

NIH Awards New Grant to Develop Better Treatments for Focal Dystonias

Officials at the National Institutes of Health (NIH) have announced the funding of a five year clinical research grant 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, M.D., Ph.D., Professor of Neurology and Human Genetics at Emory University in Atlanta, GA.

The \$5.6 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.

"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."

One component of this grant is aimed at developing an accurate diagnostic test for identifying patients with spasmodic dysphonia who do not have other voice disorders. This was identified as the highest priority need when a research planning conference co-sponsored by the NSDA was held at the NIH in June 2005. The report

http://rs6.net/tn.jsp?et=1102795368222&s=7717&e=001N8oLuhSWXzinBwkMsvUOm1188t09Z7rAzeBVIZq3oWDeNRkg_JbLtSLdfvQPSXKOkvYfRPrwvfqPUom5p7PG_mGqAbkIGzrWTgkmLCKFzIxyINb78EaYG2Zik6_3rEJPq4ye9j_4_rTkDRs0BP-jnRBlwr9uU33LMTI8YOBNOYao_YnPdFiK-5eLi2jApZewH7Sbt4ASBU= of that meeting provided the impetus for this project and contained a pilot study of a proposed diagnostic test.

The study will take place over five years and has three parts. In the first, the diagnostic test will be evaluated at four voice centers (Washington University at St Louis; Medical College of Wisconsin in Milwaukee; New York Center for Voice and Swallowing Disorders associated with Columbia University, and Emory University in Atlanta) to determine whether otolaryngologists, speech pathologists and neurologists at each center can use it accurately and reliably for determining which patients have spasmodic dysphonia and which patients have other voice disorders such as psychogenic dysphonia, muscular tension dysphonia or vocal fold paresis.

In the second phase it will be determined if medical professionals not specializing in voice can also use it to accurately and reliably diagnose spasmodic dysphonia. In the final phase, a double blind treatment study will determine if this new test can accurately quantify changes in severity of the disorder for conducting clinical trials in spasmodic dysphonia. If successful this study will provide a new instrument to serve as a basis for increasing research on spasmodic dysphonia, as we will then be able to identify persons with spasmodic dysphonia and determine the severity of their voice disorder.

"This funding will allow us to develop the first test for accurately identifying who has spasmodic dysphonia and will allow us to measure treatment effects. This will provide the base from which to increase research attention to further understanding and improved treatment for spasmodic dysphonia," says Christy Ludlow, Ph.D., Scientific Director of the National Spasmodic Dysphonia Association. The NSDA is proud to be part of the research coalition and hopes it will bring a greater interest to this field of research.