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**For Immediate Release**

**MORE THAN 40 MILLION AMERICANS – NEARLY ONE IN SEVEN – ARE AFFECTED BY  
MOVEMENT DISORDERS ACCORDING TO LATEST DATA REVIEW**

**Forty-Five Professional and Patient Groups Join *Life in Motion* Campaign to Educate  
Patients, Enhance Quality of Care for Wide Array of Chronic Neurological Conditions**

NEW YORK, April 11, 2005 – WE MOVE (Worldwide Education and Awareness of Movement Disorders) announced today at the American Academy of Neurology's 57<sup>th</sup> Annual Meeting in Miami Beach, Florida, that more than 40 million Americans – nearly one in seven people – are affected by chronic and often debilitating movement disorders, including tremor, Parkinson's disease, Tourette's syndrome, Huntington's disease, dystonia, and spasticity, according to the most recent review of prevalence data on such conditions. WE MOVE also reported that a patient with a movement disorder may visit more than 15 doctors over the course of five years before receiving an accurate diagnosis.

In response to this public health problem, WE MOVE is spearheading a coalition of more than 40 professional and patient advocacy groups to launch *Life in Motion* – a campaign to raise awareness about the more than 30 neurological conditions that may be classified as movement disorders, and encourage earlier diagnosis and treatment.

"The number of people challenged by movement disorders is more than twice the number of people with diabetes and more than four times the number of those surviving cancer," said Susan Bressman, M.D., President of WE MOVE and Chairperson of the Department of Neurology at Beth Israel Medical Center. "Yet many people have little to no knowledge of such devastating disorders as restless legs syndrome, spasticity, and dystonia which affect more than 40 million people in the U.S. and place a significant burden on patients' lives. The *Life in Motion* campaign will bring much-needed attention to the broad spectrum of movement disorders to help stimulate earlier diagnosis and effective treatment."



*The Life in Motion campaign is supported by WE MOVE™*

Actress Geri Jewell, a star of the HBO drama series “Deadwood,” has joined WE MOVE and its coalition partners in this awareness campaign. Ms. Jewell, who has cerebral palsy and is challenged with movement disorders, achieved acclaim early in her career as the first person with a visible disability to appear in an ongoing role on a primetime television series, as Cousin Geri in the hit comedy “Facts of Life.”

“The *Life in Motion* campaign will make a significant difference in the lives of millions of people and I feel privileged to be a part of such an important campaign,” said Ms. Jewell. “I know from personal experience how having a movement disorder makes a person vulnerable to being misunderstood in many ways, large and small, and to worry that life and its possibilities have been diminished. Changing this for the millions of people with movement disorders requires education to empower people to take more control over their care and their lives, which is what *Life in Motion* is all about,” continued Ms. Jewell.

### **The *Life in Motion* Resource Center**

As part of this nationwide awareness campaign, WE MOVE has established a *Life in Motion* Web site, [www.life-in-motion.org](http://www.life-in-motion.org), that includes downloadable patient education brochures and information on movement disorders. The Web site also includes information on the *Life in Motion* campaign, *Life in Motion* coalition members, an online press room, a glossary of terms, as well as links to the WE MOVE Web site, [www.wemove.org](http://www.wemove.org). WE MOVE is the most comprehensive resource for movement disorder information and education, and is the only organization of its kind. In addition, patients, their families and caregivers, as well as the general public, may call the *Life in Motion* Resource Center automated toll-free number at 1-866-LIM-3136 (1-866-546-3136) to obtain brochures and other educational material, including treatment information, free-of-charge. In the coming months, a television public service announcement, unveiled at the AAN meeting, featuring country singer Johnny Bush who suffers from spasmodic dysphonia, a form of dystonia that affects the vocal cords, will premier announcing the *Life in Motion* Resource Center and encouraging those who think they may be challenged by a movement disorder to seek help.

### **About Movement Disorders**

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 contractions or spasms of muscles manifested by involuntary movements, such as tremors, dystonia and tics, or stiffness of

muscles as seen with spasticity. 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.

“Movement disorders are chronic conditions that can’t be completely cured. They can, however, be effectively managed if they are properly diagnosed and treated, allowing patients to live with less pain, less discomfort, fewer limitations and greater confidence,” said Stanley Fahn, M.D., H. Houston Merritt Professor of Neurology and Movement Disorders Division Chief, Columbia University in New York City, and past president of the American Academy of Neurology. “The first step is obtaining an appropriate diagnosis, which usually requires referral to a neurologist who is trained to evaluate these complex disorders and is knowledgeable about the latest treatments.”

According to Joseph Jankovic, M.D., Director of the Parkinson’s Disease Center and Movement Disorders Clinic at Baylor College of Medicine, Houston, Texas and past president of the Movement Disorders Society, neurologists categorize movement disorders into two broad categories: “hyperkinetic” and “hypokinetic.” Hyperkinetic disorders are those that cause excess unwanted movement and muscle contractions, such as dystonia, spasticity, myoclonus, tremors, and tics. Hypokinetic disorders are associated with slowness of movement, stiffness or rigidity, and other symptoms. These disorders include Parkinson’s disease, progressive supranuclear palsy, multiple system atrophy, and others. Some movement disorders, such as restless legs syndrome, are characterized by abnormal and unpleasant sensations and an urge to move.

Effective treatment depends on the underlying cause of the condition and may include oral medications; botulinum toxin injection therapy targeted to spastic or abnormally contracting muscles; surgery (including deep brain stimulation); and physical therapy. In many cases, combinations of several drugs and therapies are used. The effective management of a movement disorder usually involves a multi-disciplinary team of specialists and may include the patient’s primary care physician as well as the neurologist, physiatrist (physical rehabilitation specialist), nurses, and physical, occupational, and speech therapists. Social workers, teachers, and psychologists may also be involved to help patients and their families or caregivers cope with the psychosocial impact of these conditions.

“Patients often find it overwhelming to deal with not only their condition but also the constant referrals to specialists for tests and treatments,” said Dr. Bressman of WE MOVE. “A major goal of the *Life in Motion* campaign is to help patients and their caregivers navigate the complex and often fragmented health care system and take a more active role in managing their own care.”

**Life in Motion Coalition Members**

American Academy of Cerebral Palsy & Developmental Medicine  
American Academy of Neurology  
American Association of Neuroscience Nurses  
American Academy of Physical Medicine & Rehabilitation  
American Parkinson's Disease Association, Inc.  
American Stroke Association  
Bachmann-Strauss Dystonia and Parkinson Foundation, Inc.  
Benign Essential Blepharospasm Research Foundation, Inc.  
Care4Dystonia, Inc.  
Child Neurology Foundation  
Child Neurology Society  
Dystonia Medical Research Foundation  
Easter Seals  
Huntington's Disease Society of America  
Huntington's Study Group  
International Dystonia On-Line Support Group  
International Essential Tremor Foundation  
International Rett Syndrome Association  
Movement Disorder Society  
Musicians with Dystonia  
National Ataxia Foundation  
National Multiple Sclerosis Society  
National Organization for Rare Disorders, Inc.  
National Parkinson Foundation, Inc.  
National Spasmodic Dysphonia Association  
National Spasmodic Torticollis Association  
National Spinal Cord Injury Association  
National Stroke Association  
North American Brain Injury Society  
On-Line SD Support Group  
The Parkinson Alliance  
Parkinson Association of the Rockies  
Parkinson's Disease Foundation  
Parkinson Foundation of the Heartland  
Parkinson Pipeline Project  
Parkinson Study Group  
Pediatric Neurotransmitter Disease Association  
Restless Legs Syndrome Foundation  
Rett Syndrome Research Foundation  
Society for Progressive Supranuclear Palsy, Inc.  
Spasmodic Torticollis/Dystonia, Inc.  
Spastic Paraplegia Foundation, Inc.  
Tourette Syndrome Association, Inc.  
Tremor Action Network  
United Cerebral Palsy Research and Educational Foundation  
Wilson's Disease Association

## **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. The mission of WE MOVE is to facilitate the communication of emerging clinical advances and therapeutic approaches to the management and treatment of movement disorders. Through its award-winning, HON-compliant Web sites, and as an accredited provider of continuing medical education (CME), WE MOVE strives to meet the educational needs of healthcare professionals, patients, and caregivers. WE MOVE develops up-to-date training programs and comprehensive, interactive teaching materials to assist the community in deepening their understanding of movement disorders, their pathophysiology, etiology, differential diagnosis, and state-of-the-art interventions. 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.

More than 130,000 people visit the WE MOVE award-winning Web sites each month to access accurate, timely, and balanced information and resources on movement disorders, [www.wemove.org](http://www.wemove.org) (consumers); [www.mdvu.org](http://www.mdvu.org) (professionals).

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