

Becoming A Myotonic Dystrophy Advocate: Advancing Federal Funding for Research

Friday, September 8th
Hyatt Regency
San Francisco, California

2017 MDF Annual Meeting

Myotonic Dystrophy Research Funding

- DM Research Funding – Flat
 - FY15, 16, 17 - \$9 Million
- Opportunities
 - Building Congressional Support
 - Attracting Younger Researchers
 - Meeting with Senior NIH Institute Directors
 - NIAID & NINDS
- Department of Defense Peer Revised Medical Research

FY18 House Labor, HHS Appropriations Bill

Myotonic Dystrophy.—The Committee recognized there are significant gaps in our scientific understanding of the causes of myotonic dystrophy and there are still no FDA approved treatments for this inherited genetic disorder that can cause multiple organ systems to fail or severely disrupt their function that affects approximately 100,000 Americans. The Committee encourages the NIH to fund efforts to recruit young researchers to this field and stimulate more high quality research proposals to advance this critical scientific field. Myotonic dystrophy research holds significant promise for major advances across many neurodegenerative diseases, particularly other triplet repeat expansion diseases.

Department of Defense

Peer Revised Medical Research

- Supports Biomedical Research With Goal of Enhancing Health of Military Service Members, Veterans, & Retirees
- Since Establishment in 1999 PRMRP Funding Totaled \$1.37 billion; Supported Almost 1000 Grants; 128 Different Topic Areas
- Congress Appropriated \$300 Million for the FY17 Program to Solicit Proposals in 48 Topic Areas

Current Legislative Status

- FY18 Starts October 1st
- Senate Subcommittee Plans September Vote
- Senator Feinstein DM Research Amendment
- Outreach to Defense Subcommittee Members

Senate Defense Appropriations Subcommittee Members

Cochran (MS), Chair

McConnell (KY)

Shelby (AL)

Alexander (TN)

Collins (ME)

Murkowski (AK)

Graham (SC)

Blunt (MO)

Daines (MT)

Moran (KS)

Durbin (IL), Ranking

Leahy (VT)

Feinstein (CA)

Murray (WA)

Reed (RI)

Tester (MT)

Udall (NM)

Schatz (HI)

Van Hollen (MD)

Make Your Voice Heard

- Web Resources – congress.gov; senate.gov; house.gov; myotonic.org
- Call U.S. Capitol Switchboard @ (202) 224-3121
- What to Say?
 - ▣ Name, Hometown & State
 - ▣ DM Overview – A Serious Inherited Neuromuscular Disorder Can Cause Multiple Organ Systems To Fail Or Severely Disrupt Their Function
 - ▣ Personal Story
 - ▣ Support Feinstein DM Amendment.
 - ▣ Please Provide Written Reply
-

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

Building Relationships

- Get To Know Your Representatives & Senators
- Visit State & District Offices
- Invite Family & Friends To Help Out
- Post Pictures & Messages on Social Media
- Visit D.C.

Myotonic Dystrophy 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

Myotonic Dystrophy Background

- No FDA Approved Therapies To Treat Or Slow Disease Progression
- Flat NIH Funding \$9 million 3 Straight Years
- MDF Surveys Indicate Many Active Duty Military & Veterans Impacted by DM
- DM Research Will Lead to Better Understanding & Improved Treatments for Neurological & Neuromuscular Conditions That Hinder Military Readiness

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Questions?

Need Help?

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