

Life in Motion Coalition Members

What if...

- ...Suddenly your head and neck twisted downward or to the side and you couldn't stop it or make it right?
- ...Your eyes blinked uncontrollably and so forcefully that you had trouble seeing, driving, or reading?
- ...Your hands trembled so that you could no longer write clearly, drink from a glass without spilling, or braid your daughter's hair?
- ...The muscles in your arms, legs, or hands tightened into painful contractions and you couldn't relax them?
- ...You couldn't sleep at night because every time you relaxed you felt like you had to move your legs?
- ...You were suddenly unable to speak above a whisper?

What if...

- ...No one could tell you what was wrong?

More than 40 million Americans know the answers to at least some of these questions...

- ...Because they live with movement disorders: chronic, often painful, and disabling neurological conditions that affect a person's ability to control the way their body moves.



LIFE IN motion



A CAMPAIGN
to raise awareness
and improve quality
of care for more than
40 million Americans
with movement disorders

www.life-in-motion.org
1-866-LIM-3136 (1-866-546-3136)

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Movement disorders are conditions that originate in areas deep within the brain.

They are caused by changes to specific regions of the brain and nervous system, the cause of which is mostly unknown. These special areas, which control movement, send chemical messages to other parts of the brain. These signals set off a chain of events that eventually result in movement of muscles. In people with a movement disorder, this communication system is disrupted and interferes with the ability to produce and coordinate voluntary movements or the inability to stop unwanted involuntary movements.

The most common movement disorders include:

- o **Essential tremor** – Involuntary, rhythmic shaking of a body part
- o **Parkinson's disease** – Slowed movements, involuntary shaking in an arm or leg, muscle rigidity or stiffness, and postural instability
- o **Restless Legs Syndrome** – Uncomfortable sensations in the legs at rest
- o **Ataxia** – Poorly coordinated movements
- o **Dystonia** – Sustained muscle contractions, usually producing twisting and repetitive movements or painful postures or positions
- o **Spasticity** – An increase in muscle stiffness that worsens with rapid movement and may be associated with increased reflexes and weakness; associated with stroke, multiple sclerosis, cerebral palsy, and traumatic brain or spinal cord injury
- o **Tics/Tourette's Syndrome** – Sudden, involuntary, repetitive, muscle movements and sounds

This is a partial list. These are all complex disorders that cause an array of symptoms that may vary from person-to-person, and may not be recognized by all medical professionals.

A person with a movement disorder may visit more than 15 doctors over the course of five years before receiving an accurate diagnosis...

...And during this time, people often struggle to cope with new limitations and daily challenges beyond their movement disorder, including misunderstandings and social stigma – at home and at work.

Movement disorders are chronic conditions that cannot be cured. They can however be effectively managed. People can live with less pain and fewer daily challenges when they are properly diagnosed and appropriately treated. Referral to a neurologist, physiatrist or other specialist familiar with these conditions is essential for accurate diagnosis and coordination of a comprehensive team approach to treatment. Nurses, physical therapists, occupational therapists, speech therapists, psychologists, teachers, and social workers often are an integral part of the management team.

About WE MOVE

WE MOVE is a not-for-profit organization that has been educating and informing the movement disorder community for more than a decade. WE MOVE believes that increased knowledge and understanding promote timely, accurate diagnosis, and up-to-date treatment, resulting in a better quality of life for individuals affected by movement disorders.

Over 130,000 people visit the WE MOVE award-winning Web sites each month to access accurate, timely, and balanced information and resources... medical information, chat rooms, discussion forums, and newsletters. WE MOVE provides information to meet the educational needs of medical professionals, patients, and caregivers.

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www.life-in-motion.org

Raising Awareness, Improving Quality of Care: About the *Life in Motion* Campaign

WE MOVE recognizes that diagnosis and appropriate treatment remain challenges for many people living with movement disorders. As part of the *Life in Motion* campaign, WE MOVE brings together over 40 patient advocacy organizations, foundations, and professional societies all committed to raising awareness about these conditions, emphasizing the importance of early diagnosis, and illustrating available treatment options.

The *Life in Motion* campaign provides patients, their families, and caregivers with information, support, and practical tools they can use to more effectively communicate with their healthcare team and take a more active role in managing their own care to achieve their treatment goals. Campaign initiatives include media outreach, public service announcements, community outreach highlighting real stories of people living with movement disorders, and the creation of the *Life in Motion* Resource Center to provide direct access to a wealth of information and to the many patient and professional organizations with information, support, and other resources to share.

To Learn More...

Please visit the *Life in Motion* Resource Center at www.life-in-motion.org, or call this toll-free number 1-866-LIM-3136 (1-866-546-3136). Additional information will be sent to you free-of-charge.

You'll be able to obtain detailed information about specific movement disorders, diagnosis, and treatment options, a directory/quick links to *Life in Motion* coalition members, the new brochure "Managing Your Life in Motion: A Guide for Patients With Movement Disorders, their Families, and Caregivers," and other valuable resources.