



Agenda for The Dystonia Coalition's First Annual Meeting

Thursday, 5 November 2009

L'Enfant Plaza Hotel, 480 L'Enfant Plaza, SW, Washington, DC 20024 Phone #: 202-484-1000

8:00am	CONTINENTAL BREAKFAST	
8:30am	Welcome	Buz Jinnah
8:35am	A Perspective from the Dystonia Foundations What do the Foundations want to see?	Janet Hieshetter J. Aquines, K. Kuman, H. Miller, N. Rendino, R. Staab
9:00am	A Brief Overview of the Dystonia Coalition	Buz Jinnah
9:10am	Comments & Questions	
9:15am	Career Development Program: Goals and Selection Criteria	Mark Hallett
9:20am	Summary of plans from the first Awardee	Maren Carbon-Correll
9:30am	Pilot Project Program: Goals and Selection Criteria	Stewart Factor
	Pilot Project: Development & Validation of Clinical Diagnostic Guidelines & a Novel Severity Rating Scale for Primary Blepharospasm	Giovanni DeFazio
9:40am	Pilot Project: <i>THAP1</i> Sequence Variants in Primary Dystonia	Mark LeDoux
9:50am	Pilot Project: Dose Escalation of Sodium Oxybate for Idiopathic Cervical Dystonia	Steve Frucht
10:00am	Coalition's Integration with the Data Management Coordinating Center (DMCC)	Jeffrey Krischer
10:30am	BREAK	
10:45am	Project 3: Testing a Rating Scale for Spasmodic Dysphonia	Christy Ludlow
11:00am	Questions to address: 1. Who will participate? 2. Is neurologist, ENT, or SLP assessor alone enough?	
11:45am	Euro-Dystonia	Alberto Albanese
11:55am	Patient Registry	Rachel Richesson J. Aquines, J. Hieshetter, K. Kuman, H. Miller, N. Rendino, R. Staab
12:05pm	LUNCH (Working Groups to meet: Project 1 Biorepository, Project 2, & Patient Registry)	
1:00pm	Project 2: Comprehensive Rating Tools for Cervical Dystonia	Cynthia Comella
1:15pm	Psychiatric Contributions in Cervical Dystonia	Mateusz Zurowski
1:30pm	Questions to address: 1. Who can participate? 2. Reimbursement plans 3. Is assessment of motor and pain enough?	
2:00pm	Project 1: Natural History & Biorepository for All Focal Dystonias	Joel Perlmutter
2:15pm	NINDS Biorepository at Coriell	Rod Corriveau/Alison Ansbach
2:30pm	Questions to address: 1. Who can participate? 2. What are the reimbursement plans? 3. The NHBR committee and <i>Memorandum of Understanding</i>	
3:00pm	Closing comments	Buz Jinnah
3:05pm	General Meeting is adjourned	