How To Be An Effective MDF Advocate for DM Research Funding

Kevin Brennan

2024 Support Group Facilitator Conference

Chicago, Illinois, April 27

Myotonic Dystrophy
FOUNDATION

What Is Grassroots Advocacy

- Ordinary Citizens Organize To Influence Legislators To Change Policies And Budgets On Issues Impacting Their Communities.
- Strength And Effectiveness Of Grassroots Movements Is Based On Their Ability To Communicate The Authentic Passion Of Regular Citizens To Improve Their Communities.
- Grassroots Advocacy Is Most Effective When A Maximum Number Of People Have A Simple, Unified Request(s) And Hold Legislators Accountable For An Answer.

Why Grassroots Advocacy Matters

- If MDF Advocates Don’t Raise Awareness and Request More Research Funding, Who Else Will?
- If Congress Doesn’t Know About DM, They Won’t Support New DM Research Funding.
- Where You Are a Constituent, You Have Power.
- The More Personal Stories and Requests for Support We Make, The Better Our Chances of Securing More DM Research Funding.

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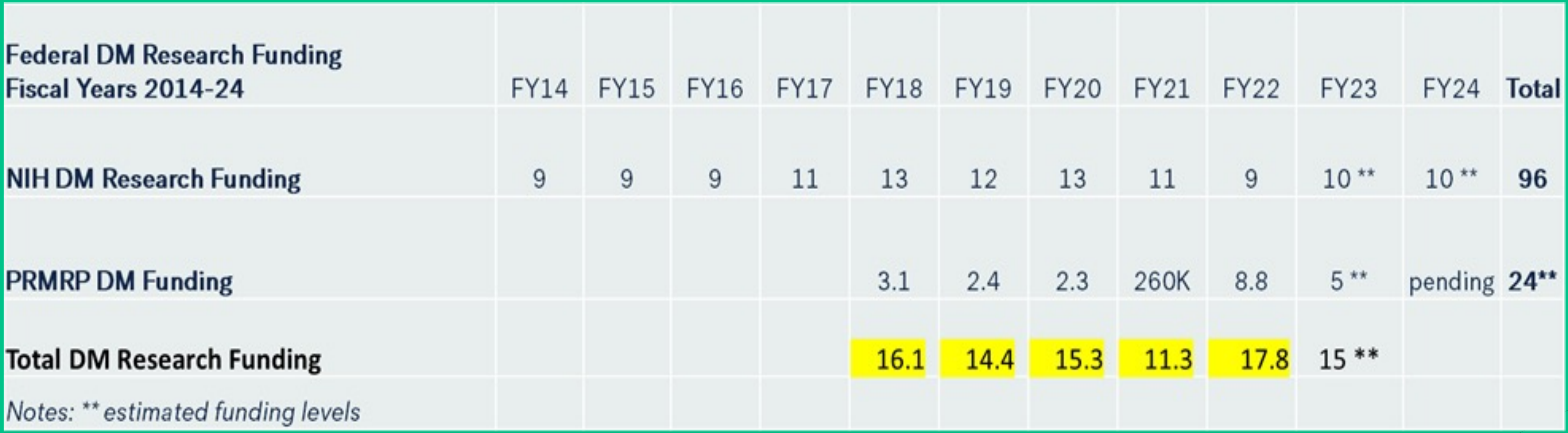
Federal Funding for DM Research



Federal DM Research Funding Fiscal Years 2014-24	FY14	FY15	FY16	FY17	FY18	FY19	FY20	FY21	FY22	FY23	FY24	**Total**
NIH DM Research Funding	9	9	9	11	13	12	13	11	9	10 **	10 **	**96**
PRMRP DM Funding					3.1	2.4	2.3	260K	8.8	5 **	pending	**24****
Total DM Research Funding					16.1	14.4	15.3	11.3	17.8	15 **		

*Notes: ** estimated funding levels*

MDF 2024 Advocacy Priorities

- Ask Congress To Support $10 Million in Dedicated DM Research Funding As Part of the Fiscal Year 2025 Congressionally Directed Medical Research Program (CDMRP).
- Ask Senators To Maintain DM Eligibility for Research Funding As Part of the Peer Reviewed Medical Research Program for 8th Year In A Row As Part of the Fiscal Year 2025 Defense Appropriations Report
- Seek State and Local Gov’t Support For International DM Awareness Day Proclamations on September 15th

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Peer-Reviewed Medical Research Program

- U.S. Senate Has Made Myotonic Dystrophy An Eligible Research Focus for Seven Consecutive Years as part of the Department of Defense (DoD) Peer-Reviewed Medical Research Program
- PRMRP Has Funded Almost $24 Million in Innovative Peer Reviewed Research
- Senate Supporters Have Included Casey (D-PA), Durbin (D-IL), and Feinstein (D-CA)
- MDF On Track For Eight Year of Eligibility

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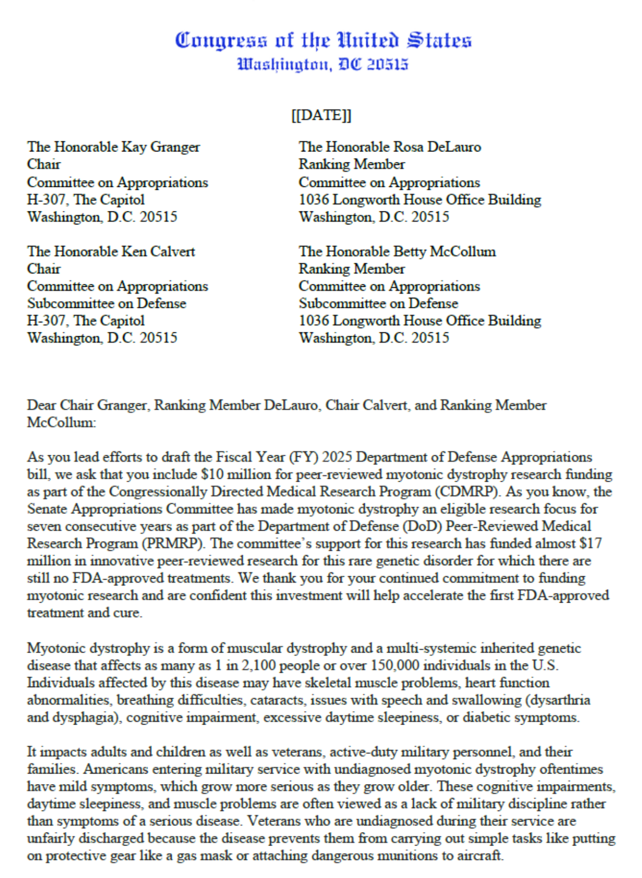
Urge Your Representative to Sign Kiggans-Moskowitz CDMRP Letter



Congress of the United States
Washington, DC 20515

[[DATE]]

The Honorable Kay Granger
Chair
Committee on Appropriations
H-307, The Capitol
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
Committee on Appropriations
1036 Longworth House Office Building
Washington, D.C. 20515

The Honorable Ken Calvert
Chair
Committee on Appropriations
Subcommittee on Defense
H-307, The Capitol
Washington, D.C. 20515

The Honorable Betty McCollum
Ranking Member
Committee on Appropriations
Subcommittee on Defense
1036 Longworth House Office Building
Washington, D.C. 20515

Dear Chair Granger, Ranking Member DeLauro, Chair Calvert, and Ranking Member McCollum:

As you lead efforts to draft the Fiscal Year (FY) 2025 Department of Defense Appropriations bill, we ask that you include $10 million for peer-reviewed myotonic dystrophy research funding as part of the Congressionally Directed Medical Research Program (CDMRP). As you know, the Senate Appropriations Committee has made myotonic dystrophy an eligible research focus for seven consecutive years as part of the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP). The committee's support for this research has funded almost $17 million in innovative peer-reviewed research for this rare genetic disorder for which there are still no FDA-approved treatments. We thank you for your continued commitment to funding myotonic research and are confident this investment will help accelerate the first FDA-approved treatment and cure.

Myotonic dystrophy is a form of muscular dystrophy and a multi-systemic inherited genetic disease that affects as many as 1 in 2,100 people or over 150,000 individuals in the U.S. Individuals affected by this disease 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.

It impacts adults and children as well as veterans, active-duty military personnel, and their families. Americans entering military service with undiagnosed myotonic dystrophy oftentimes have mild symptoms, which grow more serious as they grow older. These cognitive impairments, daytime sleepiness, and muscle problems are often viewed as a lack of military discipline rather than symptoms of a serious disease. Veterans who are undiagnosed during their service are unfairly discharged because the disease prevents them from carrying out simple tasks like putting on protective gear like a gas mask or attaching dangerous munitions to aircraft.

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CDMRP Campaign: How Can You Help

- Email/Call Your Representative
- Request Virtual Meeting With Congressional Staff
- Get An Answer

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Visit MDF Advocacy Action Center

Hi Kevin in Washington, DC!

Request Support for Kiggans Moskowitz Letter - Include $10 million in Myotonic Dystrophy Research Funding for CDMRP

Request your House Member to support the congressional letter authored by **Reps. Jen Kiggans (R-VA) and Jared Moskowitz (D-FL)** urging the House Appropriations Defense Subcommittee to include $10 million for peer-reviewed myotonic dystrophy research funding as part of the Congressionally Directed Medical Research Program (CDMRP).

Join Myotonic Dystrophy Foundation (MDF) Advocates across the U.S. who are making their voices heard in Congress!

Congress has made myotonic dystrophy an eligible research focus for seven consecutive years as part of the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP). Congress's support for this research has funded almost $24 million in innovative peer reviewed research for this rare genetic disorder for which there are still no FDA approved treatments. It remains one of the least funded serious genetic disorders. **This modest increase in myotonic dystrophy research funding will help advance basic science and accelerate the day we have our first FDA approved treatments and a cure.**

Compose Your Message

- Delegate Eleanor Norton

1. Use the message below as is or customize it with your personal story!
2. Fill in your name and address to automatically find and add your congressional representatives.

Note: If you do not have a mobile phone, un-check "Send me text alerts" to be able to complete the form.

Subject

Co-sign the congressional letter by Reps. Kigga

Message Body

I am writing to ask you to co-sign the congressional letter authored by Reps. Jen Kiggans (R-VA) and Jared Moskowitz (D-FL) urging the House Appropriations Defense Subcommittee to include $10 million for

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Being An Advocate Is Easy!

Interested MDF Advocates can visit **www.myotonic.org/myotonic-dystrophy-advocacy** or scan the QR code to the right and visit our new Advocacy Action Center to look up your Senators and Representatives and find a preloaded sample email to use in urging Congress to support more DM research funding. Please remember to personalize your emails by adding something about your own journey living with or caring for someone with myotonic dystrophy.

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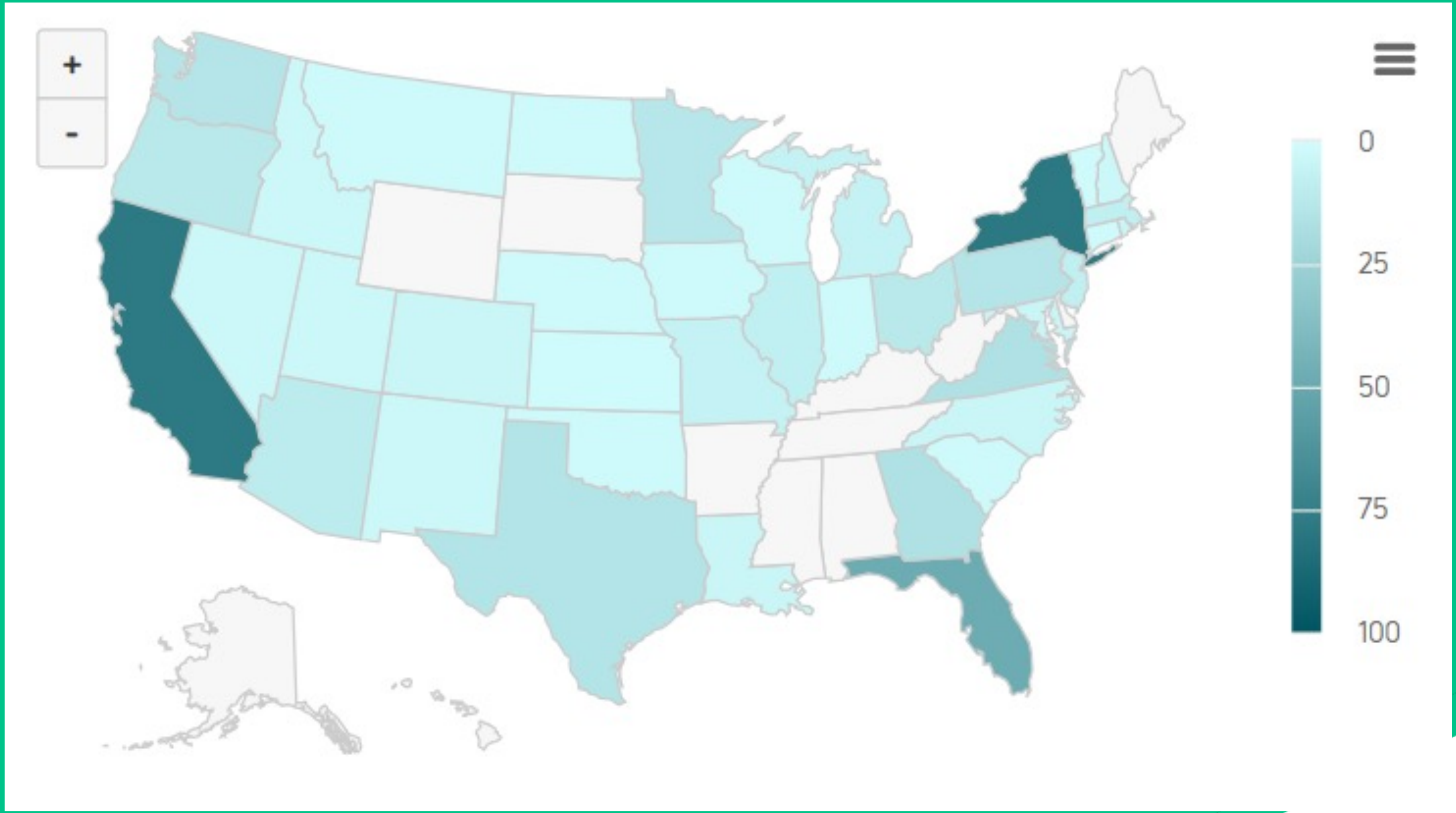
Community Emails to Congress



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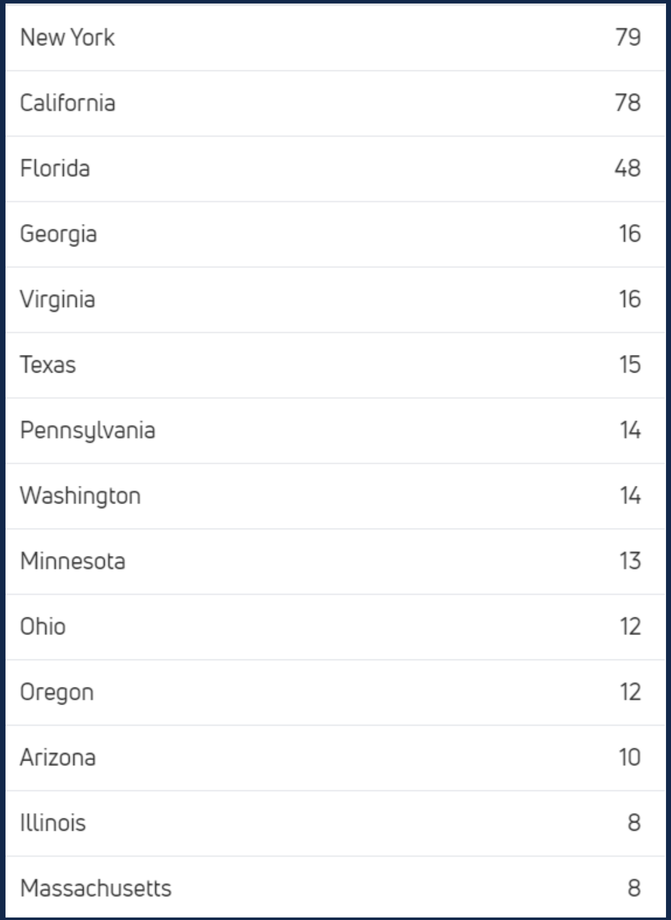
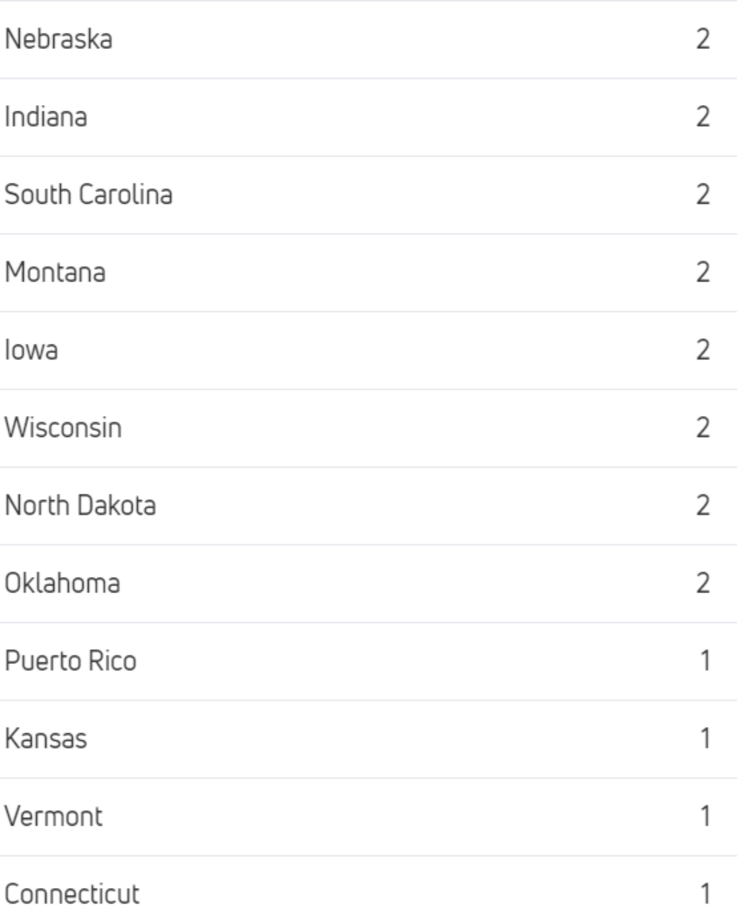
Most Community Emails By State



New York	79
California	78
Florida	48
Georgia	16
Virginia	16
Texas	15
Pennsylvania	14
Washington	14
Minnesota	13
Ohio	12
Oregon	12
Arizona	10
Illinois	8
Massachusetts	8

New Jersey	8
Missouri	6
Michigan	6
Louisiana	4
Maryland	4
Rhode Island	4
North Carolina	4
Colorado	4
District of Columbia	3
Utah	3
New Hampshire	3
Nevada	3
Idaho	3
New Mexico	3



Nebraska	2
Indiana	2
South Carolina	2
Montana	2
Iowa	2
Wisconsin	2
North Dakota	2
Oklahoma	2
Puerto Rico	1
Kansas	1
Vermont	1
Connecticut	1

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How To Request A House Meeting

- Call U.S, Capitol Operator - (202) 224-3121 – Ask To Be Connected To Your Representative's D.C. Office

- Dear Congressional Staffer:

  My name is Jane Doe and I am a Myotonic Dystrophy Foundation advocate from YOUR HOMETOWN. I'm calling to request a virtual meeting with the Representative's health staff to discuss a bipartisan letter (attached) by Reps. Kiggans (R-VA) and Moskowitz (D-FL) to the House Appropriations committee in support of our request for $10 million in dedicated federal funding for myotonic dystrophy research under the Congressionally Directed Medical Research Program (CDMRP). I'm available to meet virtually with you on XX, XX, and XX. This matter is time sensitive as the letter to the House Appropriations Committee will close in a few days. Thank you for your kind attention to my request.

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What To Say During Your Virtual Meeting

- Explain Who You Are & Reason For The Meeting
- Tell Your Personal Story That Highlights Need For Research
  - Explain Diagnostic Odyssey
  - Explain There Are No FDA Approved DM Treatments
- Ask To Sign Kiggans Moskowitz Letter Requesting $10 M For DM Research As Part Of CDMRP
- Send Thank You Note/Email

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How Has Signed So Far?

- Rep. Kiggans (R-VA)
- Rep. Moskowitz (D-FL)
- Rep. Fitzpatrick (R-PA)
- Rep. Panetta (D-CA)
- Rep. Tonko (D-NY)
- Rep. Blumenauer (D-OR)
- Rep. Craig (D-MN)
- Rep. Suozzi (D-NY)

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Senate CDMRP Letter

- Senator Amy Klobuchar (D-MN)
- Recruiting Senate Republican Co-Lead

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Securing State/Local Proclamation for International DM Awareness Day

- State & Local Proclamations Are An Excellent Way to Increase DM Awareness
- Contact Your Governor, State Legislator, or Mayor Via Phone or Email to Ask About the Process for Getting a DM Proclamation
- Some Offices Will Have Official Applications to Complete. If There Isn't an Application, Send a Short Email or Letter with Your Request
- Schedule Meeting with the Official and/or Their Staff to Tell Them Why This is Important to You. Request Your Meetings Several Months Before September 15th to Ensure They Have Plenty of Time to Assist with Your Proclamation Request

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International DM Awareness Day Next Steps

- Provide Your Elected Official With Sample Proclamation Text
- Ask for Public Presentation of the DM Proclamation and Contact Local Media to Cover the Event
- Take Photos of the Event and Share Your Photos on Social Media, with Local Media, and With MDF

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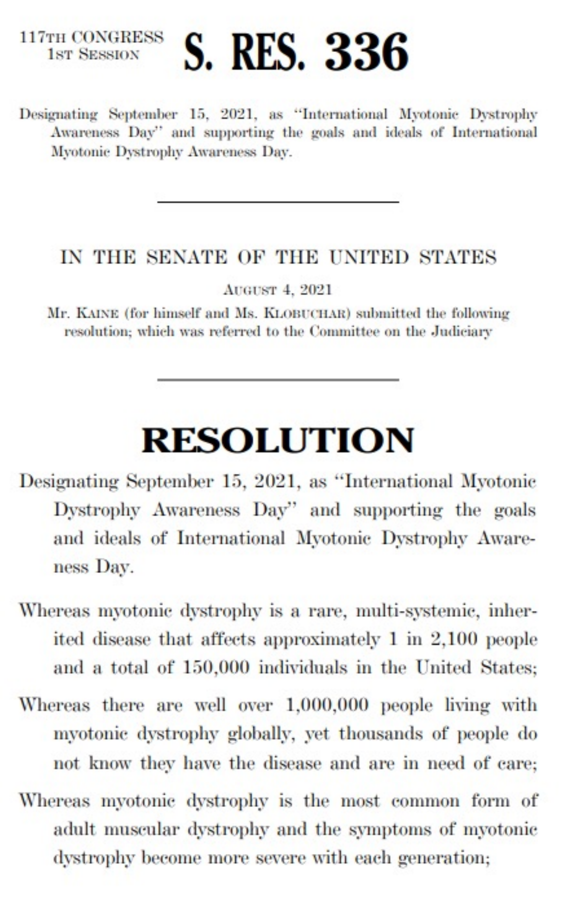
Sample DM Proclamation Language



117TH CONGRESS
1ST SESSION

S. RES. 336

Designating September 15, 2021, as "International Myotonic Dystrophy Awareness Day" and supporting the goals and ideals of International Myotonic Dystrophy Awareness Day.

IN THE SENATE OF THE UNITED STATES

AUGUST 4, 2021

Mr. KAINE (for himself and Ms. KLOBUCHAR) submitted the following resolution; which was referred to the Committee on the Judiciary

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RESOLUTION

Designating September 15, 2021, as "International Myotonic Dystrophy Awareness Day" and supporting the goals and ideals of International Myotonic Dystrophy Awareness Day.

Whereas myotonic dystrophy is a rare, multi-systemic, inherited disease that affects approximately 1 in 2,100 people and a total of 150,000 individuals in the United States;

Whereas there are well over 1,000,000 people living with myotonic dystrophy globally, yet thousands of people do not know they have the disease and are in need of care;

Whereas myotonic dystrophy is the most common form of adult muscular dystrophy and the symptoms of myotonic dystrophy become more severe with each generation;

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Final Charge

- You Are Powerful. Your Voice Must Be Heard.
- Senators and Representatives Were Elected By Voters/Your Fellow Citizens.
- They Are Public Servants - They Work For You.
- You Are Embarking On A Great Adventure – Representing The MDF Community & Creating Change.
- Know You Are Making a Difference.

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