

How To Be An Effective DM Advocate for A Cure

Webinar
February 25, 2016

Goals for the Webinar

- ▶ What Are We Trying To Accomplish?
 - ▶ Increase DM Research Funding
 - ▶ Department of Defense Congressionally Directed Research Programs
 - ▶ National Institutes of Health
- ▶ How Are We Going To Accomplish This?
 - ▶ Review Relevant Congressional Committees & Key Players
 - ▶ Review Legislative Action Plan
 - ▶ Discuss Advocacy Tools

Department of Defense Congressionally Directed Medical Research Programs (CDMRP)

- ▶ Established By Congress In 1992 By Breast Cancer Advocates
- ▶ Invests In High Impact, High Risk, High Gain Research
- ▶ Has Grown From \$25 Million to Over \$1 Billion Annually
- ▶ Has Funded 43 Diseases, Conditions & Areas of Research
 - ▶ Including Duchenne Muscular Dystrophy, Epilepsy, ALS, Autism
- ▶ Has Awarded 13,261 Grants From 1992-2014 Totaling \$9.7 Billion
- ▶ Need To Recruit House and Senate Sponsor For DM Research Request
 - ▶ House Bill Includes Disease Specific Line Item Funding
 - ▶ Senate Bill Includes Pool of Funding & Disease Line Item Funding
- ▶ GOAL: Include DM In Compromise Defense Bill CDMRP Disease Funding Pool In Early Fall

National Institutes of Health DM Research Funding

- ▶ DM Research Funding Has Been Flat - \$9 M (FY11-16)
- ▶ Other Disease Research Comparables
 - ▶ Duchene/Becker Muscular Dystrophy \$32 M (FY11) - \$33 (FY16)
- ▶ DM 3.0 Federal Research Goal **(33 Million In 3-5 Years)**
- ▶ Strategies:
 - ▶ Educate Congress About DM, Personal and Economic Impact
 - ▶ Recruit Congressional Advocates
 - ▶ Leverage Congressional Support to Increase NIH Focus on DM Research
 - ▶ Seek Appropriations Provision “Report Language” on DM Research
 - ▶ Congressional Letters to NIH
 - ▶ MDF Annual Meeting

Senate Appropriations Committee

Members

Thad Cochran, Chairman (Mississippi)
Mitch McConnell (Kentucky)
Richard Shelby (Alabama)
Lamar Alexander (Tennessee)
Susan Collins (Maine)
Lisa Murkowski (Alaska)
Lindsey Graham (Republican - South Carolina)
Senator Mark Kirk (Illinois)
Roy Blunt (Missouri)
John Hoeven (North Dakota)
John Boozman (Arkansas)
Shelley Moore Capito (West Virginia)
Bill Cassidy (Louisiana)
James Lankford (Oklahoma)
Steve Daines (Montana)

Barbara Mikulski, Vice Chair (Maryland)
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Patty Murray (Washington)
Dianne Feinstein (California)
Richard Durbin (Illinois)
Jack Reed (Rhode Island)
Jon Tester (Montana)
Tom Udall (New Mexico)
Jeanne Shaheen (New Hampshire)
Jeff Merkley (Oregon)
Christopher Coons (Delaware)
Brian Schatz (Hawaii)
Tammy Baldwin (Wisconsin)
Chris Murphy (Connecticut)

House Appropriations Committee

Republican Members

Harold Rogers, Kentucky, Chairman
Rodney P. Frelinghuysen, New Jersey
Robert B. Aderholt, Alabama
Kay Granger, Texas
Michael K. Simpson, Idaho
John Abney Culberson, Texas
Ander Crenshaw, Florida
John R. Carter, Texas
Ken Calvert, California
Tom Cole, Oklahoma
Mario Diaz-Balart, Florida
Charles W. Dent, Pennsylvania
Tom Graves, Georgia
Kevin Yoder, Kansas
Steve Womack, Arkansas

Jeff Fortenberry, Nebraska
Tom Rooney, Florida
Chuck Fleischmann, Tennessee
Jaime Herrera Beutler, Washington
David Joyce, Ohio
David Valadao, California
Andy Harris, MD, Maryland
Martha Roby, Alabama
Mark Amodei, Nevada
Chris Stewart, Utah
Scott Rigell, Virginia
David Jolly, Florida
David Young, Iowa
Evan Jenkins, West Virginia
Steven Palazzo, Mississippi

House Appropriations Committee

Democratic Members

Nita M. Lowey, New York
Marcy Kaptur, Ohio
Peter J. Visclosky, Indiana
José E. Serrano, New York
Rosa L. DeLauro, Connecticut
David E. Price, North Carolina
Lucille Roybal-Allard, California
Sam Farr, California
Chaka Fattah, Pennsylvania
Sanford D. Bishop, Jr., Georgia
Barbara Lee, California

Michael M. Honda, California
Betty McCollum, Minnesota
Steve Israel, New York
Tim Ryan, Ohio
C.A. Dutch Ruppersberger, Maryland
Debbie Wasserman Schultz, Florida
Henry Cuellar, Texas
Chellie Pingree, Maine
Mike Quigley, Illinois
Derek Kilmer, Washington

DM Congressional Campaign Milestones

- ▶ President Delivered State of the Union – Jan. 12th
- ▶ White House Submits FY17 Budget to Congress – Feb. 9th
- ▶ House and Senate Appropriations Hearings – March-April
 - ▶ MDF Submits Appropriation Requests
 - ▶ Launch DM Grassroots Advocacy Push
 - ▶ Request Slot for MDF To Testify At Public Witness Hearing
- ▶ House & Senate Pass Appropriations Bills – late July target
 - ▶ Additional Opportunity for Advocates to Contact Congress
- ▶ MDF Annual Meeting in D.C. - September 15-17th
- ▶ New Fiscal Year Begins Oct 1st
- ▶ Presidential Election Nov 8th

Who Should I Contact?

▶ Rare Disease Day: February 29th, 2016

- ▶ Email, Call, or Visit Your Representative or Senator's District or State Office.
- ▶ To find your Senators and Representative and their office phone numbers and email addresses, please feel free to use the attached link.
<https://www.opencongress.org/people/zipcodelookup>
- ▶ If you know your Senators and Representative and would like to call them, you may also dial the U.S. Capitol Switchboard at (202) 224-3121. A switchboard operator will connect you directly with the Senator or Representative's office at your request.

What Should I Say?

Sample Email and/or Call Talking Points

- ▶ My name is _____ and I'm from [your hometown and state].
- ▶ I have or have a friend or loved one living with myotonic dystrophy - a form of muscular dystrophy.
- ▶ Myotonic dystrophy is a multi-systemic inherited disease that affects an estimated 100,000 Americans. Although often viewed as a muscle disease, individuals affected by myotonic dystrophy may have skeletal muscle problems, heart function abnormalities, breathing difficulties, cataracts, issues with speech and swallowing (dysarthria and dysphagia), cognitive impairment, excessive daytime sleepiness, or diabetic symptoms.

What Should I Say?

- ▶ Federal funding for myotonic dystrophy research has been minimal and there are no approved treatments for the condition.
- ▶ I am contacting you today as part of Rare Disease Month to ask for your support for efforts to include Myotonic Dystrophy as part of the Department of Defense Congressionally Directed Medical Research Programs.
- ▶ I'd like to share with you [my mailing address or email address] so that you can reply to my request for support.
- ▶ Thank you!

What Else Can I Do?

- ▶ Let MDF Know If You Live In a Targeted State or Congressional District
- ▶ Seek Opportunities To Develop A Relationship With Member and Their Staff
- ▶ Draft A Letter to The Editor About Our DM Congressional Priorities
- ▶ Invite Families and Friends To Become DM Advocates
- ▶ Stay Connected With MDF For Action Alerts All Year
- ▶ Attend the MDF Annual Meeting In DC And Make Your Voice Heard

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