



MYOTONIC
DYSTROPHY
FOUNDATION

Care and a Cure



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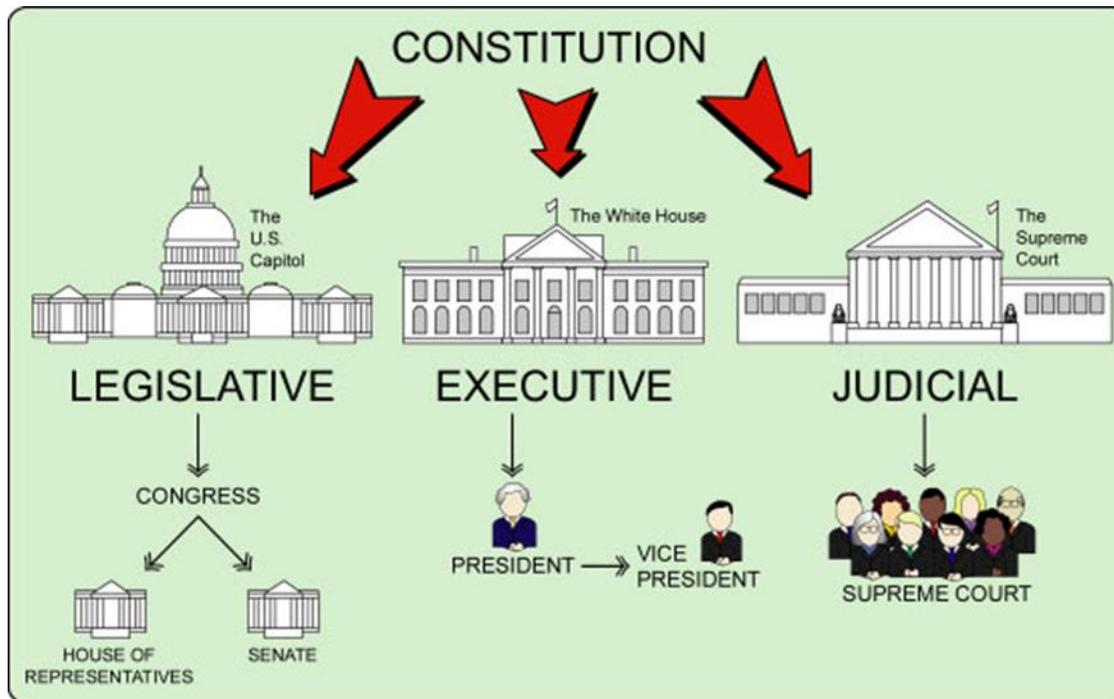
BECOMING A DM ADVOCATE

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Session Overview

- Background
- Overview of Congress and Federal Agencies
- Elections and their Role in Congress
- What We're Advocating for and Why
- How to get Engaged and Stay Engaged

Advocacy 101: A Quick Civics Refresher



Executive Agencies

- The Department of Health and Human Services (HHS) is a cabinet level department that seeks to improve the health, well-being, and safety of Americans.
- The National Institutes of Health (NIH), a part of HHS, is the nation's biomedical and public health research agency.
- The Food and Drug Administration (FDA), also an agency under HHS, regulates pharmaceuticals (among other things).

Why We Focus on The Congress

- While each branch is important, the Congress makes laws and determines how much money is spent on certain activities (e.g., *the power of the purse*).
- Congress is also the closest branch to the people via our Senators and, even closer to home for most persons, are our Representatives.
- The Administration implements laws and runs the government on a day-to-day basis but these actions are guided and shaped by the parameters put forward by Congress via law.

Understanding Congressional Committees

- Committees help organize the Congress and legislative process.
- They have assigned roles and responsibilities, including jurisdiction over issues, sectors of the economy and government departments and agencies.
- Committees hold hearings, debate policy and develop and amend (markup) legislation.
- While any Member of Congress can introduce legislation on any issue, members on a committee enjoy greater clout/ability to influence policy and legislation within the panel's purview.
- This is why MDF prioritizes visits involving members of key committees.

How is Election Season Impacting Congress?

- 1/3 of the US Senate is up for re-election in November
- ALL of the House of Representatives is up for re-election
- The extreme partisanship and upcoming elections are de-incentivizing members to work together so close to election day
- Many politicians are predicting a Democratic wave, especially in the House of Representatives

The Current Climate

- Partisanship or the divide between Republicans and Democrats remains very high and is impacting the ability to legislate and govern.
- The midterm elections taking place in November of this year have become high priority, and many members are focused on preserving their seats and appealing to their base voters.
- President Trump's administration continues to endure frequent staff changes and scandals related to his campaign and its ties to Russia

What's on Congress's Plate Today?

A lot:

- Passing and getting signed into law a budget plan for Fiscal Year 2019 (starts Oct. 1)
- The opioid crisis
- Filling the Supreme Court vacancy
- Reauthorization of the Pandemic All-Hazards Preparedness Act (PAHPA)

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
- House Bill Includes Disease Specific Line Item Funding
- Senate Bill Includes Pool of Funding (PRMRP) & Disease Line Item Funding
- GOAL: Continue inclusion of DM in the Peer Reviewed Medical Research Program (PRMRP) that is part of the CDMRP

History of PRMRP

- Is a part of the Congressionally Directed Medical Research Program (CDMRP)
- Established in Fiscal Year 1999
- Supports research across the full range of science and medicine, with an underlying goal of enhancing the health and well-being of military Service members, Veterans, retirees, and their family members.
- “Committed to funding research that has the potential to profoundly impact the development and implementation of medical devices, drugs, and clinical guidance that will enhance the precision and efficacy of prevention, diagnosis, and treatment across a wide range of disciplines.”

Understanding PRMRP Funding

- Every year, as part of the Defense Appropriations bill, the Senate releases a list of eligible diseases to apply for PRMRP funding
- Once this bill becomes law, then interested parties apply for a research grant
- It is not guaranteed that each disease will receive funding
- Peer-reviewers and consumer reviewers are nominated for each eligible research area

Congress' Role

- The PRMRP is a Senate program, therefore only the Senate Defense Appropriations bills contain its funding
- As legislation is being crafted, members of the Senate Defense Appropriations Committee are given the opportunity to weigh in on PRMRP eligible disease areas
- This year, in particular, Senators Feinstein and Durbin were incredibly helpful in renewing DM's PRMRP designation

SUCCESS!

- Though it's quite turbulent in Washington right now, MDF had a major legislative win last year, in 2017, and this year, in 2018.
- Myotonic Dystrophy was added as an eligible research area in the Peer Reviewed Medical Research Program (PRMRP), a program in the Congressionally Directed Medical Research Program (CDMRP) for Fiscal Year 2018 and Fiscal Year 2019.
- MDF has been advocating for PRMRP inclusion for many years now, but only in the last two years, in large part thanks to the help of a network of advocates like yourselves, were we successful.

How You Can Get Involved

- Call your Representative or Senator to tell them you support the PRMRP, and specifically DM inclusion in the program.
- If your Senator is on the list of Defense Appropriations Subcommittee Members, call him or her to thank them for support for DM and the PRMRP.

Senate Defense Appropriations Subcommittee

Members

- Shelby, (AL) Chair
- McConnell (KY)
- Alexander (TN)
- Collins (ME)
- Murkowski (AK)
- Graham (SC)
- Blunt (MO)
- Daines (MT)
- Moran (KS)
- Hoeven (ND)
- Durbin (IL), Ranking
- Leahy (VT)
- Feinstein (CA)
- Murray (WA)
- Reed (RI)
- Tester (MT)
- Udall (NM)
- Schatz (HI)
- Baldwin (WI)

Why Do We Need Help if We Were Successful?

- While we were thrilled to gain the PRMRP inclusion for FY19, our work continues as we want to ensure that it will be included in future budgets.
- MDF was successful in 2017 and 2018 because there were multiple advocates across the country contacting their Senators about PRMRP.
- We must keep that momentum going as we advocate for DM to be included in PRMRP in the future and for the PRMRP program in general.

SENATOR DURBIN



The Power of Constituent Advocates

YOU are the single most important advocate in Washington. Why?

- **YOU** vote for or against members of Congress.
- **YOU** live nearest to your members of Congress. You see them at the July 4th parade, at town hall meetings, in the grocery store, at their kids' school, at houses of worship, etc.
- **YOU** have a deeply personal, authentic and powerful message that is crafted by your own life experience and needs.
- **YOU** have taken time out of your lives to make your voices heard on issues that are important to you.

How to be an Advocate at Home

- You don't have to be in Washington to be an advocate – your representatives have offices in your home state too.
- You can meet with staff in those offices, or correspond via email or phone call with the Washington staff.
- Remember, you don't have to be a policy expert. The staff will want you to help them better understand myotonic dystrophy and to hear about your personal experiences with DM
- Being a successful advocate takes work, just like any relationship.
- Having a solid foundation is almost always helpful so they understand you and Myotonic Dystrophy BEFORE you come in with a 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 to ask for your *support/thank you* for efforts to keep Myotonic Dystrophy as an eligible research area in the Department of Defense Peer Reviewed Medical Research Program.
- 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!

Who Should I Contact?

- 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 Else Can I Do?

- Seek Opportunities To Develop A Relationship With Member and Their Staff
- Draft A Letter to The Editor About Our DM Congressional Priorities
- Invite Family and Friends To Become DM Advocates
- Stay Connected With MDF For Action Alerts All Year

Advocacy Webinar: Presenter Contact

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