

Myotonic Dystrophy Foundation: 2021 Rare Disease Day

Congressional Meeting Request Instructions And Suggested Meeting Talking Points

NOTE: If you need help looking up how to contact your Representatives and Senators, please visit www.congress.gov. And if you have further questions, please contact kbrennan@bluebird-strategies.com

** Use the full name of the disease instead of DM or MMD because they will not be familiar with it.

Talking Points to Request a Meeting with Staff:

- 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 as part of Rare Disease Day.
- My purpose for the visit is to increase awareness of rare diseases like myotonic dystrophy and ask for your support for increased federal funding for myotonic dystrophy research at the NIH

NOTE: They will likely request your phone number and/or email so the staff can contact you to set-up a meeting. Below are suggested talking points for that call/virtual meeting.

Suggested Talking Points for Meetings with Staff:

NOTE: Calls/virtual meetings with staff usually take 20 minutes for please be mindful of time as you share your personal story and 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. Describe briefly in 5-7 minutes:
 - Examples: Year of Diagnosis, Impact on Daily Life, Significant Medical Life Events, Impact on Employment
- **YOUR ASK OF THEM:**
 - 1) Please support an increase in federal funding for myotonic dystrophy research at the National Institutes of Health,
 - 2) Support continued inclusion of myotonic dystrophy as part of the fiscal year 2022 Department of Defense Peer Reviewed Medical Research Program (PRMRP), and soon to be introduced legislation recognizing Myotonic Dystrophy Awareness Day.
- Do you have any questions?
- Thank you for your support.