How To Be A Successful DM Advocate On Capitol Hill

Advocacy Training Presentation
Timeline for Friday Congressional Meetings

8:30 - 9:00  Advocacy Training
9:30 - 12:00 Senate Meetings
12:00 - 1:00 DM Congressional Briefing
1:00 - 4:00 House Meetings

**Return to Hotel After Congressional Briefing or Final Meeting**
Congressional Meeting Schedules

- Your Meetings Are With Your Representative’s and State’s Senate Offices
- Review Congressional Meeting Schedules
  - Member of Congress
  - House or Senate Building & Room Number
  - Name of Staff

2016 MDF Annual Conference
Sept. 15 – 17, 2016   Washington, DC
Pre- Meeting To Do’s

- Review Your Meeting Schedule
  - Know Where Your Meetings Are
- Give Yourself Time To Get To Your Meeting
  - Be on Time or Call If You Are Running Late
- When You Arrive
  - Let Receptionist Know You Are With The Myotonic Dystrophy Foundation
  - And Who You Are There To See…
Congressional Meeting Basics

- You Will Most Likely Meet With Staff
- Meeting Will Take Approximately 15 Minutes
- Remember You Don’t Have to Be A Congressional Expert...
- You Are A **DM** Expert
What Do You Need To Say?

- State Your Hometown & Address
  - All Politics Are Local
- Tell Your Personal DM Story
- Review MDF Legislative Requests
  - National Institutes of Health DM Funding
  - Congressionally Directed Medical Research Program
- Questions?
  - Don’t Worry If You Can’t Answer Every Question – Follow-Up
- Thank You & Follow-Up
  - Get Staff Business Card
Advocacy Request #1: National Institutes of Health

- Background
  - DM is an inherited, progressive genetic disorder that can cause multiple organ systems to fail or severely disrupt their function
  - It causes physical and cognitive disability that significantly limits personal mobility and the ability to perform daily life activities and work as disease severity worsens
  - 1 in 2,500 individuals, or approximately 100,000 Americans, are living with DM
Advocacy Request #1:
National Institutes of Health (Continued)

- There are no FDA approved therapies to treat it or slow disease progression
- In FY15, the NIH funded $9 million for DM research activities
- **REQUEST:** Please support $10 billion (over 5 years) increase for National Institutes of Health in House passed 21st Century Cures Act
- **REQUEST:** Please support House Labor Health & Human Services report that requests NIH DM plan in President’s FY18 budget request

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Advocacy Request #2: Congressionally Directed Medical Research Program

- Surveys indicate there are many active duty military and veterans impacted by DM, we currently do not have prevalence studies.
- Many of the challenges facing persons with DM including muscle weakness, myotonia, fatigue and executive function impairment can impact military readiness.
- DM research will lead to better understanding and improved treatments for neurological and neuromuscular conditions that hinders readiness of U.S. Service Members.
Advocacy Request #2: Congressionally Directed Medical Research Program (Continued)

- Given that DM affects many U.S. Service Member families and dependents;
- And that DM research holds significant promise for major advances across all neurodegenerative diseases and other triplet repeat diseases
- **REQUEST**: Please add DM to the list of conditions eligible for funding under the Congressionally Directed Medical Research Program
Congressional Folders

- Myotonic Dystrophy 101
- National Institutes of Health One-Pager
- Congressionally Directed Medical Research Program One-Pager
- Myotonic Dystrophy Foundation Backgrounder
Post-Meeting Follow-Up

- Fill Out Congressional Feedback Form & Submit to MDF Staff
- Send Thank You Email to Staff
- Participate in Future Action Alerts
- Visit with Your Senate and Representative Offices Back Home
Need Help

☐ Paul Formaker
paul.formaker@myotonic.org
415-872-7924 office

☐ Kevin Brennan
kevin.brennan@faegreBD.com
202-253-0924 mobile

☐ Kelly Nickel
kelly.nickel@FaegreBD.com
303-638-9724 mobile