**The Dystonia Coalition 11th Annual Meeting Agenda**

31 May 2023, 8:30 AM-15:30 PM

Dublin, Ireland

[**Register Here (Open to Everyone)**](https://nam11.safelinks.protection.outlook.com/?url=https%3A%2F%2Fdystoniafoundation.formstack.com%2Fforms%2Fdystonia_coalition_annual_meeting_2023_registration_form&data=05%7C01%7Cgamze.kilic.berkmen%40emory.edu%7C06c6e6084cb84f56482608dae1dbd405%7Ce004fb9cb0a4424fbcd0322606d5df38%7C0%7C0%7C638070631524740488%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=Tkr55RDx4IePbB1QYAJtZh31msAP0RT1HPDej2exCrU%3D&reserved=0)

8:30-8:40 Welcoming Remarks Jinnah

**Introduction Chair: Jinnah**

8:40-8:55 A brief overview of The Dystonia Coalition Jinnah

The purpose of this meeting is to describe the many activities of the Dystonia Coalition. This meeting is open to all Dystonia Coalition Investigators. It is also open to anyone who wants to learn more about the activities of the Dystonia Coalition, including members of patient advocacy groups, NIH, and the pharmaceutical industry. All are welcome.

Comments & questions

9:05-9:30 **Natural History Project Perlmutter**

Since 2009, this project has been collecting clinical data for individuals with all types of dystonia. By now there are nearly 4000 cases, and the data have been used to address numerous questions about the spectrum of the phenotype and its evolution over time.

Comments & questions

9:40-10:05 **Objective Measures Project Peterson**

This project uses digital video to supplement clinical rating scales with objective information regarding diagnosis and severity of the most common adult-onset focal dystonias.

Comments & questions

10:15-10:40 **Biobank Project Cruchaga**

This project involves the collection of biomaterials from individuals with all types of dystonia, with the goal of developing a shared repository for genetics and for exploring novel blood-based biomarkers

Comments & questions

10:50-11:05 **COFFEE BREAK**

11:05-11:30 **Patient-Centered Outcomes Project Richardson**

This project involves the development of a simple app that patients can use to track the severity of their symptoms over time.

Comments & questions

11:40-11:50 **Pilot Project Program: A program that supports pilot projects Jinnah**

Comments & questions

12:00-12:10 **Career Development: A program that supports junior investigators Jinnah**

Comments & questions

12:20-13:00 **LUNCH BREAK**

13:00-13:15 **Patient Advocacy Groups (PAG) Hieshetter & Kuman**

Comments & questions

**Future of the DC (Sustainability) Chair: Jinnah & Perlmutter**

13:25-14:15 Introduction Perlmutter Discussion / Suggestions

14:15-15:00 **Dystonia Consensus Chair: Jinnah & Perlmutter**

Where are we? Jinnah

Discussion / Suggestions

15:00-15:30 DC Steering & Executive Committees Meet to Review Progress