WELCOME TO DC:  
#CONGRESSFIGHT4ME  

WEDNESDAY, MARCH 27, 2019  |  1:00PM ET  

SOLVE ME/CFS AND #MEACTION  
ADVOCACY WEEK  
APRIL 1-7, 2019
ABOUT THE WEBINAR

• THE AUDIENCE IS MUTED; USE THE QUESTION BOX TO SEND US QUESTIONS.

• WEBINARS ARE RECORDED AND THE RECORDING IS MADE AVAILABLE ON OUR YOUTUBE CHANNELS
  • http://youtube.com/SolveCFS
  • http://bit.ly/meactionyoutube

• WE WILL ANSWER AS MANY QUESTIONS AS WE CAN. IF YOUR QUESTION IS NOT ANSWERED, PLEASE E-MAIL IT TO: MEADVWEEK19@GMAIL.COM

• RECORDING WILL BEGIN ON THE NEXT SLIDE
WELCOME TO DC:
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WEDNESDAY, MARCH 27, 2019 | 1:00PM ET
Emily Taylor, Director of Advocacy and Community Relations
Solve ME/CFS Initiative

M.A. American Politics, Claremont Graduate University

With over 15 years of policy and advocacy experience in both the non-profit and government sectors, Emily draws inspiration from her mother who has battled ME and chronic autoimmune conditions since 1999.

Erin Roediger, MA
U.S. Advocacy Manager
#MEAction

Having worked in the non-profit field for over 15 years + work on multiple electoral campaigns, Erin looks forward to utilizing her grassroots organizing experience to make a difference in the lives of people with ME.
I'm here to learn more about ME/CFS advocacy.

I'm attending ME/CFS Advocacy Day on Capitol Hill.

I'm planning/attending a local District meeting.

I'm here to learn more about ME/CFS advocacy.

Audience Poll: What action are you taking for ME/CFS Advocacy Week?
Today’s Agenda: ME/CFS Advocacy Week Actions

- **Big Picture**: The strategic purpose of ME/CFS Advocacy Week
- **The Game Plan**: Our “asks” for this year
- **Getting Prepared**: Detailed walkthrough of April 2nd events in Bethesda
- **“On the Hill”**: Detailed walkthrough of April 3rd actions on Capitol Hill
- **Questions!**: Q&A about ME/CFS Advocacy Week
BIG PICTURE

THE STRATEGIC PURPOSE OF ME/CFS
ADVOCACY WEEK
Why Does ME/CFS Advocacy Week Matter?

1. Nation-wide effort in the United States targeting Congress (U.S. Senate & House of Representatives)

2. Educate legislators and staff on ME/CFS

3. Create momentum and “buzz” for ME/CFS on Capitol Hill

4. Build Relationships for future actions

Why Congress?

1. Congress controls the $$

2. Congress can put pressure on agencies through oversight

3. Congress creates accountability

4. Congress works for us!
The Scope of ME/CFS Advocacy Week

- Over 220 advocates registered
- Over 218 meetings requested
- 10 Member level meetings already secured
- Tangible presence on the Hill
- Seeing a response from Congress
THE GAME PLAN

OUR “ASKS” FOR THIS YEAR
If you get stuck…
Refer them to the packets

Co-Sponsor our Resolution for ME/CFS Awareness
Please review the draft Resolution language in your packet and become a **co-sponsor before May 6**

Support Both our Appropriations Requests
We have **TWO appropriations request letters**: DEFENSE & LABOR-HHS. Please review them and sign on if you can.

Help us Raise Awareness on Social Media
Please have your office schedule a **social media post** for International ME/CFS Awareness Day on May 12th. There is a guide in your packet.

Three “Asks”
This is your “cheat sheet” slide
Talking Points

1. A bi-cameral (both chambers) resolution honoring International ME/CFS Awareness Day

2. Language has been reviewed by both Republican and Democratic offices and Senate HELP committee

3. Intending to introduce & pass in a “hotline” process 2nd week in May

4. If will not support, then ask to “not oppose or abstain.”
Talking Points: Defense

1. A request for committee report language in the DEFENSE appropriations bill

2. Makes ME/CFS an “eligible disease topic” for the Peer-Reviewed Medical Research Program

3. ME/CFS was already in this program in FY 2011, but was removed in FY 2012

4. This is *not* a carve out. ME/CFS grants will compete with others based on merit

5. Clinically, ME/CFS and Gulf War Illness symptoms are nearly identical
Talking Points: Labor-HHS

1. Requesting a sustained increase in funding for CDC programs from $5.4m to $9.9m

2. Increased funding is directed for:
   a) National Epidemiological Study, a 3-4 year project
   b) Medical Education Dissemination
   c) ECHO (tele-mentoring program)
   d) Accelerating results of MCAM

3. There has never been a nationwide epidemiological study of ME/CFS. This data will improve government response.
RAISE AWARENESS ON SOCIAL MEDIA

Talking Points: Int’l ME/CFS Awareness Day

1. International ME/CFS Awareness Day falls on May 12, 2019

2. Post a picture of this meeting on May 12 Facebook or Twitter to raise awareness and recognize your constituents with ME

3. Post your own picture, tagging & thanking the member’s social media and ask the member to retweet/repost your post.

4. Refer to the social media guide in your packet.
QUESTIONS
GETTING PREPARED

DETAILED WALK THROUGH OF APRIL 2ND EVENTS – MARRIOTT BETHESDA HOTEL
Tuesday April 2nd Training and Networking – Bethesda

9:00am – 12:30pm: EmPOWER M.E. Roundtable | Congressional Ballroom | Breakfast provided
Join us online - register here to watch live: https://bit.ly/2HyPUnZ

1:00pm – 3:00pm: ME/CFS Advocacy Day Check-in & Registration
1:00pm – 2:30pm: Video Interviews – Share your story!
3:00pm – 3:45pm: Training Part 1 (general best practices) | snacks
3:45pm – 4:15pm: Break
4:15pm – 4:45pm: Training Part 2 (Prime Advocacy/Mobile Tool)*
4:45pm -5:00pm: Break
5:00pm – 6:00pm: Training Part 3 (ME/CFS talking points/asks)
6:00pm – 8:00pm: ME/CFS Advocates Networking Reception | Light refreshments and cash bar
*Please bring your phone or tablet for this session.
ADDITIONAL INFO

APRIL 2\textsuperscript{ND} – BETHESDA MARRIOTT

- Parking is $17 a day (working on a discount)
- There is a closer handicapped entrance to the right of the main entrance directly into our meeting space
- Check-in table will also be available in the lobby Monday evening (April 1\textsuperscript{st})
- Hotel address: 5151 Pooks Hill Road Bethesda, MD 20814
“ON THE HILL”

DETAILED WALKTHROUGH OF APRIL 3RD ACTIONS ON CAPITOL HILL
### Wednesday April 3rd
ME/CFS Advocacy Day – Capitol Hill

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>7:30am</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; Bus to Capitol Departs</td>
<td>Marriott Bethesda – Driveway</td>
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<tr>
<td>8:10am</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; Bus to Capitol Departs</td>
<td>Marriott Bethesda – Driveway</td>
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<tr>
<td>8:30am</td>
<td>Networking Breakfast Begins</td>
<td>Cannon 121 “Basecamp”</td>
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<tr>
<td>9:10am</td>
<td>3&lt;sup&gt;rd&lt;/sup&gt; Bus to Capitol Departs</td>
<td>Marriott Bethesda - Driveway</td>
</tr>
<tr>
<td>9:15am</td>
<td>Advocacy Day Team Picture</td>
<td>Cannon 121 “Basecamp”</td>
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<tr>
<td>9:40am</td>
<td>FINAL Bus to Capitol Departs</td>
<td>Marriott Bethesda - Driveway</td>
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<tr>
<td>10:00am</td>
<td>Congressional Meetings Begin</td>
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<tr>
<td>11:00am</td>
<td>Snacks &amp; Refreshment service begins</td>
<td>Cannon 121 “Basecamp”</td>
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<tr>
<td>1:00pm – 3:00pm</td>
<td>Tell your ME Advocacy story – recording session</td>
<td>Cannon 121 “Basecamp”</td>
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<tr>
<td>4:00PM</td>
<td>Congressional Meetings End</td>
<td></td>
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<tr>
<td>4:00pm – 6:00pm</td>
<td>ME/CFS Champions Reception</td>
<td>Cannon 121 “Basecamp”</td>
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- 1<sup>st</sup> Bus and 3<sup>rd</sup> Bus are ADA accessible
- You do not need to attend networking breakfast
- Cots, blankets and “horizontal space” will be available in Basecamp (Cannon 121)
- Plan to meet your group in the hallway outside of your meeting location 15 minutes prior to your meeting.
• Street parking (if you’re lucky) or all day parking at Union Station
• Save some steps! Take a moment to look at a map, look for a sign, or ask for directions to find the closest path to your meeting.
• Ask an intern from your first meeting to walk you to your next meeting!
• Use your mobile tool to make notes
• Complete your meeting reports online (or paper, if you wish)
Office Buildings:
- There are three House office buildings with Member offices:
  - Rayburn (largest, located at the bottom of the Capitol Hill)
  - Longworth (middle)
  - Cannon (located at the top of Capitol Hill)
- There are three Senate office buildings:
  - Russell (located nearest to the Capitol)
  - Dirksen (middle)
  - Hart (largest and newest, furthest from the Capitol building)
Logistics

- There are multiple entrances to each building.
- There are tunnels in between each, but when traveling from the House to the Senate or Senate to House you will need to exit and re-enter through security.
- Every building is secure – treat security lines like an airport.
  - You **will not** need to take off your shoes.
  - You **will** need to remove your keys, belts with large belt buckles, phones, laptops, etc.
- Dress is business casual attire.
- Wear your t-shirt!