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Agenesis of the Corpus Callosum

Agenesis of the Corpus Callosum/ACC Network

c/o 5749 Merrill Hall, Room 118

University of Maine

Orono, ME 04469-5749

1-207-581-3119

UM-ACC@maine.edu

www.bchealthguide.org

Information clearinghouse and support network for families. Distributes a family directory and publishes a newsletter.

National Organization of Disorders of the Corpus Callosum

PMB 363

18032-C Lemon Drive

Yorba Linda, CA 92886

1-714-747-0063

info@nodcc.org

www.nodcc.org

National non-profit that works to enhance the quality of life of individuals with agenesis of the corpus callosum and other disorders of the corpus callosum by gathering and disseminating information regarding these conditions.

Angelman Syndrome

Epilepsy Ontario

1 Promenade Circle

Thornhill, Ontario L4J 4P8

905-764-5099

416-229-2291

800-463-1119 (Toll free in Ontario)

905-764-1231 (Fax)

info@epilepsyontario.org

www.epilepsyontario.org

Epilepsy Ontario is a registered charitable non-profit non-governmental health organization dedicated to promoting independence and optimal quality of life for children and adults living with seizure disorders, by promoting information, awareness, support services, advocacy, education and research.

Angelman Syndrome Foundation

3015 East New York Street

Suite A2265

Aurora, IL 605004

1-630-978-4245

info@angelman.org

www.angelman.org

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

Ataxia

Friedreich's Ataxia Research Alliance (FARA)

2001 Jefferson Davis Highway

Suite 209

Arlington, VA 22202

1-703-413-4468

fara@frda.org

www.frda.org

Non-profit organization dedicated to advocacy and research activities leading to treatments and cures for Friedreich's ataxia, a fatal childhood-onset disorder, and the related sporadic ataxias.

Muscular Dystrophy Association

3300 East Sunrise Drive

Tucson, AZ 85718-3208

1-520-529-2000

1-800-572-1717

mda@mdausa.org

www.mdausa.org

Voluntary health agency that fosters neuromuscular disease research and provides patient care funded almost entirely by individual private contributors. MDA 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.

National Ataxia Foundation

2600 Fernbrook Lane
Suite 119
Minneapolis, MN 55447-4752
1-763-553-0020
naf@ataxia.org
www.ataxia.org

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

Attention-Deficit/Hyperactivity Disorder (ADHD)

The Canadian Pediatric Society

2305 St. Laurent Blvd.
Ottawa, Ont. K1G 4J8
Tel.: (613) 526-9397
Fax: (613) 526-3332
www.cps.ca

Caring for Kids is designed to provide parents with information about their child's health and well-being. Because the site is developed by the [Canadian Paediatric Society](#)—the voice of Canada's 2,000+ paediatricians—you can be sure the information is reliable.

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801
Bethesda, MD 20824
1-800-352-9424
1-301-496-5751
1-301-468-5981 (TTY)
www.ninds.nih.gov/disorders/adhd/adhd.htm

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

To support this mission, NINDS:

- Conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas.
- Provides grants-in-aid to public and private institutions and individuals in fields related to its areas of interest, including research project, program project, and research center grants.
- Operates a program of contracts for the funding of research and research support efforts in selected areas of institute need.
- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.
- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

The National Institutes of Mental Health

6001 Executive Boulevard
Room 8184, MSC 9663
Bethesda, MD 20892-9663
1-866-615-6464 (toll free)
1-301-443-4513
1-301-443-8431 (TTY)
nimhinfo@nih.org
www.nimh.nih.gov/publicat/adhd.cfm

Children and Adolescents with ADD

8181 Professional Place, Suite 150
Landover, MD 20785
1-800-233-4050
www.chadd.org

CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) is the nation's leading non-profit organization serving individuals with AD/HD and their families. CHADD has over 16,000 members in 200 local chapters throughout the U.S. Chapters offer support for individuals, parents, teachers, professionals, and others.

Autism

Autism Society Ontario

1179A King Street West, Suite 004
Toronto, ON M6K 3C5
416-246-9592
416-246-9417 (Fax)
mail@autismsociety.on.ca

www.autismsociety.on.ca

Autism Society Ontario is the leading source of information and referral on autism and one of the largest collective voices representing the autism community. Members are connected through a volunteer network of 31 Chapters throughout the Province of Ontario.

The Canadian Pediatric Society

2305 St. Laurent Blvd.
Ottawa, Ont. K1G 4J8
Tel.: (613) 526-9397
Fax: (613) 526-3332
www.cps.ca

Caring for Kids is designed to provide parents with information about their child's health and well-being. Because the site is developed by the [Canadian Paediatric Society](#)—the voice of Canada's 2,000+ paediatricians—you can be sure the information is reliable.

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801
Bethesda, MD 20824
1-800-352-9424
1-301-496-5751
www.ninds.nih.gov/disorder/autism/detail_autism.htm

The National Institutes of Mental Health

6001 Executive Boulevard
Room 8184, MSC 9663
Bethesda, MD 20892-9663
1-866-615-6464 (toll free)
1-301-443-4513
1-301-443-8431 (TTY)
nimhinfo@nih.org
www.nimh.nih.gov/publicat/autism.cfm

Birth Defect Research for Children, Inc.

930 Woodcock Road, Suite 225
Orlando, FL 32803
1-407-895-0802
staff@birthdefects.org
www.birthdefects.org

Non-profit 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.

Association for Science in Autism Treatment

389 Main Street, Suite 202
Malden, ME 02148
1-781-397-8943
info@asatonline.org
www.asatonline.org

National, not-for-profit organization formed by a group of parents and professionals concerned about the care and treatment of individuals with autism. ASAT is dedicated to disseminating accurate, scientifically valid information about autism and its treatment options.

Autism National Committee

35657 Anthony Road
Agua Dulce, CA 91390
jeff@jaynolan.org
www.autcom.org

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

Autism Network International (ANI)

P.O. Box 35448
Syracuse, NY 13235-5448
jsincla@mailbox.syr.edu
<http://ani.autistics.org>

Autistic-run self-help and advocacy organization that provides a forum for autistic people to share information, peer support, and tips for coping and problem-solving.

Autism Research Institute (ARI)

4182 Adams Avenue
San Diego, CA 92116
1-619-281-7165
www.autismresearchinstitute.com or www.autism.com/ari

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

Autism Society of America

7910 Woodmont Avenue
Suite 300

Bethesda, MD 20814-3015
1-301-657-0881
1-800-3AUTISM (328-8476)
www.autism-society.org

Promotes lifelong access and opportunities for persons within the autism spectrum and their families through advocacy, public awareness, education, and research programs. The research arm of this organization, the Autism Society of America Foundation, raises and provides funds to support biomedical and applied research to address unanswered questions about autism.

Cure Autism Now Foundation

5455 Wilshire Boulevard
Suite 715
Los Angeles, CA 90036-4234
1-323-549-0500
1-888-8AUTISM (828-8476)
info@cureautismnow.org
www.cureautismnow.org

Non-profit organization dedicated to promoting and funding autism research and accelerating the pace of scientific progress toward effective treatments and a cure.

MAAP Services

P.O. Box 524
Crown Point, IN 46308
1-219-662-1311
chart@netnitco.net
www.maapservices.org

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

National Alliance for Autism Research

99 Wall Street
Research Park
Princeton, NJ 08540
1-609-430-9160
1-888-777-NAAR (6227)
naar@naar.org
www.naar.org

Non-profit organization dedicated to finding the causes, prevention and effective treatment, and ultimately a cure for the autism spectrum disorders. Provides research

grants and fellowships, sponsors scientific conferences, funds the Autism Tissue Program, and publishes a newsletter on autism biomedical research.

National Vaccine Information Centre

421-E Church Street
Vienna, VA 22180
1-703-938-DPT3 (3783)
www.nvic.org

Non-profit organization dedicated to the prevention of vaccine injuries and deaths through public education and advocacy programs.

Batten Disease

Batten Disease Support and Research Association

120 Humphries Drive
Suite 2
Reynoldsburg, OH 43068
1-800-448-4570
bdstral@bdsra.org
www.bdsra.org

International support and research networking organization for families of children and young adults with Batten disease. Sponsors education, advocacy, and support programs.

Children's Brain Disease Foundation

Parnassus Heights Medical Building
Suite 900
350 Parnassus Avenue
San Francisco, CA 94117
1-415-665-3003

National not-for-profit organization that raises funds for medical research into the causes and treatments of Batten disease, one of a group of disorders known as the neuronal ceroid lipofuscinoses.

Nathan's Battle Foundation

459 South State Road 135
Greenwood IN 46142
1-317-888-7396
pmilto@indy.net
www.nathansbattle.com

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

Brachial Plexus Injuries/Erb's Palsy

Brachial Plexus Palsy Foundation

c/o 210 Springhaven Circle

Royersford, PA 19468

1-610-792-4234

Brachial@comcast.net

<http://membrane.com/bpp/>

Non-profit organization designed to raise funds and provide information related to the understanding of and research on brachial plexus injuries in children.

National Brachial Plexus/Erb's Palsy Association, Inc.

P.O. Box 23

Larsen, WI 54947

erbspalsy@usa.net

www.nbpepa.org

The National Brachial Plexus/Erb's Palsy Association, Inc., strives to educate, inform, and assist those affected by Brachial Plexus Palsy by offering information, contacts, resources, parent matching, and assistance developing chapters of support groups throughout the United States.

United Brachial Plexus Network

1610 Kent Street

Kent, OH 44240

1-866-877-7004

info@ubpn.org

www.ubpn.org

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

Cerebral Palsy

Ontario Federation for Cerebral Palsy

104-1630 Lawrence Avenue West

Toronto, ON M6L 1C5

416-244-9686
416-244-6543
1-877-244-9686 (toll free)
www.ofcp.on.ca

The Ontario Federation for Cerebral Palsy is a non-profit, charitable organization with a mandate to address the changing needs of people in Ontario with cerebral palsy. The OFCP goes about accomplishing its mission by way of three core activities:

- (1) Assisting individuals and member groups in the development and provision of services and programs including accommodation in all parts of the province of Ontario.
- (2) Advocating and promoting awareness, understanding and acceptance of persons with cerebral palsy.
- (3) Encouraging and supporting research, education and programs related to cerebral palsy.

The National Institutes of Neurologic Disease and Stroke:

P.O. Box 5801
Bethesda, MD 20824
1-800-352-9424
1-301-496-5751
1-301-468-5981 (TTY)
www.ninds.nih.gov/disorders.cerebral_palsy/cerebral_palsy.htm

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

To support this mission, NINDS:

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- Provides grants-in-aid to public and private institutions and individuals in fields related to its areas of interest, including research project, program project, and research center grants.
- Operates a program of contracts for the funding of research and research support efforts in selected areas of institute need.
- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.
- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

Pathways Awareness Foundation

150 North Michigan Avenue, Suite 2100

Chicago, IL 60601

1-312-893-6620

1-800-955-CHILD (2445)

friends@pathwaysawareness.org

www.pathwaysawareness.org

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

Pedal with Pete

P.O. Box 274

Kent, OH 44240

1-800-304-PETE (7383)

petezeid@aol.com

www.pedalwithpete.com

Non-profit organization dedicated to raising money for research in order to improve the quality of life for those with cerebral palsy. Aim is to help in the fight for the prevention, treatment, and cure of cerebral palsy.

United Cerebral Palsy (UCP)/ UCP Research & Educational Foundation

1600 L Street, NW, Suite 700

Washington, DC 20036

1-202-973-7140

1-800-USA-5UCP (872-5827)

national@ucp.org

www.ucp.org

Foundation: www.ucp.org/ucp_general.cfm/1/4

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

Charcot-Marie-Tooth Disorder**Charcot-Marie-Tooth Association (CMTA)**

2700 Chestnut Parkway

Chester, PA 19013

1-610-499-9264

1-800-606-CMTA (2682)
CMTAssoc@aol.com
www.charcot-marie-tooth.org

Provides education and support to persons with Charcot-Marie-Tooth disorders, their families, and the health professionals who treat them.

Epilepsy

Epilepsy Canada

National Office
1470 Peel St., Suite 745
Montreal, QC H3A 1T1
514-845-7855
1-877-SEIZURE (734-0873)
514-845-7866 (Fax)
epilepsy@epilepsy.ca
www.epilepsy.ca

Epilepsy Canada is the only national non-profit organization whose mission is to enhance the quality of life for persons affected by epilepsy through promotion and support of research and facilitation of education and awareness initiatives that build understanding and acceptance of epilepsy.

Epilepsy-dot-com

www.epilepsy.com

Epilepsy.com is an online resource provided by the Epilepsy Therapy Development Project. Our mission is to inform and empower two groups of patients and their families: those facing newly diagnosed epilepsy, and those struggling with epilepsy that has resisted treatment

Epilepsy Foundation

4351 Garden City Drive
Landover, MD 20785-7223
1-800-332-1000
www.epilepsyfoundation.org

The Epilepsy Foundation will ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through research, education, advocacy and services.

Epilepsy Ontario

1 Promenade Circle
Thornhill, Ontario L4J 4P8
905-764-5099
416-229-2291
800-463-1119 (Toll free in Ontario)
905-764-1231 (Fax)
www.epilepsyontario.org

Epilepsy Ontario is a registered charitable non-profit non-governmental health organization dedicated to promoting independence and optimal quality of life for children and adults living with seizure disorders, by promoting information, awareness, support services, advocacy, education and research.

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801
Bethesda, MD 20824
1-800-352-9424
1-301-496-5751
1-301-468-5981 (TTY)
www.ninds.nih.gov./disorders/epilepsy/epilepsy.htm

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- Operates a program of contracts for the funding of research and research support efforts in selected areas of institute need.
- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.
- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

Antiepileptic Drug Pregnancy Registry

Massachusetts General Hospital East
CNY-149, 10th Floor
149 Thirteenth Street

Charlestown, MA 02129-2000
1-888-AED-AED4 (233-2334)
ebaldwin@partners.org
www.aedpregnancyregistry.org

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

Charlie Foundation

1223 Wilshire Boulevard, Suite 815
Santa Monica, CA 90403
1-310-395-6751
1-800-FOR-KETO (367-5386)
ketoman@aol.com
www.charliefoundation.org

Non-profit organization that raises money for scientific research focusing on the ketogenic diet. Offers education programs and materials for families and dieticians.

Citizens United for Research in Epilepsy (CURE)

730 North Franklin, Suite 404
Chicago, IL 60610
1-312-255-1801
info@CUREepilepsy.org
www.CUREepilepsy.org

Non-profit grassroots organization formed by parents and families to raise funds for epilepsy research.

Epilepsy Foundation

4351 Garden City Drive
Landover, MD 20785-2267
1-301-459-3700
1-800-EFA-1000 (332-1000)
postmaster@efa.org
www.epilepsyfoundation.org

National charitable organization dedicated to the welfare of people with epilepsy. Works for children and adults affected by seizures through education, advocacy, services, and research towards a cure.

The Epilepsy Institute

257 Park Avenue South
New York, NY 10010
1-212-677-8550
www.epilepsyinstitute.org

Non-profit organization that provides comprehensive social services and resources for people with epilepsy and their families.

Parents Against Childhood Epilepsy (PACE)

7 East 85th Street, Suite A3

New York, NY 10028

1-212-665-PACE (7223)

pacenyemail@aol.com

www.paceusa.org

Non-profit research resource that provides information and support to families of children with epilepsy.

Fragile X Disease

Fragile X Research Foundation of Canada

167 Queen Street West

Brampton, ON L6Y 1M5

www.fragile-x.ca

FRAXA Research Foundation

45 Pleasant Street

Newburyport, MA 01950

1-978-462-1866

info@fraxa.org

www.fraxa.org

Funds research and sponsors educational and support programs on Fragile X.

National Fragile X Foundation

P.O. Box 190488

San Francisco, CA 94119-0488

1-800-688-8765

natlfx@fragilex.org

www.fragilex.org

Provides support, education, awareness, research, and legislative advocacy programs concerning conditions that result from fragile X, including fragile X syndrome, fragile X-associated tremor/ataxia syndrome, and premature ovarian failure.

Friedreich's Ataxia

(see also Ataxia)

Friedreich's Ataxia Research Alliance

2001 Jefferson Davis Highway

Suite 209

Arlington, VA 22202

1-703-413-4468

fara@frda.org

www.frda.org

National non-profit organization dedicated to the pursuit of educational, scientific, and research activities leading to treatments for Friedreich's ataxia and the related sporadic ataxias.

Guillain-Barré Syndrome

Epilepsy Ontario

1 Promenade Circle

Thornhill, Ontario L4J 4P8

905-764-5099

416-229-2291

800-463-1119 (Toll free in Ontario)

905-764-1231 (Fax)

www.epilepsyontario.org

Epilepsy Ontario is a registered charitable non-profit non-governmental health organization dedicated to promoting independence and optimal quality of life for children and adults living with seizure disorders, by promoting information, awareness, support services, advocacy, education and research.

GBS/CIDP Foundation International

P.O. Box 262

Wynnewood, PA 19096

1-610-667-0131

info@gsfsfi.com

www.gsfsfi.com

Voluntary, non-profit organization that provides support to patients of Guillain-Barré and their families, awards grants to researches, and offers educational materials to the public and professional communities.

Headache

American Chronic Pain Association

P.O. Box 850
Rocklin, CA 95677-0850
1-916-632-0922
1-800-533-3231
ACPA@pacbell.net
www.theacpa.org

Provides self-help coping skills and peer support to people with chronic pain. Sponsors local support groups throughout the United States and provides assistance in starting and maintaining support groups.

American Council for Headache Education

19 Mantua Road
Mt. Royal, NJ 08061
1-856-423-0258
1-800-255-ACHE (2243)
achehq@talley.com
www.achenet.org

Non-profit 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.

National Headache Foundation

820 North Orleans
Suite 217
Chicago, IL 60610
1-773-388-6399
1-888-NHF-5552 (643-5552)
www.headaches.org

Non-profit organization dedicated to assisting headache sufferers, their families, and the healthcare practitioners who treat the. Promotes research into headache causes and treatments and educates the public.

Infantile Spasms

Epilepsy Ontario

1 Promenade Circle
Thornhill, Ontario L4J 4P8
905-764-5099
416-229-2291
800-463-1119 (Toll free in Ontario)
905-764-1231 (Fax)
www.epilepsyontario.org

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The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801
Bethesda, MD 20824
1-800-352-9424
1-301-496-5751
1-301-468-5981 (TTY)
www.ninds.nih.gov/disorders/infantilepsasms/infantilepsasms.htm

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- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.
- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

Epilepsy-dot-com

www.epilepsy.com/epilepsy/epilepsy_infantilepasms.html

Epilepsy.com is an online resource provided by the Epilepsy Therapy Development Project. Our mission is to inform and empower two groups of patients and their families: those facing newly diagnosed epilepsy, and those struggling with epilepsy that has resisted treatment

Intracranial Hypertension Syndrome**Intracranial Hypertension Research Foundation**

6517 Buena Vista Drive

Vancouver, WA 98661

1-360-693-4473

info@ihrfoundation.org

www.ihrfoundation.org

International non-profit foundation that promotes, encourages, and facilitates progress through research in the understanding and management of chronic primary and secondary intracranial hypertension. Provides a support system, educational programs, and communication tools for patients. For physicians and scientist, sponsors research in both basic and clinical sciences and education, training, and patient care programs.

Pseudotumor Cerebri Support Network

8247 Riverside Drive

Powell, OH 43065

ptcduncan@juno.com

www.pseudotumorcerebri.com

Non-profit organization that offers information, resources and support.

Landau-Kleffner Syndrome

(see also Epilepsy)

American Speech-Language-Hearing Association

10801 Rockville Pike

Rockville, MD 20852-3279

1-301-897-5700

1-800-638-8255

actioncenter@asha.org

www.asha.org

Offers public information about a wide range of adult and childhood speech, language, and hearing disabilities, including aphasia.

Epilepsy Foundation

4351 Garden City Drive
Landover, MD 20785-2267
1-301-459-3700
1-800-EFA-1000 (332-1000)
postmaster@efa.org
www.epilepsyfoundation.org

National charitable organization dedicated to the welfare of people with epilepsy. Works for children and adults affected by seizures through education, advocacy, services, and research towards a cure.

National Aphasia Association

7 Dey Street, Suite 600
New York, NY 10007
1-212-267-2814
1-800-922-4NAA (4622)
naa@aphasia.org
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.

Language and Learning Disabilities

American-Speech-Language-Hearing Associates

10801 Rockville Pike
Rockville, MD 20852-3279
1-301-897-5700
1-800-638-8255
actioncenter@asha.org
www.asha.org

Offers public information about a wide range of speech, language, and hearing disabilities in both children and adults.

Attention Deficit Disorder Association

P.O. Box 543
Pottstown, PA 19464
1-484-945-2101

mail@add.org
www.add.org

Non-profit organization focused on the needs of adults of all ages with AD/HD, their children, and families.

CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder

8181 Professional Place
Suite 150
Landover, MD 20785
1-301-306-7070
1-800-233-4050
www.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

Lissencephaly

Lissencephaly Network

10408 Bitterroot Court
Ft. Wayne, IN 46804
1-260-432-4310
lissencephalyone@aol.com
www.lissencephaly.org

Non-profit organization that serves children and families affected by lissencephaly and other neuronal migrational disorders.

Meningitis

Meningitis Foundation of America, Inc.

6610 Shadeland Station, Suite 200
Indianapolis, IN 46220
1-317-595-6395
1-800-668-1129
support@musa.org
www.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

22910 Chestnut Road
Lexington Park, MD 20653
1-866-FONE-NMA (366-3662)
support@nmaus.org
www.nmaus.org

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

Metabolic Disorders

Muscular Dystrophy Association

3300 East Sunrise Drive
Tucson, AZ 85718-3208
1-520-529-2000
1-800-572-1717
mda@mcausa.org
www.mdausa.org

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

National MPS Society, Inc.

P.O. Box 736
Bangor, ME 04402
1-207-947-1445
info@mpssociety.org
www.mpssociety.org

Provides support to individuals and families with the mucopolysaccharidoses (MPS) or mucopolysaccharidoses (ML), promotes public and professional awareness of MPS/ML, and funds research.

Migraine

Migraine Canada

www.migrainecanada.com

The content provided on this site is designed for information and educational purposes only. The materials are not intended to be a self-diagnostic and/or self-treatment tool. We encourage you to use this information as a tool for discussing your condition with your health practitioner.

National Headache Foundation

820 N. Orleans, Suite 217

Chicago, IL 60610

1-888-NHF-5552

www.headaches.org

A non-profit organization dedicated to educating headache sufferers and health care professionals about headache causes and treatments.

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801

Bethesda, MD 20824

1-800-352-9424

1-301-496-5751

1-301-468-5981 (TTY)

www.ninds.nih.gov/disorders/migraine/migraine.htm

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

To support this mission, NINDS:

- Conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas.
- Provides grants-in-aid to public and private institutions and individuals in fields related to its areas of interest, including research project, program project, and research center grants.
- Operates a program of contracts for the funding of research and research support efforts in selected areas of institute need.
- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.
- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

Mitochondrial Disorders

United Mitochondrial Disease Foundation

8085 Saltsburg Road, Suite 201

Pittsburgh, PA 15239

1-412-793-8077

info@umdf.org

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.

Muscular Dystrophy

Muscular Dystrophy Canada

2345 Young St., Suite 900

Toronto, ON M4P 2E5

1-866-MUSCLE-8 (687-2538)

416-488-7523 (fax)

info@muscle.ca

www.muscle.ca

Since 1954, Muscular Dystrophy Canada has been committed to improving the quality of life for the tens of thousands of Canadians with [neuromuscular disorders](#) and funding leading [research](#) for the discovery of therapies and cures for [neuromuscular disorders](#).

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801

Bethesda, MD 20824

1-800-352-9424

1-301-496-5751

1-301-468-5981 (TTY)

www.ninds.nih.gov/disorders/md/md/.htm

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

To support this mission, NINDS:

- Conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas.
- Provides grants-in-aid to public and private institutions and individuals in fields related to its areas of interest, including research project, program project, and research center grants.
- Operates a program of contracts for the funding of research and research support efforts in selected areas of institute need.
- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.
- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

Muscular Dystrophy Association

3300 East Sunrise Drive
Tucson, AZ 85718-3208
1-520-529-2000
1-800-572-1717
mda@mcausa.org
www.mdausa.org

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

Muscular Dystrophy Family Foundation

2330 North Meridian Street
Indianapolis, IN 46208
1-317-923-6333
1-800-544-1213
mdff@mdff.org
www.mdff.org

Provides services, resources, adaptive equipment, and home medical equipment to individuals with muscular dystrophy and their families to improve independence and quality of life. Focuses on meeting the day-to-day needs of individuals and families.

Parent Project Muscular Dystrophy (PPMD)

1012 North University Boulevard
Middletown, OH 45042
1-513-424-0696

1-800-714-KIDS (5437)
info@parentprojectmd.org
www.parentprojectmd.org

Parent-led organization dedicated to encouraging efforts to expedite treatments for muscular dystrophy while improving quality of life for the boys affected.

Myoclonus

Opsoclonus Myoclonus Support Network, Inc.

4616 Brookwood Street, NE
Albuquerque, NM 87109
505-881-2285
sandragreenberg@hotmail.com
www.geocities.com/opso-myoclonus

Serves as a resource center for opsoclonus myoclonus patients and health professionals, including physicians and researchers, and helps patients and their families to network with others affected by the syndrome. Any person affected by the syndrome is considered a community member.

Neurofibromatosis

Neurofibromatosis Society of Ontario

180 Circle Lake Road
North Bay, ON P1A 3T2
705-685-1409
1-866-THE-NFSO or 1-866-843-6376
www.nfon.ca

The NF Society of Ontario is an organization made up of volunteers providing support and services to NF families. In addition to assisting individuals and families, the NF Society of Ontario works closely with clinical and research professionals who specialize in the treatment of NF

Acoustic Neuroma Association

600 Peachtree Parkway
Suite 108
Cumming, GA 30041
1-770-205-8211
anausa@aol.com

www.ANAUSA.org

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

Children's Tumor Foundation

95 Pine Street
16th Floor
New York, NY 10005
1-212-344-6633
1-800-323-7938
info@cft.org
www.cft.org

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

March of Dimes Birth Defects Foundation

1275 Mamaroneck Avenue
White Plains, NY 10605
1-914-428-7100
1-888-663-4637
askus@marchofdimes.com
www.marchofdimes.com

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

Neurofibromatosis, Inc.

9320 Annapolis Road
Suite 300
Lanham, MD 20706-3123
1-301-918-4600
1-800-942-6825
nfinfo@nfinc.org
www.nfinc.org

Non-profit organization made up of independent state and regional chapters that provide support and services to neurofibromatosis families. Provides patient/family and public education, supports research, publishes a newsletter, and sponsors meetings and chapters nationwide.

Niemann-Pick Disease

National Niemann-Pick Disease Foundation

P.O Box 49

Ft. Atkinson, WI 53538

1-920-563-0930

1-877-CURE-NPC (287-3672)

npdf@idcnet.com

www.npdf.org

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

Prader-Willi Syndrome

(see also Angelman Syndrome)

Prader-Willi Syndrome Association

5700 Midnight Pass Road, Suite 6

Sarasota, FL 34242-3000

1-941-312-0400

1-800-926-4797

national@pwsausa.org

www.pwsausa.org

Serves as an international vehicle of communication about Prader-Willi syndrome, a genetically based developmental disability. Provides to 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.

Rett Syndrome

International Rett Syndrome Association

9121 Piscataway Road

Suite 2B

Clinton, MD 20735

1-301-856-3334

1-800-818-RETT (7388)

irsa@rettsyndrome.org

www.rettsyndrome.org

National resource for research, education, and information about Rett syndrome.

Rett Syndrome Research Foundation

4600 Devitt Drive
Cincinnati, OH 45246
1-513-874-3020
monica@rsrf.org
www.rsrf.org

RSRF's mission is to fund, promote, and accelerate biomedical research for the treatment and cure of Rett syndrome.

Spinal Muscular Atrophy

Muscular Dystrophy Canada

2345 Young St., Suite 900
Toronto, ON M4P 2E5
1-866-MUSCLE-8 (687-2538)
416-488-7523 (fax)
info@muscle.ca
www.muscle.ca

Since 1954, Muscular Dystrophy Canada has been committed to improving the quality of life for the tens of thousands of Canadians with [neuromuscular disorders](#) and funding leading [research](#) for the discovery of therapies and cures for [neuromuscular disorders](#).

Families of Spinal Muscular Atrophy

P.O. Box 196
Libertyville, IL 60048-0196
1-800-886-1762
1-847-367-7620
1-847-367-7623 (fax)
www.fsma.org

Families of Spinal Muscular Atrophy is the largest international organization dedicated solely to:

- Eradicating spinal muscular atrophy (SMA) by promoting and supporting research
- Helping families cope with SMA through informational programs and support
- Educating the public and professional community about SMA

We are a non-profit, 501(c)3 tax exempt organization. Funds will be specifically directed to scientific, educational or literary purposes in keeping with a charitable organization. The organization is proud to provide funding to *Families of S.M.A. DIRECTION* and to this web site which provide information and networking opportunities to its members. We are a volunteer-driven organization.

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801

Bethesda, MD 20824

1-800-352-9424

1-301-496-5751

1-301-468-5981 (TTY)

www.ninds.nih.gov/disorders/sma/sma/htm

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

To support this mission, NINDS:

- Conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas.
- Provides grants-in-aid to public and private institutions and individuals in fields related to its areas of interest, including research project, program project, and research center grants.
- Operates a program of contracts for the funding of research and research support efforts in selected areas of institute need.
- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.
- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

Fight SMA/Andrew's Buddies

1807 Libbie Avenue

Suite 104

Richmond, VA 23226

1-804-515-0080

aubreycampbell@fightsma.com

www.fightsma.com

National non-profit organization committed to accelerating a cure for spinal muscular atrophy.

Families of Spinal Muscular Atrophy

P.O. Box 196

Libertyville, IL 60048-0196
1-847-367-7620
1-800-886-1762
sma@fsma.org
www.curesma.com

International non-profit foundation dedicated to accelerating the development of a treatment or cure for SMA through the funding of research, drug discovery programs, and clinical trials. Assists families through informational programs and support services; sponsors and equipment pool; and educates the public and the medical community about SMA.

Muscular Dystrophy Association

3300 East Sunrise Drive
Tucson, AZ 85718-3208
1-520-529-2000
1-800-572-1717
mda@mcausa.org
www.mdausa.org

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

Spinal Muscular Atrophy Foundation

1776 Broadway
Suite 2205
New York, NY 10019
1-646-253-7101
1-877-FUND-SMA (386-3762)
info@smafoundation.org
www.smafoundation.org

Non-profit foundation dedicated to accelerating the development of a treatment or cure for SMA.

Stroke

American Stroke Association: A Division of American Heart Association

7272 Greenville Avenue
Dallas, TX 75231-4596
1-888-4STROKE (478-7653)
strokeassociation@heart.org

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

12 Clarendon Street
Boston, MA 02116
1-617-723-3870
office@bafound.org
www.bafound.org

Provides support networks and educational resources to raise public awareness regarding early detection and treatment of brain aneurysms. Information is also available for caregivers.

Children's Hemiplegia and Stroke Association (CHASA)

4101 West Green Oaks Boulevard
Suite 305
PMB 149
Arlington, TX 76016
1-817-492-4325
info437@chasa.org
www.chasa.org

Non-profit resource that offers support and information for families of children who have hemiplegia due to stroke or other causes. Also provides information regarding research on and causes of any type of pediatric stroke.

Easter Seals

230 West Monroe Street
Suite 1800
Chicago, IL 60606-4802
1-312-726-6200
1-800-221-6827
info@easter-seals.org
www.easter-seals.org

Provides services to help children and adults with disabilities and/or special needs as well as support to their families.

National Aphasia Association

7 Dey Street
Suite 600
New York, NY 10007
1-212-267-2814

1-800-922-4NAA (4622)

naa@aphasia.org

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.

National Stroke Association

9707 East Easter Lane

Englewood, CO 80112-3747

1-303-649-9299

1-800-STROKES (787-6537)

info@stroke.org

www.stroke.org

National non-profit organization that offers education, services and community-based activities in prevention, treatment, rehabilitation, and recover. Serves the public and professional communities: people at risk, patients and their health-care providers, stroke survivors, and their families and caregivers.

Research Center for Stroke and Heart Disease/National coalition for Stroke &Heart Disease Prevention

c/o Jacobs Neurological Institute

100 High Street

Buffalo, NY 14203

www.strokeheart.org

Non-profit organization dedicated to pre-venting stroke and heart disease. Manages the National Coalition for Stroke & Heart Disease Prevention.

Stroke Clubs International

805 12th Street

Galveston, TX 77550

1-409-762-1022

strokeclubs@earthlink.net

Offers mutual support, education, social and recreational programs, and activities to people who have experienced strokes, their families, and friends.

Tourette Syndrome

Tourette Syndrome Foundation of Canada

206-194 Jarvis Street

Toronto, ON M5B 2B7
1-800-361-3120 (toll free)
416-861-8398
416-861-2472 (fax)
tsfc@tourette.ca
www.tourette.ca

The Tourette Syndrome Foundation of Canada is a national voluntary organization dedicated to improving the quality of life for those with or affected by Tourette Syndrome through programs of: education, advocacy, self-help and the promotion of research.

Tourette Spectrum Disorder Association

1605 Cleveland Place
Pomona, CA 91768
1-626-447-3050
www.tourettesyndrome.org

The Tourette Spectrum Disorder Association is a non-profit organization dedicated to providing up-to-date, accurate information about Tourette syndrome. Combined with the information accessible by following our links, we think you will find helpful, comprehensive information on this often puzzling disorder.

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801
Bethesda, MD 20824
1-800-352-9424
1-301-496-5751
1-301-468-5981 (TTY)
www.ninds.nih.gov/disorders/tourette/tourette.htm

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

To support this mission, NINDS:

- Conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas.
- Provides grants-in-aid to public and private institutions and individuals in fields related to its areas of interest, including research project, program project, and research center grants.
- Operates a program of contracts for the funding of research and research support efforts in selected areas of institute need.
- Provides individual and institutional fellowships to increase scientific expertise in neurological fields.

- Conducts a diversified program of intramural and collaborative research in its own laboratories, branches, and clinics.
- Collects and disseminates research information related to neurological disorders

Tourette Syndrome Association, Inc. (TSA)

42-40 Bell Boulevard, Suite 205
 Bayside, NY 11361-2820
 1-718-224-2999
 1-888-4-TOURET (486-8738)
ts@tsa-usa.org
<http://tsa.usa.org>

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

Tremor

Tremor Action Network

P.O. Box 5013
 Pleasanton, CA 94566
 1-510-681-6565
tremor@tremoraction.org
www.tremoraction.org

Non-profit resource dedicated to increasing awareness of essential tremor by advocating for a cure through research.

International Essential Tremor Foundation

P.O. Box 14005
 Lenexa, KS 66285-4005
 1-913-341-3880
 1-888-387-3667
www.eseentialtremor.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.

National Ataxia Foundation

2600 Fernbrook Lane
 Suite 119

Minneapolis, MN 55447-4752
1-763-553-0020
naf@ataxia.org
www.ataxia.org

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

Tuberous Sclerosis Complex

Tuberous Sclerosis Canada

45 Bolland Crescent
Ajax, ON L1S 3G8
1-800-347-0252
www.tscst.org

Dedicated to the principles of providing encouragement and support to individuals and their families diagnosed with Tuberous Sclerosis Complex (TSC); raising public awareness and educating our communities of TSC; and to promote and support research aimed at the cure for TSC and/or control of Tuberous Sclerosis symptoms.

The National Institutes of Neurologic Disease and Stroke

P.O. Box 5801
Bethesda, MD 20824
1-800-352-9424
1-301-496-5751
1-301-468-5981 (TTY)
www.ninds.nih.gov/disorders/tuberous_sclerosis/tuberous_sclerosis.htm

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

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- Collects and disseminates research information related to neurological disorders

Tuberous Sclerosis Alliance

801-Roeder Road, Suite 750

Silver Spring, MD 20910

1-301-562-9890

1-800-225-6872

info@tsalliance.org

www.tsalliance.org

National non-profit voluntary health organization dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.

Other Useful Sites

Make-A-Wish Foundation of Canada

4211 Young Street, Suite 521

Toronto, ON M2P 2A9

416-224-9474

416-224-8795 (Fax)

1-888-822-9474 (toll free)

nationaloffice@makeawish.ca

www.makeawish.ca

The Make-A-Wish Foundation[®] of Canada is part of the largest not-for-profit wish granting organization in the world, serving 32 countries with International affiliates on five continents. Since our inception in 1980, the volunteers of Make-A-Wish[®] worldwide have helped make over 127,000 wishes come true.

In Canada, there are 8 chapters and a National Office. The Make-A-Wish Foundation exists for one purpose - to fulfill the special wishes of children from ages three through seventeen-years-old who have a life-threatening illness.

Ontario March of Dimes Provincial Office

10 Overlea Blvd.

Toronto, ON M4H 1A4

416-425-3463

1-800-263-3463 (toll free)

provincialoffice@dimes.on.ca
www.dimes.on.ca

Our goal is to enhance the independence and community participation of people with physical disabilities every day through a wide range of programs and services across the province.

The Children's Emergency Foundation

215 Morris Rd., Suite 112

Toronto, ON M1C 1E9

1-800-447-2458

416-287-2372 (Fax)

cef@rogers.com

www.childremergencyfoundation.org

The Children's Emergency Foundation is committed to providing emergency and long-term aid to children at risk on behalf of caring Canadian individuals and corporations.

The Easter Seal Society, Ontario

1185 Eglinton Ave. E., Suite 706

Toronto, ON M3C 3C6

416-421-8377

416-696-1035 (Fax)

1-800-668-3252

info@easterseals.org

www.easterseals.org

The Easter Seal Society, Ontario is dedicated to helping children, youth and young adults with physical disabilities achieve their full individual potential and future independence. Easter Seals funds disability solutions through financial assistance, summer camp, the Recreational Choices funding program, research, advocacy, and public and consumer education.

