



Solve ME/CFS Initiative



ME/CFS Advocacy Week | Wednesday, May 3, 2017 | 1PM ET / 10AM PT

How to conduct your local advocacy: District Meetings



Emily Taylor | Gail Cooper
SMCI | #MEAction



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Myalgic Encephalomyelitis Action Network

About Our Webinars

- Welcome to our ME/CFS Advocacy Week Training!
- Webinars are recorded, and the recording is made available on our YouTube channels:
- SMCI:
<http://YouTube.com/SolveCFS>
- MEAction:
<https://www.youtube.com/channel/UC2k7yUo-vOLXfsNCl8WSzgg>

About This Webinar

- Please use the question box to ask questions during the presentation
- There will be Q&A at the end of the presentation
- Use the “Raise Hand” button during the Q&A to get in line to ask a question
- One speaker at a time - Our organizers will unmute individuals for questions



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Save the Dates!

- Thursday, May 8 - 11: **District Advocacy Week**
- This webinar covers:
 - The materials available for your meeting
 - HOW TO CONDUCT a meeting
 - What we are asking for as part of ME/CFS Awareness week
- Refer here if you missed the first webinar for information on how to schedule a meeting and tell your story:
<https://youtu.be/awLjiyYhexQ>

Materials to be made available on Website

- One page fact sheet about ME/CFS
- Institute of Medicine report summary
- Flyer about Capitol Hill briefing on Thursday, 5/17
- Suggestions for social media language for offices to use for ME Awareness Day on 5/12
- April 6, 2017 letter signed by thirty House members, with proposed appropriations language
- And more!
- Available at: <http://solvecfs.org/2017-mecfs-advocacy-week-information-and-updates/>

The Day Before

1. Call or email the staff to confirm the meeting.
2. Confirm any reasonable accommodations you requested.
3. Make/bring several extra copies of the handouts that we will send you.
4. If you have business cards, bring them along.

Review: Best practices: Prepare for your meeting

1. Think about how you will tell your story.
2. Prepare to be brief.
3. Do your research (eg. How many people with ME/CFS in your district?)
4. Review your leave-behinds (Don't forget contact info!)
5. Check your facts
6. Practice your presentation!!!

Key ME/CFS Facts: Easy print-at-home guide

Myalgic Encephalomyelitis (ME), commonly known as Chronic Fatigue Syndrome (CFS) or ME/CFS, is a devastating disease affecting many systems.

- Estimated 1 to 2.5 million Americans afflicted
- 75 percent of patients are women
- There is no diagnostic test, no FDA-approved treatment, and no cure
- 25% of ME/CFS patients are home- or bed-bound at some point
- 84-91% of ME/CFS patients either are not diagnosed or misdiagnosed
- Fewer than a dozen specialists are available nationally
- Symptoms typically persist for years; recovery is rare
- ME/CFS costs our economy \$17- \$24 billion annually
- ME/CFS has always been in the lowest 4% of diseases funded by NIH

Review: Best practices: During your meeting

1. Take notes
2. Be positive. Do not make accusations/assumptions.
3. Listen. Don't interrupt
4. Correct with kindness (eg. I am sorry to hear you are tired, but I am very sick, not just tired.)
5. Refer to your leave-behinds (eg. "You can find that information here")
6. Make eye contact – make a connection
7. Don't be afraid to ask questions

Sample Storytelling: Do's and Don'ts

- Do be honest
- Don't be negative (just the facts)
- Do make it personal
- Don't get distracted
- Do link to your asks
- Don't make accusations/assumptions

The meeting: A sample outline

1. Say thanks for the Member/Staff for meeting / make small talk – 1 minute
2. Introduce yourself and share business cards/contact info – 3 minutes
 - Constituent details (eg. I grew up on Pine St.)
 - Mention that you are part of a national action for ME/CFS
 - Be sure to get the name and contact info of the person you are meeting with and share this with our team

The meeting: A sample outline cont....

3. Ask the person “are you familiar with ME/CFS?” – 5 minutes
 - Share “big picture” disease – teachable moment!
 - Find out if they know someone with ME/CFS or other chronic illnesses
 - Share district statistics for ME/CFS (find this information on the prevalence spreadsheet [HERE](#))
 - Point out the fact sheet
4. Tell your Story – 5 minutes

The meeting: A sample outline cont....

5. Make “The Asks” – 5 minutes

- **May 12:** is ME International Awareness Day. Ask the Representative to post on social media. Sample language is in your packet.
- **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
- **FY 17:** Please call or write the NIH and ask them to prioritize ME/CFS research funding with the recent \$2 billion increase
- **FY 18:** ME/CFS is funded entirely by the NIH and the CDC’s Prevention and Public Health Fund – please preserve these funding sources

The meeting: A sample outline cont....

6. Wrap-up and next steps – 1 minute

- Take notes about the response to the asks – try to gain firm commitment if you can
- If the staffer says they will “need to talk to my boss,” ask who that person is and what their position is
- Ask if you can keep in touch and send additional info
- Again, thank for meeting/time

After The meeting: Follow-up!

- E-mail Congress@meaction.net – let us know how the meeting went – share notes if you have them
- E-mail or call the person you met with to say thanks
- If there was a question you were unable to answer, follow-up with the correct information or send to our team to assist you.
- Send a reminder the following week for the briefing



Solve ME/CFS Initiative



Questions?

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SolveCFS.org – Get Involved –
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Thank you for joining us!

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