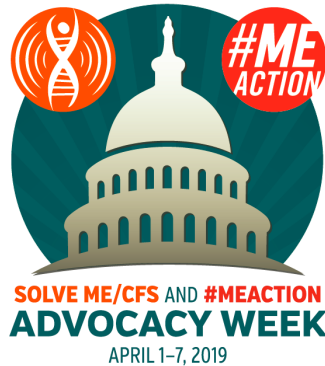


ME/CFS Advocacy Week Local Meeting Handbook



Welcome to your ME/CFS Advocacy Week Local Meeting Handbook! This Handbook's purpose is to provide you the tools and resources to make your local district meetings a success during Advocacy Week, Monday April 1st - Sunday April 7th, 2019.

During this week, people all over America will be raising their voices and asking Congress to take action for ME. Meeting with members of Congress and their district staff is important because it helps to educate them about the disease and the immediacy to act.

As a constituent, your story makes a difference!

As you attend your local district office meeting, you will be unifying with hundreds of advocates in DC and thousands more across the country. Together, we will be taking action through phone calls to members' offices and online activism. All of these actions make a difference help to spread awareness.

In this handbook, we will provide you the following:

- How to Find and Connect with your Member's Office
- Sample Email to Request Meetings
- Meeting Structure and Preparation
- Sample Meeting Agenda Outline
- Meeting Checklist

Purpose of Advocacy Week:

ME/CFS Advocacy Week brings people with ME, their loved ones, advocates, scientists, clinicians and caregivers from across the country together to call for more action and research funding, meet other advocates, and share their unique stories with members of congress, together in one voice.

Your story and your experiences are *powerful* and we need to make sure members of congress understand the unique needs of people with ME/CFS. Advocacy Week is an opportunity to speak directly to your member of congress and their staff.

Telling your story helps build a relationship and a connection. Your story makes the issue personal and relatable. Before you tell your story, often your member of congress simply thinks ME/CFS is a complicated acronym. After your meeting, ME/CFS is relatable and associated with a real person with real needs. Your meeting face-to-face transforms our cause from an impersonal issue to a real emotional experience, for which more federal support is warranted.

And, your passion translates that experience into action!

Your Local Meeting Checklist:

- Find Your Members of Congress
- Contact them and request a meeting
- Schedule your meeting
- Tell your story face-to-face!
- Follow-up after the meeting
- Let our team know how it went

How to Find your Member (Representatives and Senators):

The websites below will give you the office phone numbers and other contact information for your members of Congress. FYI, you must be a constituent to email a member through their website - email addresses for Members and staff are not on Congressional websites. Once you do establish a contact and hear back from a staff member, you will get a direct email address to contact that person.

- To find your House representative: <http://www.house.gov/representatives/find/>
- To find your Senators: <http://www.senate.gov/senators/contact/>

How to Connect with your Member's Office:

Once you find your member, you should immediately send them an email or call their office to request a meeting at their local district offices during Advocacy Week (April 1 - April 5). If you don't hear back - which is often the case - try and try again. Follow-up is key, so you may need to call the office and email again. It is important to mention that you are asking to meet during a national advocacy initiative for ME/CFS.

On the next page is a sample email you can use when requesting a meeting with your member.

If you have a personal connection with the member or a staffer, be sure to add that to your request. Make sure to include your FULL address and FULL zip code, i.e., 11111-2222. The offices need this information to confirm you are a constituent.

Request for Reasonable Accommodation:

Normally, staff only want to hear from a constituent. However, you may feel too ill to speak/meet or be nervous about speaking. You can request a meeting but explain that you are asking a non-constituent (NC) to speak for you/with you as a "reasonable accommodation" for your illness.

There are various options. You can request the NC to meet without you; you and the NC can both meet and share responsibility for talking; or you and the NC can both be there but the NC does all the talking. But a word of caution - if you're meeting with the actual member, he/she is very unlikely to agree to do it without a constituent present in person or by phone.

If your member of congress has multiple district offices, be sure to specify which district office you wish to meet at.

Sample Email:

This is a basic sample email; free free to edit it to share your story or connection to the office. We do recommend keeping the email as short as possible.

Subject: Request A Meeting for ME/CFS Advocacy Week - April 1-5

Body: Dear Mr./Ms. _____,

My name is _____ and I am a (person with ME, caregiver, family/friend) of (someone) with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). ME/CFS (formerly known as chronic fatigue syndrome) is a complex, debilitating, and chronic disease afflicting up to 2.5 million Americans. Approximately _____ to _____ constituents in our district (state) suffer from ME/CFS*. It causes profound neurological, immunological and metabolic dysfunction. The cause of the disease is unknown and there is no FDA approved treatment for it.

ME/CFS Advocacy Week is April 1-5th and we are hoping to schedule a meeting at your district office during this week to speak about our needs.

My availability is as follows:

[Provide Dates and Times]

Please let me know what time would work best.

Thank you for your attention. ,

[Your Name]

[Your Contact Info - email, address with 9 digit zip code]

*** How to find Prevalence in Your District/State:**

Look up the number of people suffering with ME/CFS in your district/state using this [prevalence spreadsheet](#). The first tab on the bottom row will take you to the numbers for your state. The remaining tabs on the bottom will take you to the numbers for each district in the states listed in that tab and includes the name of your representative and the number of people affected with ME/CFS in his/her district.

Meeting Structure:

Most meetings are between 15-20 minutes long.

A good basic outline is:

- 5 minutes for introduction/basic facts
- 3-5 minutes for your personal story
- 5 minutes for the “Ask” and closing.

First (5 minutes): Introduction and exchange of business cards/contact information, i.e., your name, address, and whether you’re a pwME, parent/caregiver, etc. Also ask how much time the staffer has. If it’s the typical 15 minutes, it is important to stay on top of the time. If it’s thirty minutes, then you know you have more time to provide factual background and/or take questions.

Ask the staffer how familiar they are with ME/CFS; do they know anyone with ME/CFS? Depending on the response, hit the major facts on the fact sheet. And definitely tell them the prevalence/economic impact in the district/state. A good line is to say something like “You undoubtedly know someone with ME/CFS but either they have yet to be diagnosed or they haven’t told you.”

Don’t be surprised (or insulted) if the staffer you meet with is very young or very new. The average Congressional staff member is 26-28 years old and remains at their position for only about 18 months.

Next (3-5 minutes): Then, tell your story. We recommend up to 5 minutes if only one constituent in the meeting. If there are two constituents are in the meeting, we recommend about 2.5 minutes per constituent. The purpose is to tell YOUR story, not to discuss ME/CFS generally. Make it personal. Succinctly describe your history and the impact ME/CFS has had on you and, as appropriate, loved ones. Stay factual. Be honest, direct, and if possible, connect your story to the local community.

Given the time constraints, it’s critical to stay focused (as tempting as it is to pour your heart out about all the ME challenges) and, as best as possible, relate your story to the “Ask.”

Final (5-minutes): Explain the “Asks,” see if they have any questions, discuss next steps, and mention the “leave behind” materials again.

Below is an example of a meeting agenda.

Rehearse, rehearse & rehearse: We recommend practicing telling your story and use a timer to see how long you are talking. You will usually find the staffer to be quite courteous. However, you may still find the meeting stressful, especially given the time constraints. The more you practice, the more confidence you will have going into the meeting.

Sample Meeting Agenda

1. Short Introductions (2 min)

- If applicable: thank member for past support (e.g. signing past appropriations letters or letter to HHS)
- "What do you know about ME/CFS?"

2. Round of introductions and personal stories (5 min)

3. Basic facts about ME/CFS (3 min)

- 1 to 2.5 mill patients, 75% women. .
- National Academy of Medicine (NAM) states that ME/CFS is a "serious, chronic, complex, multisystem disease" that "dramatically limits the activities of affected patients."
- ME/CFS patients score more poorly on quality of life surveys than any other disease measured, including multiple sclerosis, brain stroke, diabetes, renal failure, lung disease, heart failure and various cancers. Doctors who treat ME/CFS and HIV say they'd rather have HIV.
- 50-75% of patients can't work or attend school; 25% are housebound or bedbound
- CDC calls ME/CFS "America's Hidden Health Crisis"
- ME costs the US economy \$17 to \$24B dollars annually (per the CDC's estimate)
- Researchers at Stanford and Columbia say we could solve in 3-10 yrs with adequate resources.
- The NIH (Dr. Koroshetz) states ME/CFS needs roughly 10-20x current funding.
- Yet the NAM report notes there is "remarkably little research funding" for ME/CFS: only \$7-13M/yr funding (compare to MS, which gets almost \$100M with less than 1/2 as many patients).

The result:

- No known cause or cure, no FDA approved treatments (and none in the pipeline)
- No commonly accepted diagnostic or research criteria
- No clinical trials
- Only a handful of doctors know how to diagnose or treat this disease and less than 1/3 of Med school curricula cover this disease that disables 1 to 2.5 million Americans

4. Successes & bipartisan support (1 minutes)

- Bipartisan House letter to NIH asking for more attention to ME/CFS in 2016, 2017, & 2018
- Bipartisan, Bicameral letter to HHS about next steps for ME/CFS in Dec 2018

5. The Asks (5 min)

Other asks:

1. Issue a supportive statement or press release, or post on social media in support of ME/CFS patients and research.

Meeting Checklist

The Day Before:

- Email the staff to confirm the meeting. If you have requested an accommodation, remind them of that as well.
- Things to bring with you to the meeting:
 - Notepad and pen: to take detailed notes during the meeting
 - Copies of the handouts
 - Personal business cards (if you have them)

The Meeting:

- **Here are a few do's and don'ts**
 - DO: Stayed focused on your message. (And if the staff members veers off course, try to bring her back to ME, e.g. I know your time is precious; I want to make sure we cover what we'd like you to know/do before time runs out.)
 - DO: Pay attention to cues - for example, play it by ear to decide whether this is a good instance to mention that ME is another example of an illness primarily affecting women that receives less attention..
 - DON'T be afraid to ask questions. Conversely, don't hesitate to say that you don't know the answer to their questions. Just say you'll get back to them with an answer and ask us for any needed assistance.
 - DON'T forget to refer to the "leave behind" materials.
 - DO: Thank them liberally.
- **Alternative Asks**

As mentioned previously, if the staffer turns down your "Ask," you can explore whether they'd be willing to undertake any of the alternative asks.

 - Issue a supportive statement or press release, or post on social media, in support of ME/CFS patients and research
- **Closing the Meeting**

Try to get a timeframe for their action

 - Here is an example:
 - If they say "I'll talk to the Senator,"
 - You can follow-up with: "Thanks so much, I really appreciate it. Do you have any idea of the timeframe for that?"
 - If they say, "No, I don't", you can follow-up with "I understand. When would you suggest that I check back in with you?"
 - That then gives you the leave to follow-up with them.
 - If they say they need to consult with, or do a hand-off to someone else, try to get the name, position, and contact information for that person. And their business card if possible.

Always make sure to thank the member!

Post-meeting

- Fill out this [survey](#) to let us know who you are, who you met with, and what came out of the meeting.
- Send a thank you note/call:
 - After a day or two, send a thank-you email or make a thank-you call.
 - Repeat the Asks and repeat some of what they said to show you listened. (Only one person should do the follow-up.)
- If you said you'd provide them with further information, send that along with the thank-you or when you receive the information. And if you've received pushback during the meeting that you were unable to deal with then, you might use this opportunity to politely rebut what you heard.
- If they've said they'd do something and you haven't heard from them in two weeks or in the timeframe they gave you, contact them.

Here are a sample thank you email and sample follow-up email:

- **Thank You:**

Dear (who was in the meeting: staffer, congress member),

Thank you so much for meeting with me/us on xx/xx/xx to discuss ME/CFS. Your compassion and interest in the challenges people with ME/CFS confront was evident.

(Add any information that you said you would follow-up on)

Again, thank you for taking the time to meet with us and for listening to my/our stories. We look forward to working together in the coming year.

Thanks,

Add Names of who attended the meeting with you + their zip codes

- **Follow-up:**

Dear (who was in the meeting: staffer, congress member),

Thanks again for meeting with me on xx/xx/xx about ME/CFS. I very much appreciate your promise to (whatever they promised to do).

You had suggested that I check back this week about the results of our meeting with..." (or whatever is appropriate given what they'd agreed to do), etc.

Thanks,

Add Names of who attended the meeting with you + their zip codes

