The One-Hour Advocate: Raising Our Voices for DM

Elizabeth Florence, MDF Board Member
John Fitzpatrick, MDF Board Member
Woodie Kessel, MDF Board Member
Todd Stone, MDF Board Member
Review of Important Agencies

National Institutes of Health (NIH)
- Nat’l Inst. of Arthritis & Musculoskeletal & Skin Diseases (NIAMS)
- Nat’l Inst. of Neurological Disorders & Stroke (NINDS)
- Nat’l Inst. of Child Health & Human Devel. (NICHD)
- Nat’l Center for Advancing Translational Sciences (NCATS)
- ...plus 24 other Institutes & Centers

Food & Drug Administration (FDA)
- Center for Drug Evaluation & Research Organization (CDER)
- Office of Global Regulatory Operations & Policy Organization
- Office of Medical Products & Tobacco Organization
- Office of Regulatory Affairs Organization
- ...plus 9 other Offices & Centers
Idea for bill is generated

Bill is written, sponsored & introduced

Bill is referred to committee for further action
- Public hearings occur
- Expert testimony occurs
- Markup occurs
- Bill reported favorably, unfavorably, or tabled by committee

Bill moves to House or Senate floor for debate & voting

Approved bill moves to other chamber for same process

Both chambers meet to reconcile bill differences

Majority of both chambers must approve revisions

Passed bill is sent to President to veto or sign into law!

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The Importance of Follow-Up

• The legislative process is a marathon, not a sprint!
• 10,000 bills are introduced each session; only 200 become law
• 113th Congress ends in December
The End-Game Strategy: Pass the MD-CARE Act

- Different strategies for House & Senate
  - House has already passed the bill
  - Senate has yet to take action

- Appreciation is powerful! Thank your Rep for passing the bill
Connecting Our Stories to a Unified Ask

1. State your address so they know you’re a constituent
2. Tell your story
3. Make the ask

Your voice sends a strong message: I am a constituent. I vote. This issue matters to my family and me.
Following Up: Key Staff in Legislative Offices

• DC vs. District staff
  • Health Legislative Aide (DC)
  • District or State Director (district)
  • Field Representative (district)
Following Up: Checking in with MDF

- Important to keep MDF staff updated on your efforts!
- Contact Aly Galloway, MDF Community Engagement Manager
  - alyssa.galloway@myotonic.org
  - 415-800-7640
- Fill out the Congressional Feedback Form
  - http://myotonic.org/congressional-feedback-form