**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  
Janet Hieshetter
What do the Foundations want to see?  
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: THAP1 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

12:00pm  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 Memorandum of Understanding

3:00pm  Closing comments  
Buz Jinnah

3:05pm  General Meeting is adjourned