

Advocating for Myotonic Dystrophy Research Funds Rare Disease Day 2023

*Instructions and Suggested Talking Points for
Congressional Meetings and Calls*



As the new Congress begins work on the fiscal year 2024 budget that includes important federal biomedical research funding, MDF advocates from across the country will be urging our U.S. Senators to include DM as an eligible research condition under the [Peer Review Medical Research Program \(PRMRP\)](#) for the 7th year in a row.

For more additional support, resources, or questions about MDF's advocacy efforts and priorities, please contact the Foundation at info@myotonic.org.

Contacting Your Senators

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

To look up your U.S. Senators and their contact information, visit www.congress.gov.

Suggested Talking Points for Requesting a Meeting

- My name is JANE DOE and I am a constituent who lives in EVERYTOWN, STATE.
- I contacting your office to request a call/virtual meeting with the health care staff.
- I represent the Myotonic Dystrophy Foundation and we are contacting Congress on behalf of the Myotonic Dystrophy Community in honor of Rare Disease Day.
- 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).

After completing the call or request, share your outreach with MDF to let us know how it went via email at info@myotonic.org.

NOTE: Your Senator's staff will likely request your phone number and/or email so they can follow up with you to set-up a meeting.

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Suggested Talking Points for Your Meeting

Calls/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 JANE DOE and I am a constituent who lives in EVERYTOWN, STATE
- I have myotonic dystrophy. Briefly describe your experiences in **5-7 minutes**, examples include:
 - Year of Diagnosis
 - Impact on Daily Life
 - Significant Medical Life Events
 - Impact on Employment
- **YOUR ASK OF THEM:**
 - Please support the inclusion of myotonic dystrophy as part of the fiscal year 2024 Department of Defense Peer Reviewed Medical Research Program (PRMRP).
- Do you have any questions?
 - If you do not know the answer, do not feel pressured to respond. MDF is here to support you with additional information and expertise.
 - Make a note and let them know you will work with MDF to find out.
- Thank you for your support.

After your meeting, let us know how it went by emailing MDF at info@myotonic.org.