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**GUIDE TO**

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**MOVEMENT DISORDER**

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**PATIENT ADVOCACY GROUPS**

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**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](http://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](mailto:info@atcp.org)  
Web site: [www.atcp.org](http://www.atcp.org)

**Ataxia MJD Research Project, Inc.**  
1425 Alvarado Avenue  
Burlingame, CA 94010  
TEL: (650) 347-0362  
Email: [LDenning@ataxiamjd.org](mailto:LDenning@ataxiamjd.org)  
Web site: [www.ataxiamjd.org](http://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](mailto:naf@ataxia.org)  
Web site: [www.ataxia.org](http://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](mailto:Bachmann.Strauss@mssm.edu)  
Web site:  
[www.dystonia-parkinsons.org](http://www.dystonia-parkinsons.org)

**Care4Dystonia, Inc.**  
440 East 78 th Street; Suite 4F  
New York, NY 10021  
Email: [infoc4d@aol.com](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto:info@umdf.org)  
Web site: <http://www.umdf.org>



