An Overview for Support Leaders
Thank You

Thank you for your efforts and dedication to the dystonia community.
DMRF Organization

The DMRF
- Committed to serving those affected by dystonia and their families.
- Relentless drive to find a cure.

The DMRF Mission and Goals
- Advance research for more treatments and ultimately a cure.
- Promote Awareness and Education
- Support the well being of affected individuals and families.

How Will We Find a Cure?
- Working with the best people.
- Getting the community involved.
DMRF Organization

- People
  - Board of Directors
  - Medical and Scientific Advisory Council
  - Community Leadership Council
  - Volunteer Network
  - Staff
DMRF Science Program
The Key to Closing Our Doors

- Research Funding
  - Grants, Fellowships, Contracts
- Scientific Workshops and Meetings
- Clinical Fellowship Program
- Dystonia Coalition
- Collaborations
Awareness & Education

- Hand out Educational materials
- Information from DMRF mail and emails
- Community Education Programs
- Dystonia Moves Me campaign
- Social Media Platforms
- Media Outlets
Advocacy

- Dystonia Advocacy Network
  - Grassroots organization bringing dystonia-affected individuals together.
  - Dystonia Advocates speak out on legislative and policy issues.
  - Advocates develop relationships with legislative leaders.
  - Advocates gather in Washington, DC for a two-day event.
The DMRF Support Network

- Support for the Dystonia Community
- DMRF Support Groups
- DMRF Online Support Forums
Your Role in the Community

- A Support Group Leader
- A DMRF Representative
- A Resource for the Community
Leading a Support Group

- Support Group Manual
  - Support Agreement

- Support Leader Contact Information
  - DMRF website
  - Mail and email promotions

- DMRF Policies and Guidelines
  - Inclusion
  - Confidentiality
  - Group Websites & Social Media
Leading a Support Group

- Scheduling a Meeting
  - Meeting Location Ideas
  - Day/Time
  - Speakers/Topics

- Delegating

- Meeting Promotions
  - DMRF Submit A Meeting Form
  - Postcards / Email Blasts
  - DMRF Calendar
  - Social Media
  - Neighborhood Newspaper/ Local Calendar
Resources for Support Groups

- DMRF Educational Materials
- DMRF Brochures
- DMRF Fact Sheets
- DMRF Webinars
Overview of Dystonia

- Types of Dystonia
  - Generalized Dystonia
  - Focal Dystonias:
    - Cervical Dystonia/Spasmodic Torticollis
    - Spasmodic Dysphonia/Laryngeal Dystonia
    - Belpharospasm
    - Oromandibular Dystonia
    - Hand Dystonia
    - Lower Limb Dystonia
    - Musician’s Dystonia
Overview of Dystonia

- Secondary Dystonias:
  - Trauma
  - Tardive Dyskinesias & Dystonia
  - Neurological and Metabolic Disorders

- Other Forms of Dystonia:
  - Myoclonus Dystonia
  - Paroxysmal Dyskinesias
  - X-Linked Dystonia Parkinsonism
  - Rapid Onset Dystonia-Parkinsonism
  - Functional (Psychogenic) Dystonia
  - Dopa-Responsive Dystonia
Dystonia Treatments

- Oral Medications
- Botulinum Neurotoxin Injections
- Deep Brain Stimulation
- Other Surgical Procedures
- Non-Drug Therapies
- Complementary Therapies
DMRF Physician Directory

- A movement disorder neurologist can make a big difference in treatment.

- DMRF maintains a directory of physicians and healthcare providers.

- DMRF Physician Directory
DMRF Resources

People

- Paula Schneider – Leadership Chair

- DMRF Regional Coordinators

- Janet Hieshetter – DMRF Executive Director

- Veronica Diaz – Manager of Community Engagement
  - vdiaz@dystonia-foundation.org
DMRF Resources

- DMRF Website
- DMRF Newly Diagnosed
- DMRF FAQ
- DMRF Common Misunderstandings
DMRF Resources

- **Self-Care Webinar**

- **Mental Health Resources**
  - DMRF Webinar – “Resources to Assist Members in Crisis”
  - Mental Health Handouts
  - DMRF Web Page – “Emotional and Mental Health”
Community Involvement

- Join the DMRF
- Participate in Dystonia Studies
- Help Promote Awareness
- Attend an Education Meeting
- Host a Fundraising Event / start a Facebook Fundraiser
Final Thoughts

- The DMRF is here to provide support and guidance.
- This is a partnership.
- Thank you.
Reach out to Veronica Diaz at 312-447-5097 or vdiaz@dystonia-foundation.org