outreach through education and awareness, while offering hope and support to those affected by NF.

See also Acoustic Neuroma Association, page 1, and March of Dimes, page 13.

Neuromyelitis Optica

Guthy-Jackson Charitable Foundation
9663 Santa Monica Boulevard, Suite 700
Beverly Hills, CA 90210
310-620-3074
https://guthyjacksonfoundation.org

Funds basic science research to find answers that will lead to the prevention, clinical treatment programs and a potential cure for Neuromyelitis Optica (NMO) Spectrum Disease.
Niemann-Pick Disease
(See also Genetic Disorders)

Ara Parseghian Medical Research Foundation
4729 E. Sunrise Drive, Suite 327
Tucson, AZ 85718-4535
520-577-5106
www.parseghian.org

Funds research projects that will lead to a treatment for Niemann-Pick disease type C and other pediatric neurological diseases and cholesterol metabolism disorders.

National Niemann-Pick Disease Foundation
P.O. Box 49
Ft. Atkinson, WI 53538
920-563-0930
877-287-3672
https://nnpdf.org

International nonprofit organization made up of parents, medical and educational professionals, friends, relatives, and others who are committed to finding a cure for Niemann-Pick disease.

See also National Tay-Sachs and Allied Diseases Association, page 71.

Pain

American Chronic Pain Association
P.O. Box 850
Rocklin, CA 95677-0850
916-632-0922
800-533-3231
https://theacpa.org

Nonprofit organization that facilitates peer support and education for individuals with chronic pain so they may live more fully in spite of their pain. Raises awareness among the health care community and general public on the issues of living with chronic pain.

See also Arthritis Foundation, page 29.
Parkinson’s Disease

American Parkinson Disease Association
135 Parkinson Avenue
Staten Island, NY 10305-1425
718-981-3001
800-223-2732
Young Onset Center 877-223-3801
www.apdaparkinson.org

Seeks to “Ease the Burden – Find the Cure” through funding scientific research. Provides comprehensive patient/caregiver support and education.

Davis Phinney Foundation
357 S. McCaslin Boulevard, Suite 105
Louisville, CO 80027
303-733-3340
866-358-0285
www.davisphinneyfoundation.org

Dedicated to helping people with Parkinson’s disease to live well today. Provides information, inspiration, tools, resources, and opportunities to people living with PD and care partners to better manage their disease and promote increased engagement in health.

The Bachmann-Strauss Dystonia & Parkinson Foundation
P.O. Box 38016
Albany, NY 12203
212-509-0995
www.dystonia-parkinson.org

Nonprofit foundation that supports patients, family members, researchers, clinicians, and volunteers working in partnership to find better medical treatments and a cure for dystonia and Parkinson’s disease.
The Michael J. Fox Foundation for Parkinson’s Research
Grand Central Station
P.O. Box 4777
New York, NY 10163-4777
212-509-0995
800-708-7644
www.michaeljfox.org

Dedicated to finding a cure for Parkinson’s disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson’s today. Applies extraordinary scientific, business and media assets to this singular focus—thus creating a unique and dynamic organization.

Parkinson Alliance
P.O. Box 308
Kingston, NJ 08528
609-688-0870
800-579-8440
www.parkinsonalliance.org

Raises and distributes money for the most promising research leading to a cure for Parkinson’s disease. Umbrella organization responsible for the Parkinson’s Unity Walk; Team Parkinson, a fundraising organization on the West Coast; as well as DBS4PD.org, a web-based platform that offers patient surveys and current science review.

Parkinson’s Foundation
1359 Broadway, Suite 1509
New York, NY 10018
800-473-4636
https://parkinson.org

National nonprofit organization that supports Parkinson’s disease research, education, and public advocacy programs.
Parkinson’s Institute and Clinical Center
2500 Hospital Drive
Building 10, Suite 1
Mountain View, CA 94040
408-734-2800
800-655-2273
www.thepi.org

Nonprofit organization conducting patient care and research activities in the neurological specialty area of movement disorders.

Parkinson’s Resource Organization
74090 El Paseo, Suite 104
Palm Desert, CA 92260-4112
760-773-5628
877-775-4111
www.parkinsonsresource.org

Helps families affected by Parkinson’s disease. Offers emotional and educational support groups, publishes a monthly newsletter about quality of life and family issues, provides information and referral services, promotes advocacy and public awareness, and provides respite for family caregivers.

See also Lewy Body Dementia Association, page 40.

Pelizaeus-Merzbacher Disease
(See also Leukodystrophy and Myelin Disorders, page 50)

The PMD Foundation
P.O. Box 898
Salado, TX 76571
254-313-9107
www.pmdfoundation.org

Tax-exempt, nonprofit organization that serves families, researchers, and others affected by Pelizaeus-Merzbacher disease by supporting education, research, services, and advocacy programs.
Peripheral Neuropathy

The Foundation for Peripheral Neuropathy
485 Half Day Road, Suite 350
Buffalo Grove, IL 60089
877-883-9942
www.foundationforpn.org

Nonprofit organization whose mission is to dramatically improve the lives of people living with peripheral neuropathy.

American Diabetes Association
2451 Crystal Drive, Suite 900
Arlington, VA 22202
800-342-2383
www.diabetes.org

Nonprofit health organization providing diabetes research, advocacy services, and information, including the complications of diabetes, such as diabetic neuropathy.

Peroxisomal Disorders

The Global Foundation for Peroxisomal Disorders
P.O. Box 33238
Tulsa, OK 74135
347-470-4373
www.thegfpd.org

Nonprofit organization that helps children and families faced with a Peroxisome Biogenesis Disorder – Zellweger Spectrum Disorder (PBD-ZSD) diagnosis and to assist family members and professionals through education, research, and support services.

Polymyositis
(See Myositis)

Port Wine Stain
(See Birthmarks and Sturge-Weber Syndrome)
Post-Herpetic Neuralgia
(See Shingles)

Post-Polio Syndrome

Post-Polio Health International
(including International Ventilator Users Network)
4207 Lindell Boulevard, Suite 110
St. Louis, MO 63108-2930
314-534-0475
www.post-polio.org

Works to enhance the lives and independence of polio survivors and ventilator users through education, advocacy, research, and networking programs.

See also March of Dimes, page 13.

Prader-Willi Syndrome
(See also Angelman Syndrome)

Prader-Willi Syndrome Association
8588 Potter Park Drive, Suite 500
Sarasota, FL 34238
800-926-4797
www.pwsausa.org

Serves as an international vehicle of communication about Prader-Willi syndrome, a genetically based developmental disability. Provides parents and professionals a national and international network of information, support services, and research endeavors to meet the needs of affected children and adults and their families.

Primary Lateral Sclerosis
(See Spastic Paraparesis/Spastic Paraplegia)
Progressive Supranuclear Palsy

CUREPSP - Foundation for PSP/CBD and Related Brain Diseases
1216 Broadway, 2nd Floor
New York, NY 10001
347-294-2873
800-457-4777
www.curepsp.org

Dedicated to increasing awareness of progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and other atypical Parkinsonian disorders; funds research, educates healthcare professionals, and provides support, information and hope for affected persons and their families.

Pseudotumor Cerebri
(See Intracranial Hypertension Syndrome)

Rare Disorders

National Organization for Rare Disorders (NORD)
55 Kenosia Avenue
Danbury, CT 06810-1968
203-744-0100
Toll-free voicemail: 800-999-6673
www.rarediseases.org

Federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.
Reflex Sympathetic Dystrophy Syndrome/Complex Regional Pain Syndrome

(See also Pain)

International Research Foundation for RSD/CRPS
1910 East Busch Boulevard
Tampa, FL 33612
813-907-2312
www.rsdfoundation.org

Nonprofit organization dedicated to education and research on RSDS/CRPS. Works to establish an international research network to help educate medical professionals and support research worldwide.

Reflex Sympathetic Dystrophy Syndrome Association
P.O. Box 502
99 Cherry Street
Milford, CT 06460
203-877-3790
877-662-7737
https://rsds.org

National nonprofit organization that promotes greater public and professional awareness of reflex sympathetic dystrophy syndrome, a painful neurological condition. Raises funds for research and educates patients, their families and friends, insurance and healthcare providers, professionals, and the public.

Restless Legs Syndrome
(See Sleep Disorders)
Rett Syndrome

International Rett Syndrome Foundation/
Rettsyndrome.org
4600 Devitt Drive
Cincinnati, OH 45246
513-874-1298
800-818-7388
www.rettsyndrome.org

Focused, comprehensive research and family empowerment in regard to Rett syndrome and related MeCP2 disorders.

Rett Syndrome Research Trust
67 Under Cliff Road
Trumbull, CT 06611
203-445-0041
www.rsrt.org

Accelerates the development of treatments and cures for Rett Syndrome and related MECP2 disorders.

Shingles

(See also Pain)

National Shingles Foundation
603 W. 115 Street, Suite 371
New York City, NY 10025
212-222-3390
www.vzvfoundation.org

Nonprofit organization devoted solely to combating VZV infections: chickenpox, shingles, and post-herpetic neuralgia. Supports research that may lead to a better understanding of VZV infections and to their prevention, treatment, and cure.
Sjögren’s Syndrome
(See also Peripheral Neuropathy)

Sjögren’s Syndrome Foundation
10701 Parkridge Boulevard, Suite 170
Reston, VA 20191
301-530-4420
800-475-6473
www.sjogrens.org

Dedicated to fighting Sjögren’s through research, education, and awareness.

See also Arthritis Foundation, page 29.

Sleep Disorders

American Sleep Apnea Association
641 S Street, N.W., 3rd Floor
Washington, DC 20001
888-293-3650
www.sleepapnea.org

Provides information about sleep apnea to the public, publishes a newsletter, and serves as an advocate for people with the disorder.

American Sleep Association
1002 Lititz Pike #229
Lititz, PA 17543
contactasa@sleepassociation.org
www.SleepAssociation.org

Increases awareness about the importance of sleep and the dangers of sleep disorders.

Hypersonnia Foundation, Inc.
4514 Chamblee Dunwoody Road #229
Atlanta, GA 30338
678-842-3512
www.hypersonniafoundation.org

Strives to improve the lives of people with hypersonnia. Provides support, education, and funds research.
Narcolepsy Network  
P.O. Box 2178  
Lynwood, WA 98036  
401-667-2523  
888-292-6522  
www.narcolepsynetwork.org  
National nonprofit organization that sponsors education, awareness, and support programs.

National Sleep Foundation  
1010 N. Glebe Road, Suite 420  
Arlington, VA 22201  
703-243-1697  
www.sleepfoundation.org  
National nonprofit organization that works to improve public health and safety by promoting understanding of sleep and sleep disorders. Supports education and research, and offers postdoctoral fellowships and grants for sleep researchers.

Project Sleep  
P.O. Box 70206  
Los Angeles, CA 90070  
323-577-8923  
https://project-sleep.com  
Provides awareness about sleep health and sleep conditions.

Restless Legs Syndrome Foundation  
3006 Bee Caves Road, Suite D206  
Austin, TX 78746  
512-366-9109  
www.rls.org  
Provides educational materials on restless legs syndrome and related disorders and supports medical research into the cause and cure for the disorder.
Wake Up Narcolepsy
P.O. Box 60293
Worcester, MA 01606
978-751-3693
www.wakeupnarcolepsy.org

Nonprofit organization dedicated to speeding narcolepsy diagnosis through greater awareness and funding medical research to find a cure.

Sotos Syndrome

Sotos Syndrome Support Association
P.O. Box 4626
Wheaton, IL 60189
888-246-7772
https://sotossyndrome.org

Nonprofit organization that offers an information clearinghouse and support network for families affected by Sotos syndrome, or cerebral gigantism.

Spasmodic Dysphonia/Spasmodic Torticollis

National Spasmodic Dysphonia Association
300 Park Boulevard, Suite 335
Itasca, IL 60143
800-795-6732
www.dysphonia.org

Works to advance medical research into the causes of and treatments for spasmodic dysphonia, promotes physician and public awareness of the disorder, and sponsors support groups for patients and their families.

National Spasmodic Torticollis Association
9920 Talbert Avenue
Fountain Valley, CA 92708
714-378-9837
800-487-8385
www.torticollis.org

Nonprofit organization formed to give information and support to people with spasmodic torticollis, also known as cervical dystonia. Offers an outreach program designed to increase awareness. Chapters are located nationwide.
Spastic Paraparesis/Spastic Paraplegia

Spastic Paraplegia Foundation, Inc.
1605 Goularte Place
Fremont, CA 94539-7241
877-773-4483
https://sp-foundation.org

Volunteer nonprofit organization dedicated to finding cures for hereditary spastic paraparesis and primary lateral sclerosis.

See also Genetic Alliance, page 32, and National Ataxia Foundation, page 7.

Spina Bifida

Spina Bifida Association
1600 Wilson Boulevard, Suite 800
Arlington, VA 22209
202-944-3285
800-621-3141
https://spinabifidaassociation.org

Nonprofit association that provides information and referrals through a clearinghouse and toll-free number. Promotes research into the causes, treatment, and prevention of spina bifida; conducts public awareness campaigns; and encourages socialization and training for people with spina bifida.

See also March of Dimes, page 13.

Spinal Cord Injury
(See Trauma)
Spinal Muscular Atrophy
(See also Kennedy’s Disease)

Cure SMA
925 Busse Road
Elk Grove Village, IL 60007
847-367-7620
800-886-1762
www.curesma.org

Provide funding for SMA research through our comprehensive research model; leading providers of family support and patient services.

Spinal Muscular Atrophy Foundation
126 East 56th Street, 30th Floor
New York, NY 10022
646-253-7100
877-386-3762
www.smafoundation.org

Nonprofit foundation dedicated to accelerating the development of a treatment or cure for SMA.

See also Muscular Dystrophy Association, page 49.

Stem Cell Research

National Institutes of Health
1 Center Drive
Bethesda, MD 20892
stemcells.nih.gov

See also Pediatric Brain Foundation, page 14.
Stroke
(See also Aphasia)

American Stroke Association: A Division of American Heart Association
7272 Greenville Avenue
Dallas, TX 75231-4596
888-478-7653
www.strokeassociation.org

Offers a wide array of programs, products, and services, from patient education materials to scientific statements with cutting-edge information for healthcare professionals.

Brain Aneurysm Foundation
269 Hanover Street, Building 3
Hanover, MA 02339
781-826-5556
888-272-4602
https://bafound.org

The Brain Aneurysm Foundation is the nation’s only nonprofit organization solely dedicated to providing critical awareness, education, support, and research funding to reduce the incidence of brain aneurysms.

Children’s Hemiplegia and Stroke Association (CHASA)
4101 West Green Oaks Boulevard
Suite 305, #149
Arlington, TX 76016
817-492-4325
http://chasa.org

Nonprofit organization that offers support and information to families of children who have hemiplegia due to stroke or other causes. Sponsors a number of programs for families, offers support groups and information about research studies, and sponsors conferences and childhood stroke awareness campaign research studies.
cureCADASIL
10 Schalks Crossing Road, Suite 501A-133
Plainsboro, NJ 08536
307-215-9840
https://curecadasil.org

Works to raise awareness of CADASIL, improve understanding by physicians, and ensure correct patient diagnosis.

Fibromuscular Dysplasia Society of America (FMDSA)
26777 Lorain Road, Suite 408
North Olmsted, OH 44070
216-834-2410
888-709-7089
www.fmdsa.com

A public health charity working toward better diagnosis and treatment of fibromuscular dysplasia by building awareness, funding research, providing patient support, and educating patients and the healthcare community.

The Hazel K. Goddess Fund for Stroke Research in Women
785 Park Avenue, #3E
New York, NY 10021
www.thegoddessfund.org

Nonprofit organization that focuses on critical issues specific to stroke in women, including research, prevention, treatment, education, and advocacy.

Heart Rhythm Society
1325 G Street, N.W., Suite 900
Washington, DC 20003
202-464-3400
www.hrsonline.org

Nonprofit organization with a mission to improve the care of patients by advancing research, education and optimal health care policies and standards.
International Alliance for Pediatric Stroke
P.O. Box 77896
Charlotte, NC 28271
www.iapediatricstroke.org

Nonprofit organization that provides leadership for partnerships with global pediatric stroke communities for advancing awareness, knowledge, and research for babies and children who have been impacted by stroke.

The Joe Nickro Foundation
26780 N. 77th Street
Scottsdale, AZ 85266
877-803-7650
www.joeniekrofoundation.org

Nonprofit organization committed to supporting patients and families, research, treatment and awareness of brain aneurysms, arteriovenous malformations, and hemorrhagic stroke.

YoungStroke
P.O. Box 692
1201 Creel Street
Conway, SC 29528
843-655-2835
http://youngstroke.org

National patient advocacy organization benefiting adult stroke survivors under 65. Works to change public perception of stroke through education and promotes research to enhance quality of life for survivors and their caregivers. Initiatives include education for health professionals and patients, public service campaigns, support group launches and more.

See also National Aphasia Association, page 6.
Sturge-Weber Syndrome  
*(See also Birthmarks)*

Sturge-Weber Foundation  
12345 Jones Road, Suite 125  
Houston, TX 77070  
800-627-5482  
www.sturge-weber.org

International nonprofit organization established for support, referral, advocacy, and research into the management and cause of Sturge-Weber syndrome. Also serves parents, professionals, and others concerned with Klippel-Trenaunay syndrome and port wine stain.

Syringomyelia  
*(See also Chiari Malformation)*

American Syringomyelia & Chiari Alliance Project  
P.O. Box 1586  
Longview, TX 75606-1586  
903-236-7079  
800-272-7282  
https://asap.org

Nonprofit organization that works to improve the lives of people with syringomyelia, Chiari malformations, and related disorders. Publishes a newsletter and offers other written information, videotapes, an annual conference, and other services.

Worldwide Syringomyelia & Chiari Task Force  
P.O. Box 491975  
Lawrenceville, GA 30049  
914-510-2873  
www.wstfccure.org

Nonprofit organization that works to educate the world about syringomyelia and provide those diagnosed with hope.

*See also Christopher and Dana Reeve Foundation, page 74, Paralyzed Veterans of America, page 74, and Spina Bifida Association, page 65.*
Tay-Sachs Disease
(See also Genetic Disorders and Metabolic Disorders)

National Tay-Sachs and Allied Diseases Association
2001 Beacon Street, Suite 204
Boston, MA 02135
617-277-4463
http://ntsad.org

The mission of the National Tay-Sachs and Allied Diseases Association is to lead the fight to treat and cure Tay-Sachs, Canavan and related genetic diseases, and to support affected families and individuals in leading fuller lives.

See also March of Dimes, page 13.

Temporomandibular Joint Disease
(See also Pain)

TMJ Association, Ltd.
P.O. Box 26770
Milwaukee, WI 53226-0770
262-432-0350
www.tmj.org

Dedicated to promoting awareness, education, and scientific research regarding temporomandibular disorders, a complex and poorly understood set of conditions characterized by pain in the jaw joint and surrounding tissues and limitations in jaw movements.

Tic Douloureux
(See Trigeminal Neuralgia)
Tourette Syndrome

Tourette Association of America
42-40 Bell Boulevard, Suite 205
Bayside, NY 11361-2820
888-486-8738
http://tourette.org

Association dedicated to serving people with Tourette syndrome and funding scientific research. TAA maintains chapters in each state and cooperates with contacts in 45 foreign countries. Inquirers receive free material and a local physician referral listing. TAA publishes materials for families, physicians, and researchers and offers a quarterly newsletter.

Transverse Myelitis

Cody Unser First Step Foundation
P.O. Box 56696
Albuquerque, NM 87187
505-999-9550
www.codysfirststep.org

Nonprofit organization dedicated to raising research funds, public awareness, and quality of life for those affected by all forms of spinal cord-related paralysis, including transverse myelitis.

Transverse Myelitis Association
1787 Sutter Parkway
Powell, OH 43065-8806
614-317-4884
855-380-3330
https://myelitis.org

Nonprofit organization dedicated to advocacy for those who have rare neuroimmunologic diseases of the central nervous system, including transverse myelitis (TM), acute disseminated encephalomyelitis (ADEM), optic neuritis, and neuromyelitis optica (Devic’s disease).

See also Guthy-Jackson Charitable Foundation, page 52, and Myelin Project, page 50.
Trauma
Includes **Head Injury** and **Spinal Cord Injury**

**Brain Injury Association of America, Inc.**
1608 Spring Hill Road, Suite 110
Vienna, VA 22182
703-761-0750
800-444-6443
www.biausa.org

Nonprofit organization dedicated to people with brain injury and their families and professionals. Offers research, education, and advocacy programs through a national office, network of state affiliates, support groups, and a brain injury information center.

**Brain Injury Resource Center**
P.O. Box 84151
Seattle, WA 98124
206-621-8558
www.headinjury.com

Nonprofit clearinghouse founded and operated by head injury activists. Offers information, discussion groups, programs for building advocacy and self-care skills, and referrals to additional information and resources.

**Brain Trauma Foundation**
250 Greenwich Street
7 World Trade Center, 34th Floor
New York, NY 10007
212-772-0608
www.braintrauma.org

Nationwide organization devoted to improving the outcome for traumatic brain injury patients. Focuses on the acute phase of traumatic brain injury (TBI) and methods to improve chances of a meaningful recovery. Involved with guidelines development, professional education, quality improvement, and clinical research.
The Christopher & Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research and improving the quality of life for people living with paralysis through grants, information and advocacy.

Miami Project to Cure Paralysis
1095 NW 14th Terrace
Lois Pope LIFE Center
Miami, FL 33136
305-243-6001
800-782-6387
www.themiamiproject.org
Supports research and related programs in the area of spinal cord injury.

Paralyzed Veterans of America
801 Eighteenth Street, NW
Washington, DC 20006-3517
202-872-1300
800-232-1782
www.pva.org
Works to help members and their families, as well as all veterans and people with disabilities. Offers expertise on a wide variety of issues involving the special needs of veterans of the armed forces who have experienced spinal cord dysfunction.

ThinkFirst
National Injury Prevention Foundation
1801 N. Mill Street, Suite F
Naperville, IL 60563
630-961-1400
800-844-6556
www.thinkfirst.org
National injury prevention program dedicated to preventing brain, spinal cord, and other traumatic injuries through the education of individuals, community leaders, and creators of public policy. ThinkFirst is a 501(c)(3) organization.
Tremor

Diann Shaddox Foundation for Essential Tremor
241 Boxelder Drive
Aiken, SC 29803
803-761-2860
www.diannshaddoxfoundation.org

Nonprofit organization that seeks to educate and increase awareness about people afflicted with Essential Tremor and to donate medical research grants to doctors to find a cause and cure.

Tremor Action Network
P.O. Box 5013
Pleasanton, CA 94566
510-681-6565
https://tremoraction.org/

Nonprofit resource dedicated to increasing awareness of essential tremor and tremor-related movement disorders by advocating for a cure through research. Offers support for patients, family members, and caregivers through a quarterly newsletter, videos, printed materials, and guidance from advocates.

HopeNet
14425 Coachway Drive
Centreville, VA 20120
703-543-8131
804-754-4455
https://thehopenet.org

Nonprofit group dedicated to increasing the awareness of essential tremor.
International Essential Tremor Foundation
P.O. Box 14005
Lenexa, KS 66285-4005
913-341-3880
888-387-3667
www.essentialtremor.org

Provides educational information, funds research on tremor disorders, and offers services and support to individuals diagnosed with essential tremor, their families, and healthcare providers. Information and support includes a quarterly newsletter, support groups, and physician information and referrals.

*See also National Ataxia Foundation, page 7.*

Trigeminal Neuralgia/Tic Douloureux
(See also Pain)

Facial Pain Association
22 S.E. Fifth Avenue, Suite D
Gainesville, FL 32601
352-384-3600
800-923-3608
https://fpa-support.org

Nonprofit voluntary organization that serves as an advocate for patients living with neuropathic facial pain, including trigeminal neuralgia, by providing information, encouraging research, and offering support.

*See also International RadioSurgery Association, page 1.*

Tuberous Sclerosis

Tuberous Sclerosis Alliance
801 Roeder Road, Suite 750
Silver Spring, MD 20910
301-562-9890
800-225-6872
www.tsalliance.org

National nonprofit voluntary health organization dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.
Vestibular Disorders

Vestibular Disorders Association
5018 NE 15th Avenue
Portland, OR 97211
800-837-8428
https://vestibular.org

Nonprofit organization that provides information and support to people with inner-ear balance disorders, including Meniere’s disease and positional vertigo.

Von Hippel-Lindau Disease

VHL Alliance
1208 VFW Parkway, Suite 303
Boston, MA 02132-4344
617-277-5667
800-767-4845 x1
https://www.vhl.org

Dedicated to research, education, and support to improve diagnosis, treatment, and quality of life for those affected by VHL. Offers competitive research and provides education and support through publications, online support groups, 24-hour hotline, mentor program, and telephone discussion groups.

Wilson Disease

Wilson Disease Association
1732 First Avenue, #20043
New York, NY 10128
414-961-0533
866-961-0533
www.wilsonsdisease.org

An organization striving to promote the well-being of patients with Wilson disease and their families and friends.

See also American Liver Foundation, page 42.
II. Other Resources

A. Brain and Tissue Resources

NIH NeuroBioBank
https://neurobiobank.nih.gov/

The NIH-funded NeuroBioBank (NBB) was established in September 2013 as a national resource for investigators utilizing human post-mortem brain tissue and related biospecimens for their research to understand conditions of the nervous system. Brain and tissue donation sites in the NeuroBioBank are:

University of Maryland Brain and Tissue Bank (formerly NICHD Brain and Tissue Bank for Developmental Disorders)
University of Maryland, School of Medicine
655 West Baltimore Street, Room 13-013 BRB
Baltimore, MD 21201-1559
410-706-1755
800-847-1539
www.medschool.umaryland.edu/BTBank/

Harvard Brain Tissue Resource Center
McLean Hospital
115 Mill Street
Belmont, MA 02478
800-272-4622
https://hbtrc.mclean.harvard.edu

Human Brain and Spinal Fluid Resource Center
West Los Angeles Healthcare Center
11301 Wilshire Boulevard (127A)
Building 115, Room 130
Los Angeles, CA 90073
Pager: 310-636-5199
brainbank.ucla.edu
University of Miami Brain Endowment Bank
University of Miami Department of Neurology
1951 NW 7th Avenue, Suite 240
Miami, FL 33136
305-243-6219
800-862-7246
www.brainbank.med.miami.edu

Mt. Sinai Brain Bank
James. J. Peters VA Medical Center
130 West Kingsbridge Road
Room 4F-33A
Bronx, NY 10468
718-584-9000, x6083
212-807-5541
https://icahn.mssm.edu/research/nih-brain-tissue-repository/donate

Brain Tissue Donation Program at the University of Pittsburgh
Biomedical Science Tower W164
3811 O’Hara Street
Pittsburgh, PA 15213-2582
412-624-7802
tnp.pitt.edu

Other research donation sites include:

National Prion Disease Pathology Surveillance Center
Institute of Pathology
Case Western Reserve University
2085 Adelbert Road, Room 419
Cleveland, OH 44106
216-368-0587
www.cjdsurveillance.com

National Disease Research Interchange
8 Penn Center, 15th Floor
1628 JFK Boulevard
Philadelphia, PA 19103
215-557-7361
800-222-6374
https://ndriresource.org
National NeuroAIDS Tissue Consortium
The EMMES Corporation
401 North Washington Street
Rockville, MD 20850
301-251-1161, ext. 186
866-668-2272
www.nntc.org

Neurologic AIDS Research Consortium
Department of Neurology
Washington University School of Medicine
Campus Box 8111
660 S. Euclid Avenue
St. Louis, MO 63110
314-747-8426

B. Miscellaneous Resources
(Including Comprehensive Organizations)

American Brain Coalition
P.O. Box 1549
Maple Grove, MN 55311
763-557-2913
www.americanbraincoalition.org
Nonprofit organization comprised of more than 85 of the United States’ leading professional neurological, psychological, and psychiatric associations and patient organizations, clinicians, researchers, industry, and government agencies. Seeks to advance the understanding of the function of the brain, and to reduce the burden of brain disorders through public advocacy.

Dana Foundation
505 Fifth Avenue, 6th Floor
New York, NY 10017
212-223-4040
www.dana.org
Private philanthropic organization that supports brain research through grants and educates the public about the successes and potential of brain research. Coordinates the International Brain Awareness Week campaign; supports a network of neuroscientists.
National Organization for Rare Disorders (NORD)
55 Kenosia Avenue
Danbury, CT 06813-1968
203-744-0100
Toll-free voicemail: 800-999-6673
www.rarediseases.org

Federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Research!America
241 18th Street South, Suite 501
Arlington, VA 22202
703-739-2577
www.researchamerica.org

Research!America builds active public support for more public and private research to find treatments, cures, and prevention for both physical and mental diseases and disorders.

C. Government Agencies, Organizations, and Programs

Agency for Healthcare Research and Quality
Office of Communications and Knowledge Transfer
Department of Health and Human Services (DHHS)
540 Gaither Road
Rockville, MD 20850
301-427-1364
800-358-9295
www.ahrq.gov

Centers for Disease Control and Prevention
Department of Health and Human Services
Office of Public Inquiries
1600 Clifton Road
Atlanta, GA 30333
404-639-3311 or 404-639-3543
800-232-4636
www.cdc.gov
Centers for Medicare and Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244-1850
410-786-3000
877-267-2323
www.cms.hhs.gov

Food and Drug Administration
10903 New Hampshire Avenue
Silver Spring, MD 20993
301-827-4573
888-463-6332
www.fda.gov

Health Resources and Services Administration
(HRSA) Information Center
Department of Health and Human Services
8280 Greensboro Drive, Suite 300
McLean, VA 22102
888-275-4772
877-489-4772 TTY
www.ask.hrsa.gov

National Institutes of Health (NIH)
9000 Rockville Pike
Bethesda, MD 20982
301-496-4000
www.nih.gov

NIH Institutes, Centers, and Offices include:

National Institute of Neurological Disorders and Stroke
Brain Resources and Information Network
301-496-5751
www.ninds.nih.gov

Patient Recruitment and Public Liaison Office
800-411-1222
www.cc.nih.gov/participate.shtml

Genetic and Rare Diseases Information Center
301-251-4925
http://rarediseases.nih.gov
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