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GUIDE TO

MOVEMENT DISORDER

PATIENT ADVOCACY GROUPS

AND FOUNDATIONS



WE MOVE continuously updates the detailed contact information contained within this *Guide*; however, the information is subject to change without notice. The most current information may be accessed at the **WE MOVE** Web site at www.wemove.org.

Inclusion of any organization in the *Guide* does not, in any way, imply endorsement by **WE MOVE**. **WE MOVE** is not responsible for the content of educational materials from other organizations, foundations, support groups, or agencies. In addition, **WE MOVE** is not responsible for any advice or referrals obtained from organizations listed within the *Guide*.

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WE MOVE is a not-for-profit organization that is committed to educating and informing healthcare professionals, patients, and the public about neurologic movement disorders. At **WE MOVE**, we believe that a clear understanding of the diagnosis and treatment of movement disorders is the foundation for better clinical management. **WE MOVE** develops training and educational materials for health professionals, provides accurate, up-to-date information for patients, and promotes the growth and maintenance of patient advocacy organizations and foundations.

The Guide to Movement Disorder Patient Advocacy Groups and Foundations is a comprehensive collection of national support organizations and foundations, arranged alphabetically by disease. These organizations share a common goal... to facilitate accurate and timely diagnosis of movement disorders and access to up-to-date treatment.

WE MOVE recognizes the ongoing efforts of these organizations and foundations and encourages healthcare professionals to utilize and support these groups.



If you or a member of your family has been diagnosed with a movement disorder...

- > Use this *Guide* to locate a national support organization.
- > Contact the national organization for assistance in locating a regional or local support group in your area.
- > Consider establishing a new group (if there is no listing for your area).
- > Distribute the *Guide* to your friends and family. They may know someone with a movement disorder or want to learn more about a specific disorder.
- > Share the *Guide* with your healthcare professionals. They may be interested in obtaining a copy of their own for their offices.

We invite you to visit the **WE MOVE** Web site...
The Hub of Movement Disorder Activities on the Web.

The **WE MOVE** Web site is the Internet's most comprehensive resource for movement disorder information and educational activities. Patients and their caregivers will find in-depth, timely information on specific movement disorders, including details on diagnosis and new treatment options.

On the award-winning **WE MOVE** Web site you may...

- > Subscribe to **WE MOVE News**, a free electronic research news service. Receive the latest news on movement disorders... delivered right to your desktop via e-mail.
- > Review a comprehensive glossary of movement disorder terms. Complex terms are defined in layman's language.
- > Learn about **WE MOVE** Web chats or read transcripts of previous chats with experts on various movement disorders.
- > Click on hypertext links to access important review articles on movement disorders.
- > Access useful Web sites including the National Institutes of Health, Food and Drug Administration, and others through **WE MOVE's** dynamic Linkage Library.
- > Enter the National Library of Medicine's PubMed area and search the medical literature for additional information.
- > Follow dynamic linkage to Online Mendelian Inheritance in Man.



The **WE MOVE** Web site is proud to conform to the *Health on the Net Code of Conduct for Organizations* (HonCode) on the Web.



Ataxia

A-T Children's Project
668 S. Military Trail
Deerfield Beach, FL 33442
TEL: (800) 5-HELP-A-T
Email: info@atcp.org
Web site: www.atcp.org

Ataxia MJD Research Project, Inc.
1425 Alvarado Avenue
Burlingame, CA 94010
TEL: (650) 347-0362
Email: LDenning@ataxiamjd.org
Web site: www.ataxiamjd.org

National Ataxia Foundation
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447-4752
TEL: (763) 553-0020
FAX: (763) 553-0167
Email: naf@ataxia.org
Web site: www.ataxia.org

Dystonia (all forms)

**Bachmann-Strauss Dystonia
& Parkinson Foundation, Inc.**
One Gustave L. Levy Place,
Box 1490, New York, NY 10029
TEL: (212) 241-5614
FAX: (212) 987-0662
Email:
Bachmann.Strauss@mssm.edu
Web site:
www.dystonia-parkinsons.org

Care4Dystonia, Inc.
440 East 78 th Street; Suite 4F
New York, NY 10021
Email: infoc4d@aol.com
Web site:
<http://www.care4dystonia.org>

**Dystonia Medical
Research Foundation**
One East Wacker Drive, Suite 2430
Chicago, IL 60601-1905
TEL: (312) 755-0198
FAX: (312) 803-0138
Email:
dystonia@dystonia-foundation.org
Web site:
<http://www.dystonia-foundation.org>

Blepharospasm

**Benign Essential Blepharospasm
Research Foundation, Inc.**
PO Box 12468
Beaumont, Texas 77726-2468
TEL: (409) 832-0788
FAX: (409) 832-0890
Email: bebrf@blepharospasm.org
Web site:
<http://www.blepharospasm.org>

Spasmodic Dysphonia

**National Spasmodic
Dysphonia Association**
300 Park Blvd; Suite 350
Itasca, IL 60143
TEL: (800) 795-NSDA
Email: NSDA@dysphonia.org
Web site:
<http://www.dysphonia.org>

Spasmodic Torticollis (Cervical Dystonia)

**National Spasmodic
Torticollis Association**
9920 Talbert Avenue
Fountain Valley, CA 92708
TEL: (800) HURTFUL
Email: nstamail@aol.com
Web site: <http://www.torticollis.org>

Spasmodic Torticollis/Dystonia, Inc.
P.O. Box 28
Mukwonago, WI 53149
TEL: (888) 445-4598
Email:
info@spasmodictorticollis.org
Web site:
<http://www.spasmodictorticollis.org>

Essential Tremor

- See Tremor

Huntington's Disease

**Huntington's Disease
Society of America**
158 West 29th Street, 7th Floor
New York, NY 10001-5300
TEL: (800) 345-HDSA or
(212) 242-1968
FAX: (212) 239-3430
Email: hdsainfo@hdsa.org
Web site: <http://www.hdsa.org>

Multiple System Atrophy (Shy-Drager)

**The Shy-Drager/Multiple System
Atrophy Support Group**
P.O. Box 279
Austin, Coupland, TX 78615
TEL: (866) 737-4999
FAX: (512) 251-3315
Email:
Don.Summers@shy-drager.com
Web site:
<http://www.shy-drager.com>

Myoclonus

Moving Forward
2934 Glenmore Avenue
Kettering, OH 45409
TEL: (513) 293-0409

Myoclonus Families United
155 E. 35th Street
Brooklyn, NY 11234
TEL: (718) 252-2133

Parkinson's Disease

**American Parkinson's
Disease Assoc., Inc.**
1250 Hylan Boulevard
Staten Island, NY 10305
TEL: (800) 223-2732 or
(718) 981-8001
FAX: (718) 981-4399
Email:
apda@apdaparkinson.org
Web site:
<http://www.apdaparkinson.org>

**Bachmann-Strauss
Dystonia & Parkinson
Foundation, Inc.**
One Gustave L. Levy Place,
Box 1490
New York, NY 10029
TEL: (212) 241-5614
FAX: (212) 987-0662
Email:
Bachmann.Strauss@mssm.edu
Web site:
<http://www.dystonia-parkinsons.org>

**Michael J. Fox Foundation
for Parkinson's Research**
20 Exchange Place, Suite 3200
New York, NY 10005
TEL: (212) 509-1650
FAX: (212) 509-2390
Web site:
<http://www.michaeljfox.org>

National Parkinson Foundation, Inc.
1501 N.W. 9th Avenue
Miami, FL 33136
TEL: (305) 243-6666 or
(800) 327-4545
FAX: (305) 243-6073
Email: contact@parkinson.org
Web site: <http://www.parkinson.org>

Parkinson Alliance
Post Office Box 308
Kingston, NJ 08528-0308
TEL: (800) 579-8440
FAX: (609) 688-0875
Email:
admin@parkinsonalliance.org
Web site:
<http://www.parkinsonalliance.org>

Parkinson's Action Network (PAN)
1025 Vermont Avenue NW,
Suite 2210
Washington, DC 20005
TEL: (202) 638-4101 or
(800) 850-4726
FAX: (202) 638-7257
Email: info@parkinsonsaction.org
Web site:
<http://www.parkinsonsaction.org>

Parkinson's Disease Foundation
710 West 168th Street 3rd floor
New York, NY 10032
TEL: (800) 457-6676 or
(212) 923-4700
FAX: (212) 923-4778
Email: pdfcpmc@aol.com
Web site: <http://www.pdf.org>

**Young Onset
Parkinson's Association**
111 Shawnee Loop North
Pataskala, OH 43062-8123
TEL: (866) 869-YOPA
FAX: (866) 869-9672
Email: directors@yopa.org
Web site: <http://www.yopa.org>

Progressive Supranuclear Palsy

Society for PSP, Inc.
11350 McCormick Road, Exec Plaza
III, Suite 906
Hunt Valley, MD 21031
TEL: (410) 785-7004
FAX: (410) 785-7009
Email: SPSP@psp.org
Web site: <http://www.psp.org>

Restless Legs Syndrome

Restless Legs Syndrome Foundation
819 Second Street SW
Rochester, MN 55902
TEL: (507) 287-6465
FAX: (507) 287-6312
Email: rlsfoundation@rls.org
Web site: <http://www.rls.org>

Rett Syndrome

International Rett Syndrome Association
9121 Piscataway Road, Suite 2B
Clinton, Maryland 20735
TEL: (301) 856-3334
FAX: (301) 856-3336
Email: khunter@rettsyndrome.org
Web site: <http://www.rettsyndrome.org>

Rett Syndrome Research Foundation
4600 Devitt Drive
Cincinnati, OH 45246
TEL: (513) 874-3020
FAX: (513) 874-2520
Email: monica@rsrf.org
Web site: <http://www.rsrf.org>

Spasticity

Brain/Head Injury Association of America
105 North Alfred Street
Alexandria, VA 22314
TEL: (800) 444-6443
FAX: (703) 236-6001
Email: PublicRelations@biausa.org
Web site: <http://www.biausa.org>

Cerebral Palsy

United Cerebral Palsy Associations
1660 L Street NW, Suite 700
Washington, DC 20036
TEL: (800) USA 5UCP or (202) 842-1226
FAX: (202) 842-3519
Email: infoucpc@aol.com
Web site: <http://www.ucpa.org>

Multiple Sclerosis

Multiple Sclerosis Association of America
706 Haddonfield Road
Cherry Hill, NJ 08002
TEL: (800) 833-4MSA(4672)
FAX: (609) 661-9797
Email: msaa@msaa.com
Web site: <http://www.msfacts.org>

Multiple Sclerosis Foundation
6350 N. Andrews Avenue
Ft. Lauderdale, FL 33309
TEL: (800) 441-7055 or (954) 776-6805
FAX: (954) 938-8708
Email: support@msfacts.org
Web site: <http://www.msfacts.org>

National Multiple Sclerosis Society
733 3rd Avenue, 6th Floor
New York, NY 10017-3288
TEL: (800) FIGHT MS (344-4867) or (212) 986-3240
FAX: (212) 986-7981
Email: info@nmss.org
Web site: <http://www.nmss.org>

Spinal Cord Injury

Christopher Reeve Paralysis Foundation
500 Morris Avenue
Springfield, NJ 07081
TEL: (800) 225-0290 or (973) 379-2690
FAX: (973) 912-9433
Email: info@crpf.org
Web site: <http://www.ChristopherReeve.org>

National Spinal Cord Injury Association

6701 Democracy Boulevard
Bethesda, MD 20817
TEL: (800) 962-9629 or
(301) 588-6959
FAX: (301) 214-4006
Email: info@spinalcord.org
Web site:
<http://www.spinalcord.org>

Stroke

American Stroke Association

A Division of American Heart Association
7272 Greenville Avenue
Dallas, TX 75231
TEL: (888) 4 STROKE
FAX: (800) 787-8985
Email: strokeassociation@heart.org
Web site: <http://www.StrokeAssociation.org>

National Stroke Association

9797 E. Easter Lane
Englewood, CO 80112
TEL: (800) STROKES or
(303) 649-9299
FAX: (303) 649-1328
Web site: <http://www.stroke.org>

Stroke Club International

805 12th Street
Galveston, TX 77550
TEL: (409) 762-1022
Email: strokeclub@aol.com

Tics & Tourette's Syndrome

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, NY 11361
TEL: (718) 224-2999 or
(800) 237-0717
FAX: (718) 279-9596
Email: ts@tsa-usa.org
Web site: <http://tsa-usa.org>

Tremor

International Essential Tremor Foundation

PO Box 14005
Lenexa, KS 66285-4005
TEL: (888) 387-3667 or
(913) 341-3880
FAX: (913) 341-1296
Email: Staff@essentialtremor.org
Web site:
<http://www.essentialtremor.org>

Tremor Action Network

PO Box 5013
Pleasanton, CA 94566-0513
TEL: (925) 462-0111
FAX: (925) 369-0485
Email: tremor@tremoraction.org

Wilson's Disease

Wilson's Disease Association International

1802 Brookside Drive
Wooster, OH 44691
TEL: (330) 264-1450 or
(800) 399-0266
Email: wda@sssnet.com
Web site:
<http://www.wilsonsdisease.org>

Conditions Associated with Movement Disorders

Pediatric Neurotransmitter Disease Association

6 Nathan Drive
Plainview, NY 11803
TEL: (516) 937-0049
FAX: (516) 937-0049
Email: PND@PNDAssoc.org
Web site: <http://www.pndassoc.org>

PICK Parents of Infants and Children with Kernicterus

One W. Superior St., Suite 2410
Chicago, IL 60610
TEL: (205) 705-6524
Email: kdixon@uab.edu
Web site:
<http://www.PICKonline.org>

Reflex Sympathetic Dystrophy Syndrome Association of America

PO Box 502
Milford, CT 06460
TEL: (203) 877-3790
FAX: (203) 882-8362
Email: info@rsds.org
Web site: <http://www.rsds.org>

Spastic Paraplegia Foundation

209 Park Rd.
Chelmsford, MA 01824
TEL: (703) 495-9261
Web site: <http://sp-foundation.org>

**United Mitochondrial
Disease Foundation (UMDF)**
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239
TEL: (412) 793-8077
FAX: (412) 793-6477
Email: info@umdf.org
Web site: <http://www.umdf.org>

