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 28th 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.

Myotonic

Requesting a Meeting

Ask to be connected to Scheduler

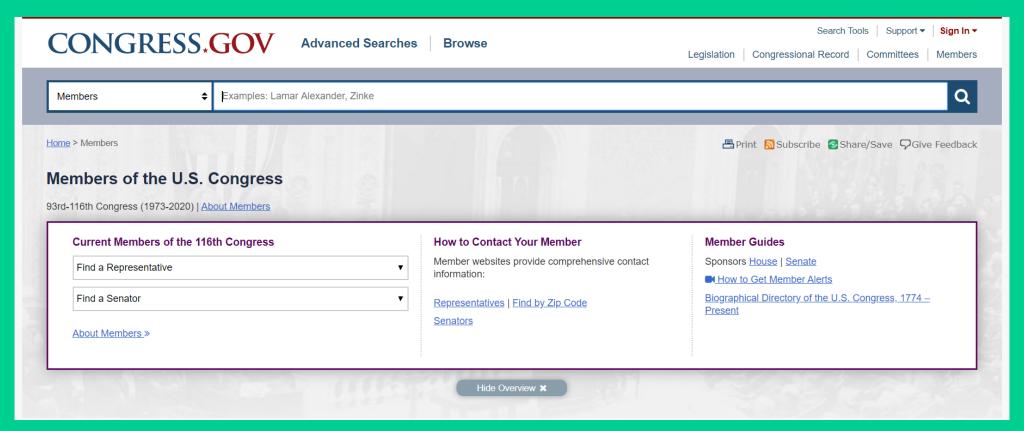


 My name is Jane Doe and I am a constituent who lives in AU Park, Washington, D.C.

 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





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 to stay updated





April 20th, 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?

Contact Kevin Brennan at kbrennan@bluebird-strategies.com

