



2016 MDF ANNUAL CONFERENCE

September 15-17 2016, Washington DC



MYOTONIC
DYSTROPHY
FOUNDATION

Care and a Cure

How To Be A Successful DM Advocate On Capitol Hill

Advocacy Training Presentation

2016 MDF Annual Conference

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



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



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

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