



● ● ●

# 2023 Annual Meeting

## Patient Advocacy Group Overview

**Kimberly Kuman**

*Patient Advocacy*

*Group Liaison*

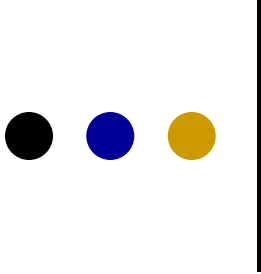
Dysphonia International

**Janet L. Hieshetter**

*Administrative Unit Representative*

Dystonia Medical

Research Foundation



# Current DC Patient Advocacy Groups (PAGs)

- Beat Dystonia
- Benign Essential Blepharospasm Research Foundation\* (BEBRF)
- Dysphonia International\*
- Dystonia Europe
- Dystonia Ireland
- Dysphonia Medical Research Foundation\* (DMRF)
- Dystonia Medical Research Foundation Canada
- Dystonia Network of Australia
- Dystonia UK
- National Spasmodic Torticollis Association\*
- New Zealand Dystonia Patient Network
- Tyler's Hope

*\*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



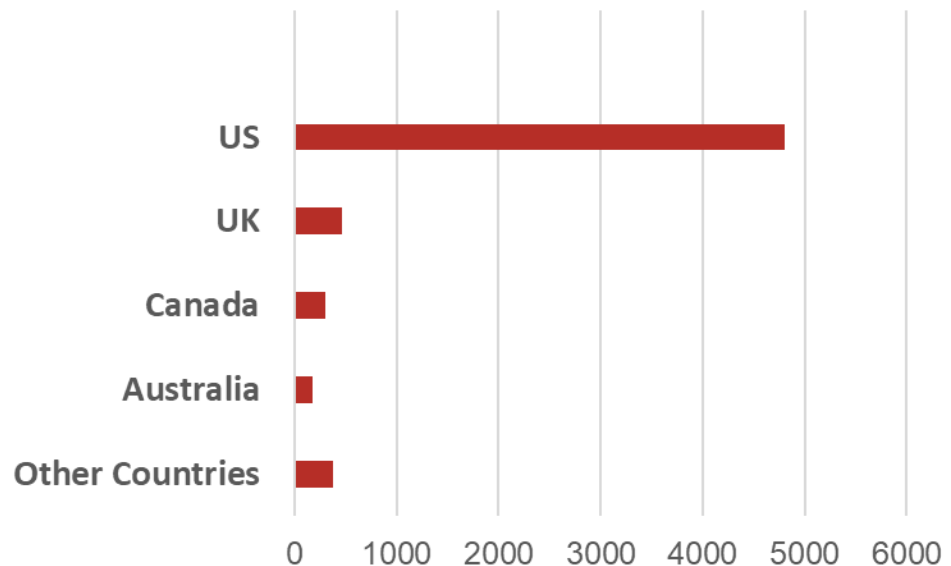
# The Global Dystonia Registry

- 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, BEBRF, Dysphonia International, DMRF Canada

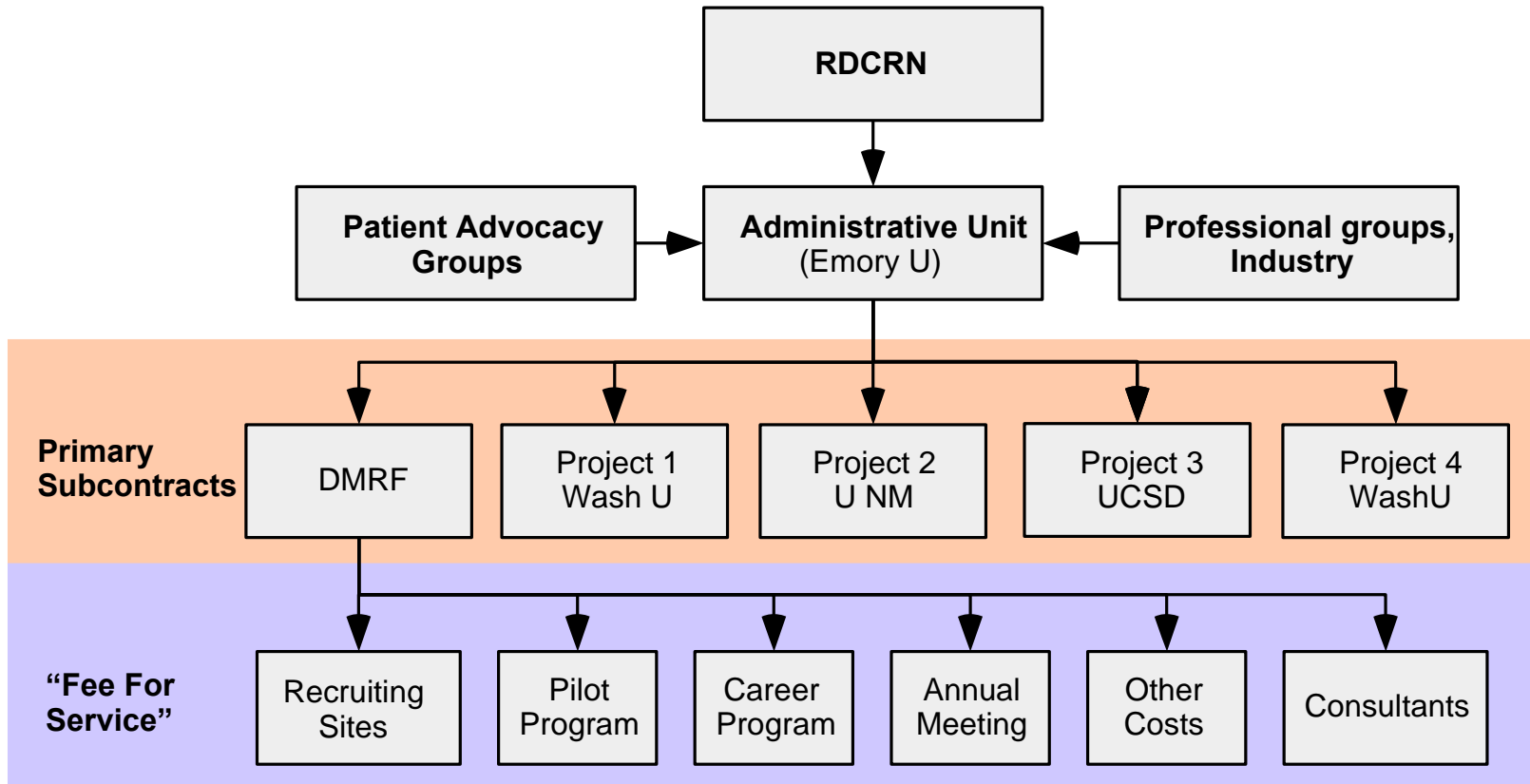
Gender



By Country



# Administrative Function of the DMRF

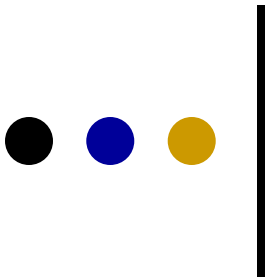




# Administrative Function of the DMRF

- 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**



DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION

*serving all dystonia-affected persons*



*serving all dystonia-affected people  
déservant toutes personnes atteintes de dystonie*

