CONSTITUENT TALKING POINTS – MAY, 2017

1. Thank you for taking the time & brief introductions.

(1) Mention whether you are someone with ME/CFS, a parent, etc.

(2) Explain the term ME/CFS – they may know the disease as chronic fatigue syndrome or myalgic encephalomyelitis.

(2) You are part of a national effort led by #MEAction and the Solve ME/CFS Initiative.

(3) Identify where you live in the district, any connection you have to member or staff, or a noteworthy connection to the district. (eg. I’ve lived in X neighborhood for 20 years and used to be chair of the PTA at Y School.)

2. Give business cards. Get their name/contact info pass it on to our team.

3. Ask, “are you familiar with ME/CFS or know anyone who has it?”

- if yes, do you have any preliminary questions you’d like me to cover?

- if no, share basic background. Refer them to fact sheet and the information in their packet

* ***affects up to 2.5 million American children and adults of all races.***
* ***75 percent of patients are women.***
* ***There is no diagnostic test, no FDA-approved treatment, and no cure.***
* *At least 25% of ME/CFS patients are home- or bed-bound at some point in their lives.*
* *84-91% of ME/CFS patients either are not yet diagnosed8 or are misdiagnosed.*
* *Symptoms typically persist for years; recovery is rare.*
* ***ME/CFS costs our economy $17- $24 billion annually****.*
* ***ME/CFS is in the lowest 4% of diseases funded by the NIH.***
* ***Fewer than 12 ME/CFS specialists for the entire country.***

- be sure to tell them number of people with ME/CFS in your district/state and the economic impact

5. Your story 3-5 minutes MAX. If there’s two constituents talking, 3 minutes max each.

6. The Asks

1. May 12: is ME International Awareness Day. Ask the Representative to post on social media. Sample language is in your packet.
2. May 18: there is an ME/CFS briefing on Capitol Hill. Ask the Representative (or his staff) to attend. Briefing flyer is in your packet
3. FY 17: Please call or write the NIH and ask them to prioritize ME/CFS research funding with the recent $2 billion increase
4. FY 18: ME/CFS is funded entirely by the NIH and the CDC’s Prevention and Public Health Fund – please preserve these funding sources

8. Is there any other information I can provide you with?

9. thanks