

Webinar Q&A for “ME/CFS Advocacy Week Training: Welcome to DC #CongressFight4ME”

Wednesday, March 29, 2019

Watch the recording on Youtube here - <https://youtu.be/5iMlqoUkl8A>

ME/CFS Advocacy Week Online Training Part 2: Welcome to DC #CongressFight4ME

Wednesday, March 27, 2019

1:00 PM - 2:00 PM EDT//10:00 AM - 11:00 AM PDT

Solve ME/CFS Initiative and #MEAction present an online workshop to an online workshop to walk you through joining us in Washington DC for ME/CFS Advocacy Week & Lobby Day, step-by-step.

Q: What is the appropriate dress for Wednesday April 3rd on Capitol Hill?

A: Business casual – and above all COMFORTABLE SHOES! We will provide you with a t-shirt for the day.

Q: How do we get back to Bethesda Marriott after Lobby Day?

A: Because everyone schedule ends at different times and people’s ability levels vary, we were unable to provide transportation back to the hotel. We encourage you to make your own way at your own pace.

Lyft or Uber are easily accessible from Capitol Hill. At an estimated cost of \$25-\$30. You can reduce the cost by sharing rides together.

Taxis are plentiful and easy to flag down from anywhere on Capitol Hill streets. They will cost \$40-\$60 depending on traffic and can set up to 7 people in the mini-vans.

Additionally, there are two nearby metro stations that can bring you back to the Medical Center Metro station (on the red line) where a free shuttle runs every 30 minutes and can return you to the hotel.

Q: why was ME/cfs taken off the DOD Peer-Reviewed Medical Research Program in 2012?

A: This is a complex question with a lot of factors. The short answer is for two reasons: 1) The small and poor quality of the grants submitted, and 2) the lack financial resources at the time for the advocacy effort to be sustained and continued the following year.

Q: how long does it take for bus to arrive at capitol?

A: Generally, the trip from Bethesda to Capitol Hill is about 25-30 minutes. However, we are making the trip during morning rush hour so we are expecting the drive to take about 1 hour.

Q: We are patient advocates - do we need to register as lobbyists do??

A: Great question! You don't have to worry about that unless you are a paid, professional lobbyist representing an interest that is not your own. There is a lot of grey area between "advocating" and "lobbying." By telling your own story to your own representative, you are advocating and have no need to worry about lobbying registration. However, you still cannot give gifts valued over \$25 to any staff or member of congress that you meet with.

Q: Is Labor - HHS a joint DOL and HHS effort?

A: The Labor-HHS request means it applies to the appropriations legislation for that subcommittee. Labor-HHS is actually short for "Labor, Health and Human Services, Education, and Related Agencies." This committee is responsible for MANY programs, including the Centers for Disease Control (CDC). When we refer to our "Labor-HHS" request, we are referring to our request for increased funding and improved medical education for our Chronic Fatigue Syndrome program at the CDC. That request is addressed to the Labor-HHS committee because our program falls under their jurisdiction.

Q: Will you give us the MoC Congress phone number in the event we are delayed?

A: That is a great question. At the bottom of your personalized meeting schedule (or also easily available on the mobile tool) is the contact information of our partners at *Prime Advocacy*. If you are running late to a meeting, let Prime know and they will handle all the scheduling adjustments with the Congressional offices.

Q: Is Gulf War Illness already on the PRMRP list? Or is the link with mecfs that much more of a benefit?

At this time, Gulf War Illness has its own line item in the Congressional Directed Medical Research Program (CDMRP). This enables the program to be much more flexible, targeted, and responsive. Someday, we hope that ME/CFS will be integrated, or have its own matching program with set-aside funds. The PRMRP is a first step towards that goal.

Q: should I hold off on posting the photos until May 12th instead of doing so from DC?

A: You should do both! Post on April 3rd and again on May 12th. We'll have a social media guide in your packet to help you and our team will follow-up with the communications staff to help build awareness of ME/CFS.

Q: so Cannon 121 is a room at Congress?

A: That's correct! It's on the North East corner of the building.

Q: Will April 2nd training be on website on Tuesday evening? I will not be able to see training as I will be on a plane flying to DC all day Tuesday.

A: The April 2nd training will be live broadcast on the Solve ME/CFS Initiative [Facebook](#) and [Youtube](#). After the event is over, you can still find the recording there.

Q: Please explain the acronym MCAM and why this multi-site work is important enough to be in the Labor-HHS ask. Thanks.

A: MCAM stands for the Multi-site Clinical Assessment of ME/CFS. This project was started over 5 years ago by the Centers for Disease Control (CDC) to produce guidance and "characterize patients with ME/CFS in clinical practices of clinicians with expertise in the illness." The publications expected from this work are years behind and our funding increase request is directed to expedite the results of this work.

Q: Do you have any ideas of the parking garage height clearance?

A: Parking at the Bethesda Marriott is outdoors with no clearance issues. Parking on Capitol Hill varies from location to location. You can also park near [downtown Bethesda](#) and take the free hotel shuttle back to the Bethesda Marriott which runs every 30 minutes.

Q: Can we bring in water and/or snacks to the buildings?

A: Yes, they must go through security screenings first.

Q: Where can I obtain an electronic copy of these viewgraphs?

A: Slides for the webinar are available [HERE](#)

Q: How do we find out if our member has already supported the appropriations request so we seem like we know what we are talking about?

A: We'll post copies of the signed letters with the signers on the website as soon as we have them!

Q: How many meetings do you anticipate for each group?

A: Meetings will vary based on your custom schedule, the number of districts you are representing, and your ability level that you noted in your registration form. Every group will have at least 3 meetings, some groups have as many as 8! The average group will have 4-5 meetings. Meetings will last about 20 minutes each.

Q: Is Basecamp in the same room as last year?

A: Basecamp is in room 121 (right across the hall from last year).

Q: Will these asks etc be detailed in our packets in DC?

A: All of this information will be outlined in your participant packet and your congressional packet.

Q: Can you provide a copy of today's webinar as it is rich with info and I cannot take notes this fast?

A: you can watch the recording as many times and as often as you like at: <https://youtu.be/5LJFId115o>