2023 Annual Meeting
Patient Advocacy Group Overview

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Patient Advocacy Group Liaison
Dysphonia International

Janet L. Hieshetter
Administrative Unit Representative
Dystonia Medical Research Foundation
<table>
<thead>
<tr>
<th>Current DC Patient Advocacy Groups (PAGs)</th>
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<tr>
<td>Beat Dystonia</td>
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<tr>
<td>Benign Essential Blepharospasm Research Foundation* (BEBRF)</td>
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<td>Dysphonia International*</td>
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<td>Dystonia Europe</td>
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<td>Dystonia Ireland</td>
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<tr>
<td>Dysphonia Medical Research Foundation* (DMRF)</td>
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<td>Dystonia Medical Research Foundation Canada</td>
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<td>Dystonia Network of Australia</td>
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<td>Dystonia UK</td>
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<tr>
<td>National Spasmodic Torticollis Association*</td>
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<td>New Zealand Dystonia Patient Network</td>
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<td>Tyler’s Hope</td>
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*Original PAG Groups included in the initial application
PAG Collaboration and Support

- Organizational and Administrative Activities
  - Participation in DC Executive Committee Calls
  - PAG e-mail and conference call updates
  - Attendance at Annual Meetings
  - Representation on the Dystonia Coalition Website

- Research-Related Activities
  - Co-funding projects, including Main Clinical Projects, Pilot Projects and Career Development Awards, along with Travel Scholarships to annual meetings
  - Advertisement of grant programs and DC meetings to research contacts
  - Distribution of study recruitment opportunities to patients for various DC projects
  - Innovative approaches to patient registries
• Internet-based registry that launched in December 2011
• Currently close to 6,600 people registered with 90 countries represented
• Currently supported by DMRF along support from Beat Dystonia, BEBREF, Dysphonia International, DMRF Canada
Administrative Function of the DMRF

- RDCRN
- Patient Advocacy Groups
- Administrative Unit (Emory U)
- Professional groups, Industry

Primary Subcontracts:
- DMRF
- Project 1: Wash U
- Project 2: U NM
- Project 3: UCSD
- Project 4: WashU

“Fee For Service”:
- Recruiting Sites
- Pilot Program
- Career Program
- Annual Meeting
- Other Costs
- Consultants
Administrative Function of the DMRF

- Unique model with a PAG in this role
  - Manage payments for 40+ Centers
  - Organize and manage meetings and webinars for both researchers and the PAG community
  - Participate in the review of PPP/CDA grants
  - Manage community funds from PAGs
  - Represent the DC on the CPAG Steering Committee

Paying grants and fees = stretches grant funds