

Pediatric Disorders

This page will give information on national organizations for children with specific disorders or diseases. It will provide addresses, email addresses, and web sites when available.

Achondroplasia (also see Little People, Dwarfism) Little People's Research Fund

80 Sister Pierre Drive
Towson, MD 21204
(800) 232-5773
(410) 494-0055
(410) 494-0062 (fax)

Human Growth Foundation
7777 Leesburg Pike
Suite 202 S
Falls Church, VA 22043
(800) 232-5773
(703) 883-1773
(703) 883-1776 (fax)
www.genetic.org/hgf
hgfound@erols.com

Magic Foundation for Children's Growth
1327 N. Harlem Drive
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808 (fax)
www.magicfoundation.org
mary@magicfoundation.org

Angleman Syndrome

Angelman Syndrome Foundation
414 Plaza Dr. Suite 209
Westmont, IL 60559-5507
www-chem.ucsd.edu/asf

Canadian Angelman Syndrome Society
P.O. Box 37
Priddis, AB CAN TOL 1W0
(403) 931-2415
caff@cadvision.com

Apert Syndrome

Apert Support and Information Network
P.O. Box 1184
Fair Oaks, Ca 95628
(650) 961-1092
apertnet@ix.netcom.com

Apert Syndrome Pen Pal Network
P.O. Box 115
Providence, RI 02901
(401) 421-9076

Apert Syndrome Support Group
8708 Kathy Street
St. Louis, MO 63126
(314) 965-3356

Arnold-Chiari Malformation

Arnold-Chiari Family Network
c/o Maureen and Kevin Walsh
67 Spring Street
Weymouth, MA 02188
(617) 337-2368

Arthrogryposis Multiplex Congenita

General Description

Avenues: A National Support Group for Arthrogryposis Multiplex Congenita
P.O. Box 5192
Sonara, CA 95370
(209) 928-3688
www.sonnet.com/avenues
Avenues@sonara.com

Becker Muscular Dystrophy

-see Muscular Dystrophy

Beckwith-Wiedemann Syndrome

Beckwidth-Wiedemann Support Network
3206 Braeburn Cir.
Ann Arbor. MI 48108

(800) 837-2976
(734) 973-0263
(734) 973-9721 (fax)
A800BWSN@aol.com

Brachial Plexus Injury

- see Erb's Palsy

Brittle Bone Disease

- see Osteogenesis Imperfecta

Broad Thumb-Hallux Syndrome

-see Rubinstein-Taybi Syndrome

Cerebral Palsy

United Cerebral Palsy Associations
1660 L St., NW, Ste. 700
Washington, D.C. 20036-5602
(800) 872-5827
(202) 776-0406
(202) 973-7197 (TTY)
(202) 776-0414 (fax)
www.ucpa.org
ucpainc@aol.com

Ontario Federation for Cerebral Palsy
1630 Lawrence Avenue W.
Ste. 104
Toronto, ON CAN M6L 1C5
(416) 244-8003
(416) 244-6543 (fax)
www.ofcp.on.ca
ofcp@ofcp.on.ca

Charcot-Marie-Tooth Disease

Charcot-Marie-Tooth Association
601 Upland Ave
Upland, PA 19015
(800) 606-2682
(610) 499-7486
(610) 499-7487 (fax)

www.charcot-marie-tooth.org
cmfassoc@aol.com

Charcot-Marie-Tooth International
1 Springbank Dr.
St. Catharines, ON CAN L2S 2K1
(905) 687-3630
(905) 687-8753 (fax)
www.cmtint.org
cmtint@vaxxine.com

Charge Syndrome

CHARGE Syndrome Foundation
2004 Parkade Blvd.
Columbia, MO 65202-3121
(800) 442-7604
(573) 499-4694 (fax)
www.chargesyndrome.org
marion@chargesyndrome.org

Connective Tissue Disorders

Coalition for Heritable Disorders of Connective Tissue
382 Main Street
Port Washington, N.Y. 11050
(800) 862-7326
(516) 883-8712
(516) 883-8040 (fax)
www.marfan.org
staff@marfan.org

Dejerine Sottas Disease

- please see Muscular Dystrophy

Down Syndrome

Special Olympics

www.SpecialOlympics.org

National Down Syndrome Society
686 Broadway, 8th Floor
New York, N.Y. 10012-2317

(800) 221-4602
(212) 460-9330
(212) 979-2873(fax)
www.ndss.org
info@ndss.org

Association for Children with Down Syndrome
2616 Martin Ave
Bellmore, NY 11710
(516) 221-4700
(516) 221-5867 (fax)

Canadian Down Syndrome Society
811 14 st. NW
Calgary, AB CAN T2N 2A4
(403) 270-8500
(403) 270-8291 (fax)
<http://www.cdss.ca/>
dsinfo@cdss.ca

Dubowitz Syndrome

Symptoms and Self Assessment Test

Dubowitz Syndrome Parent Support Network
P.O. Box 2441
Vincennes, IN 47591
(812) 886-0575
(812) 886-1128 (fax)
inattic@aol.com

Duchenne Muscular Dystrophy

- see Muscular Dystrophy

Dwarfism

Little People of America

National Headquarters
Box 745
Lubbock, TX 79408
(888) LPA-2001 (English and Spanish)
E-mail: LPADatabase@juno.com
www.lpaonline.org

Dysostosis, Metaphyseal, Type B IV

- Scwachman Syndrome

Dystonia

Dystonia Medical Research Foundation
One E. Wacker Dr.
Ste. 2430
Chicago, IL 60601-1905
(312) 755-0198
(312) 803-0138 (fax)
www.dystonia-foundation.org

Dystonia Medical Research Foundation - Canada
116-230 Heath St. W.
Toronto, ON CAN M5P 1N8
(800) 361-8061 (canada only)
(416) 487-8326
email :dystfdtn@aol.com

Eaton-Lambert Syndrome

-see Muscular Dystrophy

Ehlers-Danlos Syndrome

- see also: Connective Tissue Disorders, Glaucoma, Visual Impairments

Ehlers-Danlos National Foundation
6399 Wilshire Blvd. #510
Los Angeles, CA 90048
(213) 651-3038
(213) 651-1366 (fax)
<http://www.ednf.org/>
email: EDNFBoard@aol.com

Ellis-Van Creveld Syndrome

- see Ectodermal Dysplasias

EMG Syndrome

- see Beckwith-Wiedemann Syndrome

Enchondromatosis

- see Ollier's Disease

Eosinophilic Granuloma

--see Histiocytosis

Erb's Palsy

National Brachial Plexus/Erb's Palsy Association, Inc.
Erb's Place
P.O. Box 23
Larsen, WI 54947

<http://www.nbpepa.org>
erbspalsy@usa.net

Osteogenesis Imperfecta

Osteogenesis Imperfecta Foundation **ation**
804 West Diamond Ave.
Suite 210
Gaithersburg, MD 20878
(301) 947-0083 or (800) 981-2663
Fax: (301) 947-0456
www.oif.org
E-mail: BoneLink@oif.org

Prader-Willi Syndrome

Basic Information

Rett Syndrome

International Rett Syndrome Association
9121 Piscataway Road
Suite 2B
Clinton, MD 20735
(800) 818-RETT
(301) 856-3334

www.rettsyndrome.org
irsa@rettsyndrome.org

Scoliosis

National Scoliosis Foundation
5 Cabot Place
Stoughton, MA 02072
(781) 341-6333
(617) 341-8333
www.scoliosis.org
Scoliosis@aol.com

Spina Bifida (Mylelomeningocoele)

Spina Bifida Association of America
4590 Macarthur Blvd, NW, Suite 250
Washington, DC 20007-4226
Voice: (800) 621-3141 or (202) 944-3285
Fax: (202) 944-3295
www.sbaa.org

Spinal Muscular Atrophy (SMA)

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

Turner Syndrome Society

14450 TC Jester
Suite 260
Houston TX 77014
Toll Free 800-365-9944; P: 832-249-9988; F: 832-249-9987
www.turner-syndrome-us.org/
tssus@turner-syndrome-us.org