

# 2023 MDF Advocacy Week

## Five Days to Make a Difference: April 17<sup>th</sup> - 21<sup>st</sup>

### Instructions & Suggested Talking Points for Requesting a Meeting

MDF invites advocates from across America to email, call, and meet with their U.S. Senators and Representatives during our 2023 Advocacy Week campaign April 17-21st to raise DM awareness and urge Congress to increase federal funding for myotonic dystrophy (DM) research to help us find a cure!

For additional support, resources, or questions about MDF's advocacy efforts and priorities, please contact the Foundation at [info@myotonic.org](mailto:info@myotonic.org).

### Contacting Your Senators

Since many Senators and their staffers are unfamiliar with **myotonic dystrophy**, we recommend all advocates use the full name of the disease in their requests & meetings.

To look up your U.S. Senators and their contact information, visit [www.congress.gov](http://www.congress.gov).

### Suggested Talking Points to Request a Senate Meeting

- My name is [ YOUR NAME ] and I am a constituent who lives in [ YOUR TOWN, YOUR STATE].
- I am contacting your office to request a call or virtual meeting with the health care staff.
- I represent the Myotonic Dystrophy Foundation and we are contacting Congress as part of our 2023 Advocacy Week.
- My purpose for the visit is to ask the Senator to please support the inclusion of myotonic dystrophy as an “eligible condition” in the fiscal year 2024 Department of Defense Peer Review Medical Research Program (PRMRP) for the 7<sup>th</sup> year in a row.

**Note:** During this call, the Senators staff will likely request your phone number and/or email to contact you to set-up a meeting.

After completing the call or request, share your outreach with MDF to let us know how it went via email at [info@myotonic.org](mailto:info@myotonic.org)!

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### Suggested Talking Points for Your Senate Meeting

Calls or virtual meetings with staff usually take 20 minutes. Please be mindful of time as you share your personal story.

*Make sure to leave time to make your request and for staff to ask questions!*

- My name is [ YOUR NAME ] and I am a constituent who lives in [ YOUR TOWN, YOUR STATE ]
- Briefly share your story in 5-7 minutes:
  - Your relationship to myotonic dystrophy. *Examples:*
    - I have myotonic dystrophy.
    - I am a caregiver for someone living with myotonic dystrophy.
    - My child is living with myotonic dystrophy.
    - A close friend of mine is living with myotonic dystrophy.
  - Your challenges associated with living with myotonic dystrophy. *Examples:*
    - Year of Diagnosis.
    - Impact on Daily Life.
    - Significant Medical Life Events.
    - Impact on Employment.
- **YOUR ASK OF THE SENATOR:**
  - Will the Senator support inclusion of myotonic dystrophy as part of the fiscal year 2024 Department of Defense Peer Reviewed Medical Research Program (PRMRP) for the 7<sup>th</sup> year in a row?
  - **Note:** the staff will likely tell you they have to review your request & seek the Senator's approval so ask if you can email them in two weeks to follow-up!
- Do the staff have any questions?
  - **Note:** If you do not know the answer, do not feel pressured to respond. MDF is here to support you with additional information and expertise!
  - Record their question and let them know you will work with MDF to find out.
- Thank them for their time and support!