

## FOR IMMEDIATE RELEASE



Dr. Michael Pitman



Dr. Gaelyn Garrett



Dr. Adam Klein



Dr. Lucy Hicklin



Dr. Carolyn Baylor

### **Cure Dystonia Now and National Spasmodic Dysphonia Association Announce a New Grant to Validate Tool for Spasmodic Dysphonia**

***Cure Dystonia Now and National Spasmodic Dysphonia Association announce a new grant to validate whether the Communication Participation Item Bank (CPIB) can be used as an outcome measure for Spasmodic Dysphonia, a neurological disorder that affects the vocal cords.***

Itasca IL— December 17, 2018—Cure Dystonia Now (CDN) and the National Spasmodic Dysphonia Association (NSDA) announced a new grant designed to validate an outcome measurement protocol for use with spasmodic dysphonia (SD). This co-funded grant is aimed to validate the use of the Communication Participation Item Bank (CPIB) as a tool to (1) measure the severity of restrictions in communication participation in SD patients and (2) accurately measure the outcome of a treatment for SD relative to the disease’s impact on communicative participation before and after treatment.

CPIB is considered an accurate outcome measure in compliance with NIH PROMIS guidelines that harness recent advances in information technology, psychometrics, and qualitative, cognitive, and health survey research. It has already been shown to be accurate for measuring the effect of multiple sclerosis, amyotrophic lateral sclerosis, Parkinson’s disease and head and neck cancer on communication. The CPIB is likely to be more relevant for evaluation of SD because SD is itself a communication disorder, not a disease that coincidentally affects communication.

The study will test whether the CPIB is a valid tool to measure communication impairment in patients with spasmodic dysphonia and whether it can detect significant changes in communication during the treatment process. If successful, it could impact current treatment options and the evaluation of novel therapies.

Lacking a universal validation tool for use within the SD population is an obstacle to data analysis. This study aims to show that CPIB can be used clinically to accurately determine the severity of a patient’s symptoms. It can also be used to evaluate the impact of existing treatments on communication participation as well as the benefits of small dosing changes to allow optimization of dosing. “We are thrilled about this project because we believe this will have a positive impact on research and treatment for those with SD,” said CDN Co-President Marc Miller.

“Once there is data-driven evidence that a treatment works, it’s easier for it to be approved and covered for that condition, said NSDA President Charlie Reavis. “That’s why we are so excited to work collaboratively with CDN on this important project.”

**The participating centers include:**

Dr. Michael Pitman, Columbia University, New York, NY

Dr. Gaelyn Garrett, Vanderbilt Voice Center, Nashville, TN

Dr. Adam Klein, Emory Voice Center, Atlanta, GA

Dr. Lucy Hicklin, St. George's Hospital, London, UK

Dr. Carolyn Baylor, University of Washington, Seattle, WA

**About Spasmodic Dysphonia**

Spasmodic Dysphonia (SD), also known as Laryngeal Dystonia, is a neurological disorder that affects the vocal cords. When a person speaks, the vocal cords spasm, either slamming together, forcing the voice to be tight, choked, or strained; or pulling apart, causing a breathy or airy voice. There is no known cause or cure but treatments include botulinum toxin injections, surgical intervention, and voice therapy. It affects an estimated 50,000 people in North America.

**About Cure Dystonia Now**—Cure Dystonia Now is a charitable foundation committed to advancing research for more and/or improved treatments, and ultimately a cure, for Dystonia.

**About the National Spasmodic Dysphonia Association**—The National Spasmodic Dysphonia Association is a non-profit dedicated to improving the lives of people affected by spasmodic dysphonia and related voice conditions through research, awareness, education and support.

**Contact:**

Kimberly Kuman, Executive Director

National Spasmodic Dysphonia Association

Office: 800-795-6732 | Cell: 847-722-4684

[kkuman@dysphonia.org](mailto:kkuman@dysphonia.org)