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**DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION**

*servicing all dystonia-affected persons*

### **NIH Awards New Grant to Develop Better Treatments for Focal Dystonias**

October 1, 2009 – Officials at the National Institutes of Health (NIH) have announced the funding of a five year award aimed at forming a multicenter Dystonia Coalition to advance clinical research on primary focal dystonias, including Cervical Dystonia, Spasmodic Dysphonia, Blepharospasm, and others. Leading the Coalition will be H. A. Jinnah, MD, PhD, Professor of Neurology and Human Genetics at Emory University in Atlanta, GA.

Dystonia is a neurological movement disorder that causes muscles to contract and spasm involuntarily. It affects men, women and children. Dystonia can be generalized, affecting many major muscle groups and resulting in twisting, repetitive movements and abnormal postures. Or dystonia can be more focal, affecting a specific part of the body such as legs, arms, hands, neck, face, mouth, or vocal cords. Currently, it is estimated that at least 300,000 individuals in North America suffer from dystonia, making it more common than Huntington's disease, muscular dystrophy, and ALS. There is no known cure.

The \$6 million award will allow the Dystonia Coalition to cultivate a better understanding of the primary focal dystonias and find better therapies. This includes projects to develop a better understanding of their natural history, establish instruments appropriate for monitoring disease severity in clinical trials, and develop proper diagnostic criteria. The creation of a biorepository to store biological samples to support future research is also planned, making these resources available to investigators worldwide. The Coalition will bring together the most committed dystonia researchers in North America and Europe, along with dystonia patient advocacy groups.

The Dystonia Medical Research Foundation (DMRF) will play an integral role by providing logistical and planning support for the Coalition. The Foundation is well-poised to serve in this capacity as it is the largest and most established patient support organization devoted to dystonia.

“Dystonias are rare and devastating diseases, with limited and sometimes inadequate treatment options,” explains Dr. Jinnah. “Funding of the Dystonia Coalition will allow us to address unmet needs in focal dystonia research, as well as make resources available to other investigators that will help to advance the field.”

“We are delighted about the funding of the Dystonia Coalition and pleased that Dr. Jinnah will be leading this effort,” says Mahlon R. DeLong, MD, Scientific Director of the DMRF. “This is a unique opportunity to provide much-needed attention to these rare diseases. The DMRF is proud to play a role in this important effort.”

The Dystonia Medical Research Foundation is dedicated to advancing research for more treatments and ultimately a cure, promoting awareness and education and supporting the needs and well being of affected individuals and families. To learn more about dystonia, contact the Dystonia Medical Research Foundation at 1-800-377-3978 or [www.dystonia-foundation.org](http://www.dystonia-foundation.org).

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