

U.S.  
Department  
of Health  
and Human  
Services

# Neurological Disorders

## Directory of Health Information Resources

# 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](http://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](http://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](http://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](http://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](http://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 57<sup>th</sup> Street, Suite 904

New York, NY 10019

212-901-8000

[www.alzdiscovery.org](http://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](http://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, 7<sup>th</sup> Floor  
New York, NY 10001  
866-232-8484  
<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](http://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/](http://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](http://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

800-782-4747

[www.alsa.org](http://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](http://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](http://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](http://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](http://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.

**A-T Ease Foundation, Inc.**  
215 Thompson Street, Suite 404  
New York, NY 10012  
212-529-0622  
[www.ateasefoundation.org](http://www.ateasefoundation.org)

Foundation that raises funds in support of research for ataxia-telangiectasia.

## **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](http://www.help4adhd.org).

**Learning Disabilities Association of America**  
4156 Library Road  
Pittsburgh, PA 15234-1349  
412-341-1515  
[www.lidaamerica.org](http://www.lidaamerica.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](http://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](http://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](http://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.

**Autism Society of America**

4340 East-West Highway, Suite 350

Bethesda, MD 20814

800-328-8476

[www.autism-society.org](http://www.autism-society.org)

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 33<sup>rd</sup> Street, Fourth Floor

New York, NY 10016

646-385-8523

[www.autismspeaks.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://www.marchofdimes.com)

[www.nacersano.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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 111<sup>th</sup> Street, 8A

New York, NY 10024

866-907-1847

[www.canavanfoundation.org](http://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](http://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](http://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](http://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, 15<sup>th</sup> 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](http://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](http://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](http://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](http://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.csfinfo.org](http://www.csfinfo.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://cjd.foundation.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](http://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](http://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. 41<sup>st</sup> Street, 8<sup>th</sup> Floor

New York, NY 10017

800-221-4602

[www.ndss.org](http://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 39<sup>th</sup> Street, Suite 701

New York, NY 10018

212-279-1066

[www.familialdysautonomia.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://www.aedpregnancyregistry.org)

Registry designed to determine what therapies are associated with increased risk of harmful fetal effects. Participation is confidential.

**Charlie Foundation for Ketogenic Therapies**  
515 Ocean Avenue, #602N  
Santa Monica, CA 90403  
310-393-2347  
<https://charlifoundation.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](http://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](http://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](http://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](http://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](http://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](http://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

Downington, PA 19335

484-879-6160

[www.curefa.org](http://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](http://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](http://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](http://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](http://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/](http://www.genome.gov/10000409/)

### **Genetic Alliance**

4301 Connecticut Avenue, NW, Suite 404  
Washington, DC 20008-2369  
202-966-5557  
[www.geneticalliance.org](http://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](http://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](http://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](http://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.

### **ISM RD-International Advocates for Glycoprotein Storage Diseases**

20880 Canyon View Drive

Saratoga, CA 95070

734-449-1190

[www.ismrd.org](http://www.ismrd.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 75<sup>th</sup> 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](http://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.hdfoundation.org](http://www.hdfoundation.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](http://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](http://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](http://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](http://www.huntershope.org)

Funds research for improved treatments and a cure for Krabbe 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](http://www.mldfoundation.org)

A 501 I(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 2<sup>nd</sup> 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](http://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](http://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.nmaus.org](http://www.nmaus.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 Maltase Deficiency Association (AMDA)**

P.O. Box 700248  
San Antonio, TX 78270  
210-494-6144  
[www.amda-pompe.org](http://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  
888-5654766  
[www.irondisorders.org](http://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](http://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, **Mucopolidosis 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](http://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](http://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://moebiusyndrome.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)*

## **Mucopolysaccharidosis**

*(See also Genetic Disorders and Metabolic Disorders)*

### **Mucopolysaccharidosis Type IV (ML4) Foundation**

1440 Spring Street, NW

Atlanta, GA 30309

877-654-5459

[ml4.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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, 15<sup>th</sup> Floor  
New York, NY 10017  
212-297-2156  
800-541-5454  
[www.myasthenia.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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  
718-981-8001  
800-223-2732  
Young Onset Center 877-223-3801  
[www.apdaparkinson.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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, 2<sup>nd</sup> Floor

New York, NY 10001

347-294-2873

800-457-4777

[www.curepsp.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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., 3<sup>rd</sup> Floor

Washington, DC 20001

888-293-3650

[www.sleepapnea.org](http://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](mailto:contactasa@sleepassociation.org)

[www.SleepAssociation.org](http://www.SleepAssociation.org)

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

### **Hypersomnia Foundation, Inc.**

4514 Chamblee Dunwoody Road #229

Atlanta, GA 30338

678-842-3512

[www.hypersomniafoundation.org](http://www.hypersomniafoundation.org)

Strives to improve the lives of people with hypersomnia. Provides support, education, and funds research.

**Narcolepsy Network**

P.O. Box 2178

Lynwood, WA 98036

401-667-2523

888-292-6522

[www.narcolepsynetwork.org](http://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](http://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](http://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](http://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](http://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](http://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](http://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 56<sup>th</sup> Street, 30<sup>th</sup> Floor

New York, NY 10022

646-253-7100

877-386-3762

[www.smafoundation.org](http://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](http://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](http://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, JN 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](http://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](http://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](http://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](http://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 Niekro Foundation**  
26780 N. 77<sup>th</sup> Street  
Scottsdale, AZ 85266  
877-803-7650  
[www.joeniekrofoundaton.org](http://www.joeniekrofoundaton.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](http://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](http://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](http://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](http://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](http://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](http://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, 34<sup>th</sup> Floor

New York, NY 10007

212-772-0608

[www.braintrauma.org](http://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.

**Christopher and Dana Reeve Foundation**

636 Morris Turnpike, Suite 3A

Short Hills, NJ 07078

800-225-0292

[www.christopherreeve.org](http://www.christopherreeve.org)

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 14<sup>th</sup> Terrace

Lois Pope LIFE Center

Miami, FL 33136

305-243-6001

800-782-6387

[www.themiamiproject.org](http://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](http://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](http://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](http://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](http://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](http://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 15<sup>th</sup> 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](http://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/](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://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](http://www.ask.hrsa.gov)

**National Institutes of Health (NIH)**  
9000 Rockville Pike  
Bethesda, MD 20982  
301-496-4000  
[www.nih.gov](http://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](http://www.ninds.nih.gov)

**Patient Recruitment and Public Liaison Office**  
800-411-1222  
[www.cc.nih.gov/participate.shtml](http://www.cc.nih.gov/participate.shtml)

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

**National Cancer Institute**

800-422-6237

[www.cancer.gov](http://www.cancer.gov)

**National Center for Advancing Translational  
Sciences**

301-594-8966

[www.ncats.nih.gov](http://www.ncats.nih.gov)

**National Center for Complementary and  
Integrative Health**

888-644-6226

[www.ncchi.nih.gov](http://www.ncchi.nih.gov)

**National Eye Institute**

301-496-5248

[www.nei.nih.gov](http://www.nei.nih.gov)

**National Heart, Lung, and Blood Institute**

301-592-8573

[www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)

**National Human Genome Research Institute**

301-402-0911

[www.genome.gov](http://www.genome.gov)

**National Institute of Allergy and  
Infectious Diseases**

301-496-5717

[www.niaid.nih.gov](http://www.niaid.nih.gov)

**National Institute of Arthritis and  
Musculoskeletal and Skin Diseases**

301-496-8190

[www.niams.nih.gov](http://www.niams.nih.gov)

**National Institute of Biomedical Imaging  
and Bioengineering**

301-496-8859

[www.nibib.nih.gov](http://www.nibib.nih.gov)

***Eunice Kennedy Shriver* National Institute of  
Child Health and Human Development**

Information Resource Center

800-370-2943

[www.nichd.nih.gov](http://www.nichd.nih.gov)



**National Institute of Dental and  
Craniofacial Research**

301-496-4261

[www.nidcr.nih.gov](http://www.nidcr.nih.gov)

**National Institute of Diabetes and Digestive  
and Kidney Diseases**

301-496-3583

[www.niddk.nih.gov](http://www.niddk.nih.gov)

**National Institute of Environmental and  
Health Sciences**

919-541-3345

[www.niehs.nih.gov](http://www.niehs.nih.gov)

**National Institute of General Medical Sciences**

301-496-7301

[www.nigms.nih.gov](http://www.nigms.nih.gov)

**National Institute of Mental Health**

301-443-4513

[www.nimh.nih.gov](http://www.nimh.nih.gov)

**National Institute on Minority Health and  
Health Disparities**

301-402-1366

[www.nimhd.nih.gov](http://www.nimhd.nih.gov)

**National Institute of Nursing Research**

301-496-0207

[www.ninr.nih.gov](http://www.ninr.nih.gov)

**National Institute on Aging**

301-486-1752

[www.nih.nih.gov](http://www.nih.nih.gov)

**National Institute on Alcohol Abuse and  
Alcoholism**

301-443-2860

[www.niaaa.nih.gov](http://www.niaaa.nih.gov)

**National Institute on Deafness and Other  
Communication Disorders**

301-496-7243

[www.nidcd.nih.gov](http://www.nidcd.nih.gov)

**National Institute on Drug Abuse**

301-443-1124

[www.nida.nih.gov](http://www.nida.nih.gov)

**National Library of Medicine**

301-594-5983

[www.nlm.nih.gov](http://www.nlm.nih.gov)

**Office of Clinical Center Communications**

301-496-2563

[www.cc.nih.gov](http://www.cc.nih.gov)

**Fogarty International Center**

301-496-2075

[www.fic.nih.gov](http://www.fic.nih.gov)



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