Medical researchers devoted to advancing treatment for dystonia have earned a five-year, $6 million grant from the Office of Rare Diseases and the National Institute of Neurological Disorders and Stroke. The grant will support a Dystonia Coalition of 18 centers in the United States, Canada and Europe.

H.A. Jinnah, MD, PhD, professor of neurology and human genetics at Emory University School of Medicine, will direct the Dystonia Coalition, with Joel Perlmutter, MD, professor of neurology and radiology at Washington University School of Medicine, as co-director.

The dystonias are a group of neurological disorders that cause muscles to contract and spasm involuntarily, collectively affecting at least 300,000 people in North America. Dystonia can affect the entire body, resulting in twisting, repetitive movement and distorted posture, or it can affect a specific part of the body such as the neck, eyes, mouth or hands.

The Dystonia Coalition will focus on the dystonias that affect a specific part of the body, because they are the most common and appear to have common genetic and environmental risk factors.

Current therapies used for dystonia include muscle relaxants, repeated injections of botulinum toxin and surgery, but both patients and clinicians widely consider them ineffective.

“The misconception that adequate therapies are available for dystonias is impeding the development of better ones,” Jinnah says. “This funding will allow our investigators to address several unmet needs and deepen our understanding of these rare and devastating diseases.”

Jinnah was recruited to Emory in 2008 from Johns Hopkins University, where he established the Dystonia Program in the Movement Disorders Clinic.

The overall goal of the Dystonia Coalition is to advance clinical research on primary focal dystonias and to find better therapies. Specific clinical research projects include establishing a repository to store samples from patients and facilitate the search for diagnostic markers, and developing diagnostic criteria and severity scales for cervical (neck) dystonia and spasmodic dysphonia, a voice disorder.

“We are delighted about the funding of the Dystonia Coalition and pleased that Dr. Jinnah will be leading this effort,” says Mahlon Delong, MD, W.P. Timmie professor of neurology at Emory University School of Medicine and scientific director of the Dystonia Medical Research Foundation. “This is a unique opportunity to provide much-needed attention to these rare diseases.”

The National Institutes of Health is establishing the Dystonia Coalition as part of a $117 million expansion of the Rare Diseases Clinical Research Network, which will coordinate research on more than 95 rare diseases. More information about the RDCRN is available at:
http://rarediseasesnetwork.epi.usf.edu/

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