

Myotonic Dystrophy  
*2020 Rare Disease Day*  
Legislative Advocacy Call to Action

Wednesday, January 29, 2020  
*Kevin Brennan, Bluebird Strategies*



# Legislative Advocacy 101

Kevin Brennan

Principal, Bluebird Strategies



# Kevin Brennan Biography

- **Congressional Experience**
  - Senator Sherrod Brown (D-OH)
  - Representative Rosa DeLauro (D-CT)
- **Patient Advocacy Experience**
  - Arthritis Foundation
- **Biopharmaceutical Experience**
  - Amgen



# Rare Disease Day 2020

- Rare Disease Day is on Friday, February 28<sup>th</sup> and is designed to raise awareness amongst the general public and legislators about rare diseases and their impact on patients' lives
- A disease affecting fewer than 200,000 people is considered rare as defined by the Orphan Drug Act of 1983
- There are 7,000 rare diseases affecting 25-30 million Americans. One in ten Americans have a rare disease and more than half of them are children



# What Can You Do on Rare Disease Day?

- Letters, Phone Calls and Emails
- Request Meeting with Member/Staff
- Post Photos of Your Visit in Social Media



# What Should You Say In Letter, Email, Call

- My name is Jane Doe and I am a constituent who lives in AU Park, Washington, D.C.
- I have myotonic dystrophy. Describe briefly:
  - Year of Diagnosis
  - Impact on Daily Life
  - Significant Medical Life Events
  - Impact on Employment
- Please support increase federal funding for myotonic dystrophy research including adding DM to FY21 Peer Reviewed Medical Search Program.

# Requesting a Meeting

- Ask to be connected to Scheduler
- My name is Jane Doe and I am a constituent who lives in AU Park, Washington, D.C.
- On behalf of Myotonic, I am requesting a meeting with Representative Smith or Senator Smith to discuss myotonic dystrophy and our interest in medical research, drug development and newborn screening legislation



# Find Your Representative & Senators

The screenshot shows the CONGRESS.GOV website interface. At the top, there is a navigation bar with the logo, "Advanced Searches", and "Browse". On the right side of the navigation bar, there are links for "Search Tools", "Support", and "Sign In". Below the navigation bar, there is a search bar with a dropdown menu set to "Members" and a search input field containing "Examples: Lamar Alexander, Zinke". To the right of the search bar is a magnifying glass icon. Below the search bar, there is a breadcrumb trail "Home > Members" and a row of utility icons: "Print", "Subscribe", "Share/Save", and "Give Feedback". The main content area is titled "Members of the U.S. Congress" and includes a sub-header "93rd-116th Congress (1973-2020) | About Members". The content is organized into three columns: "Current Members of the 116th Congress" with two dropdown menus for "Find a Representative" and "Find a Senator", and a link "About Members >"; "How to Contact Your Member" with text "Member websites provide comprehensive contact information:" and links for "Representatives", "Find by Zip Code", and "Senators"; and "Member Guides" with links for "Sponsors House | Senate", "How to Get Member Alerts", and "Biographical Directory of the U.S. Congress, 1774 - Present". At the bottom of the content area, there is a "Hide Overview" button.

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Members | Examples: Lamar Alexander, Zinke

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## Members of the U.S. Congress

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### How to Contact Your Member

Member websites provide comprehensive contact information:

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[How to Get Member Alerts](#)

[Biographical Directory of the U.S. Congress, 1774 - Present](#)

Hide Overview ✕





# What Do We Want Congress to Do?

- Increase Fiscal Year 2020 Funding for Myotonic Dystrophy Medical Research
  - Peer Reviewed Medical Research Program & National Institutes of Health
- Pass Newborn Screening Saves Lives Reauthorization Act
  - Reauthorizes CDC and State Screening Programs
- Protect the Orphan Drug Tax Credit
  - Orphan Drug Act of 1983 provides 50% tax credit on orphan drug
- Maintain Pre-Existing Disease Protections in Obamacare



# All Politics Is Local



- Congress Responds to Constituents and Voters
- Presidential, Congressional and State Elections in 10 Month
- Lots of Groups Engage in Legislative Advocacy
- Patient Advocacy Viewed Favorably by Congress; Helping Patients Viewed as Positive with Voters
- Congress is Moved by Personal, Authentic and Powerful Patient Advocate Experiences

# Follow-Up Is Key to Success

- Two Weeks – Contact Office If You Haven't Received a Reply
- Post Pictures on Social Media; Draft A Letter to The Editor
- Invite Family and Friends To Become Myotonic Legislative Advocates
- Contact Myotonic Staff with Questions and Information about Outreach
- Visit [myotonic.org](http://myotonic.org) to stay updated



A stylized, handwritten signature or logo in black ink, consisting of several loops and curves.

# April 20<sup>th</sup>, 2019 Timothy Haylon, First Myotonic Patient Advocate to Testify before Congress on DM Research



*“It is not the critic who counts; not the man who points out how the strong man stumbles, or where the doer of deeds could have done them better. The credit belongs to the man who is actually in the arena, whose face is marred by dust and sweat and blood; who strives valiantly; who errs, who comes short again and again, because there is no effort without error and shortcoming; but who does actually strive to do the deeds; who knows great enthusiasms, the great devotions; who spends himself in a worthy cause; who at the best knows in the end the triumph of high achievement, and who at the worst, if he fails, at least fails while daring greatly, so that his place shall never be with those cold and timid souls who neither know victory nor defeat.”*

-Theodore Roosevelt



# Thank you!

Questions?

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