Agenda for Dystonia Coalition's 8th Annual Meeting, Webinar
3 June 2020
Time: 9:00 AM – 12:40 PM (ET)
Register here: https://register.gotowebinar.com/register/847494073153852429

9:00-9:20 AM 9:20-9:30 AM	**Introduction to the Dystonia Coalition (DC)** Q&A	H.A. Jinnah, MD, PhD

The DC is a network of centers who collaborate on studies of dystonia. It began in 2009 with 8 centers and has since engaged more than 30 centers across the world. This presentation will summarize how the DC operates and some of its main accomplishments.

9:30-9:45 AM 9:45-9:50 AM	**Patient Advocacy Groups (PAGs): Updates and Future Plans** Q&A	J. Hieshetter/K. Kuman

The DC works closely with its PAGs. This presentation will summarize the many activities made possible by this close cooperation.

9:50-10:10 AM 10:10-10:20 AM	**Natural History Project: Progress & Plans** Q&A	J.S. Perlmutter, MD

Since 2009, more than 3000 subjects have been recruited for this project, which aims to develop a shared database that anyone can access to develop a better appreciation of the phenotypic spectrum of the dystonias, and how they evolve. Recruitment will continue, with a special focus on follow-up of original cases, and recruitment of additional new cases with the rarest subtypes

10:20-10:40 AM 10:40-10:50 AM	**Biobank Project: Progress & Plans** Q&A	C. Cruchaga, PhD

The majority of subjects in the Natural History project have provided a blood sample for DNA extraction, and numerous investigators have accessed this resource for various studies already. In the few next years, this project will be expanded to include other blood products to provide a resource to begin to delineate novel biomarkers.

10:50-11:10 AM	**BREAK**	

11:10-11:30 AM 11:30-11:40 AM	**Patient-Centered Outcomes Project** Q&A	S. Pirio Richardson, MD

Botulinum toxins are the main treatment for many patients with dystonia. Satisfaction is impacted by swings in symptoms associated with treatment cycles. Because there are no data regarding these swings, this project aims to develop a simple app for weekly recording of symptoms. The aim is to develop a better understanding of between-subject and within-subject variations in symptoms. Such data are critical for improving existing therapies, and for developing add-on therapies.

11:40 AM-12:00 PM 12:00-12:10 PM	**Objective Measures Project** Q&A	D. Peterson, PhD

There are numerous clinician-rated and patient-rated measures for the dystonias. Each one suffers certain limitations, one of the main ones being subjectivity. The goal of this project is to develop truly objective measures of the motor disorder using digital analyses of audiovisual recordings of the major subtypes of dystonia.

12:10-12:30 PM	**Q&A**	
12:30-12:35	**Closing Remarks from our External Advisory Committee**	T. Lang, MD
12:35-12:40	**Closing Remarks from our NIH sponsors**	C. Lungu, MD