9th Annual Meeting Webinar: Day 1

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Some Housekeeping Information

- Register and sign in
- Webinar is being recorded
- Lots of participants
  - DC & outside interested investigators
  - NIH representatives
  - Pharma representatives
- Everyone is muted, except speakers
- Technical problems?
  - contact Jody or Gamze by email
Dystonia Coalition: What is it?

- Not a research study
- Consortium for multicenter studies
  * infrastructure for clinical & translational research
  * address gaps in clinical trial readiness
- Support began 2009
  * NIH Rare Diseases Clinical Research Network
  * private foundations
  * pharmaceutical companies
We Want Your Comments!

- Questions & comments welcome
- Chat box
- Raise hand function
  
  *we will try to unmute so you can ask directly*
- Send comments/questions after the meeting
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>1:00pm</td>
<td>Welcome &amp; Goals</td>
<td>Jinnah</td>
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<tr>
<td>1:10-1:25pm</td>
<td>What Do We Mean by “Clinical Trial Readiness”?</td>
<td>Perlmutter</td>
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<td>1:35-1:50pm</td>
<td>What Types of Clinical Trials Do We Need to be Ready For?</td>
<td>Pirio Richardson</td>
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<tr>
<td>2:00-2:15pm</td>
<td>What Types of Therapeutic Agents Are Ready for Testing?</td>
<td>Jinnah</td>
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<td>2:25-2:35</td>
<td>BREAK</td>
<td>Lungu</td>
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<td>2:35-2:50pm</td>
<td>Can We Clearly Define Appropriate Patient Populations for Trials?</td>
<td>Hallett</td>
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<td>3:00-3:15pm</td>
<td>Do We Have Adequate Measurement Tools to Assess Outcomes?</td>
<td>Peterson</td>
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<td>3:25-3:40pm</td>
<td>Can we Develop Biomarkers for Dystonia?</td>
<td>Cruchaga</td>
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<td>3:45-4:00pm</td>
<td>Q&amp;A</td>
<td>Jinnah/Perlmutter</td>
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Agenda for Dystonia Coalition’s 9th Annual Meeting
Day 2: Awardee Presentations
2 June 2021, 1-4 PM (ET)

Link to register: https://us02web.zoom.us/webinar/register/WN_yx4JHqFFQN-9uG8iZ/Nnu4w

1:00pm Welcoming Remarks Jinnah
1:05-1:15pm Pilot Project: Goals & Selection Criteria
This talk will describe the Dystonia Coalition Pilot Projects Program.
Comments & questions Jinnah
1:20-1:35pm Non-Invasive Mechanosensory Perturbation to Test Voice-Related Motor
and Somatosensory Cortical Responses in Spasmodic Dystonia
This talk will describe a recently awarded pilot grant.
Comments & questions Hammer
1:45-1:55pm Career Development Program: Goals & Selection Criteria
This talk will describe the Dystonia Coalition Career Development Program.
Comments & questions Comella
2:00-2:15pm Repetitive somatosensory stimulation in focal hand dystonia: a study on
inhibitory circuitry plasticity of the somatosensory system and
primary motor cortex
This talk will describe a recently awarded career award.
Comments & questions Rocchi
2:20-2:30pm BREAK
2:30-2:45pm Patient Advocacy Group Update & Plans
This talk will summarize the role of patient advocacy groups in the many activities of the Dystonia Coalition.
Comments & questions Hieshetter/Kuman
2:55-3:10pm Dystonia Coalition: Where are we now & where are we going?
Year 10 Progress Report
Thanks to Our Sponsors
What’s Next? Jinnah
3:20-3:35pm Q&A
3:35-4:00pm DC Steering & Executive Committees Meet to Review Progress