



Thank you for your interest in the ME/CFS Advocacy Day in Washington DC! Your story and your experiences are powerful, and we need your voice to ensure members of Congress understand the unique needs of people with ME. Note that **you do not need prior experience to participate in this event**. We will be there to assist you every step of the way!

The week will begin with registration and advocacy workshops, and then advocates will meet with congressional representatives in person.

Your customized meeting schedule will provide ample time to get from meeting to meeting as your energy and ability allows. We will communicate with you to ensure that your number of appointments match your capacity.

Our partners at Prime Advocacy are providing all the logistical support to create your customized individual schedule which will be e-mailed directly to you on Monday April 1. In order to avoid confusion, Prime Advocacy will handle all the scheduling details for you – so you are free to enjoy the experience of the day!

## Planning your trip...

- Register [here](#).
  - You can represent up to **FOUR** different congressional districts during your visit. This can include the districts of family members, loved ones unable to travel, or other people with ME you are authorized to represent.
  - On the [registration form](#), there is one space where you can add the address of someone else you wish to represent.
  - If you are representing more than one other person, please e-mail the additional address(es) of the individual(s) you are representing to: [MEAdvWeek19@gmail.com](mailto:MEAdvWeek19@gmail.com).
  - We ask that you **do not** contact your member of Congress about your April 3rd meeting schedule, but feel free to contact them about other issues or requests.
- Book your hotel.
  - A discount room block is available from Monday April 1st – Sunday April 7th at the [Marriott Bethesda Hotel](#) at **5151 Pooks Hill Rd, Bethesda, MD 20814**. These rooms are available for both Lobby Day and NIH Conference attendees.
  - You are welcome to make your own arrangements – staying in the hotel block is **\*not\*** required for participation in ME/CFS Advocacy Day.
- What to wear:
  - Business casual attire (blue shirts will be provided for you)

- ❑ If you will be on your feet, wear your most comfortable shoes. You may bring your nicest shoes to slip on. Congressional offices are often far apart and there may be a great deal of walking and standing.
- ❑ What to bring with you on the day of:
  - ❑ Water/snacks
 

There will be drinks and snacks available in the Cannon Building Base Camp, but they may not be right for you due to food sensitivities. Be sure to bring food that will nourish you!
  - ❑ Medicine
  - ❑ Personal mobility aids
 

Please do presume extra effort -- the congressional area is huge-- and plan accordingly. There will be cots available in the Cannon Building Base Camp. Some wheelchairs will be available.
  - ❑ Cash/card for cabs
- ❑ Visit <https://washington.org/> for more information regarding the city itself!

## April 1st

- 2:00pm -- 5:00pm -- Check in the lobby of the Bethesda Marriott. While you do not have to arrive on April 1, if you do, you can check in early to avoid lines. Here you will receive additional materials regarding events during the week.

## April 2nd

- 9:00am - 12:30pm -- SMCI EmpowerME Roundtable
- 12:00PM - 3:00PM -- Registration and Video Interviews (optional)
- 3:00PM - 6:00PM -- #MEAction and SMCI advocacy training
- 6:00pm - 8:00pm -- Advocates Networking Reception (Cash bar in the evening)

## April 3rd

- 7:45am -- Buses begin from the Hotel to the Capitol Buildings (will leave about every half hour)
- 8:00am - 9:00am -- Meet at our designated room aka "Base Camp"\* for breakfast , standard fare
- 9:15am - 9:30am -- Introduction and thank-yous in Base Camp
- 10:00am -- First meetings
- 4:00pm - 6:00pm -- Reception for Congressional staffers and pwME, Cannon Building, Room 121

\*Base Camp is a room in the Cannon Building that is designated only for people attending ME/CFS Advocacy Day. This room will feature refreshments during the day and provided places to rest with blankets and cots. Also, there will be some wheelchairs available.

## Additional Information

- \*Important note\* You will be passing through security checkpoints and metal detectors in order to enter congressional offices. Please note the “Prohibited Items in the U.S. House of Representatives, U.S. Senate and Library of Congress buildings” from the [US Capitol Police](#).
- Remember that just because you have decide to attend Advocacy Day does not mean you must participate at all costs. **Your health comes first!** We value your personal well-being and your ability to advocate in the future far more than we value what might be accomplished on this one, single day. Remember that there will be other opportunities!
- In case we are unable to meet your specific dietary needs please consider bringing your own food.