“Solving M.E. Together”
Remote Congressional Meeting Training

April 16, 2020
About US

Emily Taylor
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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.

Lincoln Clapper
Director of Sales and Marketing
Prime Advocacy
M.A. International Security, University of Arizona

Lincoln Clapper comes from Gula Graham where he was part of Washington’s premier consulting and fundraising firm.

www.MEAdvocacyWeek.com
Agenda

REMOTE MEETINGS
• What to Expect
• Best Practices
• Tips and Support

SCHEDULE AND LOGISTICS OVERVIEW
• How to Access your schedule
• Group Coordination
• Saving Notes and Special Notes

COVID-19 & ME/CFS
• Our Asks
• Advocacy Strategy
• Meeting Priorities

We’ll stop and take questions after each section.
REMOTE MEETINGS

SOLVE ME/CFS
ADVOCACY DAY

APRIL 21, 2020
From home!

www.MEAdvocacyWeek.com
What to Expect

Every meeting is important

• There is a possibility you will not get to speak with the Member. The COVID-19 situation is very fluid, and the House is in Recess.
• The staffer is very important to the process. Be prepared to talk with a 27 year old.
• If speaking with a Member, give them the key points, and follow up with staff if needed.
• Do not be surprised if the meeting starts late, ends early, or time gets moved.
The 3Bs

Members & staff must run their days in 15 minute increments.

- Be brief
- Be brilliant
- Be done

Get right to the talking points:

1. COVID-19 patients are exhibiting ME/CFS symptoms (nearly 35% of patients)
2. Experts are estimating significant surges in ME/CFS cases following the pandemic, up to 3,570,000 new ME/CFS cases, more than doubling the existing cases in the United States in 36 months.
3. ME/CFS epidemics have historically followed viral outbreaks, such as the current COVID-19 epidemic
4. Our frontline responders are not equipped to identify and diagnose post-viral neuroimmune disease

...don't get bogged down with details.
Be Nice

There is nothing tired staffers hate more than angry or rude constituents. Remember you are building **long term** relationships.

*If a Member can't help now, maybe they can in the future*
Meeting Tips

Stick To Your Schedule
• Do not miss a scheduled meeting.
• **No-call, no-shows reflect very poorly on your organization.**

Cancellations/Running Late
• CALL the Prime Advocacy phone number listed in the Talking Points section for any problems. Offices are generally very accommodating if given notice.
• DO NOT reschedule the meeting on your own. Notify Prime Advocacy of the problem first.
• Offices remember bad scheduling experiences and will take that into consideration for next year.
Meeting Tips

Stay On Message

• You will guide the conversation with your opening. Introduce yourself and your story, sharing your personal experiences, and emphasizing the impact ME/CFS has on healthcare and constituents in the district.

• This will force the Member and staff to listen right from the beginning and shape the conversation.

“Bluff”

• What are you looking for: a decision, position, etc. It forces the Member and staff to hone in right from the beginning.
Meeting Tips

Speak Plainly

- Solve ME/CFS has established several major points which you will want to leave with the Member/staff. The quicker and better they understand what you are saying and what you need/want, the better for everyone and the faster they can engage with you.

- One of the most important things to do is discuss and talk about real world consequences to them as regular folks trying to live their lives. This means talking about the real impact of advocacy for the Solve ME/CFS initiative.
Meeting Tips

Establish Roles

• Meeting groups will be no more than ~5 attendees
• Call in 5 minutes prior to make sure you have a clearly defined strategy about who will initiate the conversation, speak on critical talking points, and draw on real world examples
• Not every person “needs” to speak, so don’t feel pressured to. However, it is very important the constituent is identified on the call
Meeting Tips

Don’t Assume

• Don’t assume staff know too much or too little about the topic you want to discuss.

Your story is the most compelling reason for Congress to continue to support the ME/CFS research
Keeping The Relationship

**Relationship Building**

*Always* offer to be a resource/help the member if he or she has questions in the district.

*Always* frame the issue about how it will not only help the group and constituents, but help the Member with his constituents.

*Thank* them for their time and see if they request any additional information before ending the conversation.

*One to two* weeks after the meeting – email or call the staffer you met with. *Thank* them for their time and see if they need and more info while they are considering the request.

www.MEAdvocacyWeek.com
Social Media

• Member offices are starving for positive content to put on social media, especially during this particular time. They also need content to show they are still working.

• Make their job easy and write the Twitter or Facebook post and tag that Member in the post.

• Example:
  • “A big thank you to Legislative Aide John Doe from @RepJaneDoe office for taking the time to speak with us via conference call about the effects COVID-19 has on #MECFS community. We’re thinking of your team during this time, please stay safe!”
Calling Card

**Always** - I mean always - leave your contact information before concluding. This only applies to constituents.

**Never** – Never say, “see you next year.” Say you will follow up in a few weeks.

**Always** – Get the best staff contact info from the call. Email them and leave YOUR cell.
REMOTE MEETINGS

Questions?

www.MEAdvocacyWeek.com
Accessing Your Schedule
Schedule and Logistics Overview

- Use your laptop, desktop, or tablet and pull up your web browser. **NOT** your phone

- Log into your schedule at clients.primeadvocacy.com/attendee/login with **your** email address

- Larger meetings have been capped at certain attendance totals, per office rules

- The **Status** of each meeting is in the upper right hand corner (color coded)

- Conference call lines and access codes will be displayed in the **Location** field

- Most meeting times will be offset by 5 minutes (ex: 11:55am). This is **intentional and is the start time for the meeting**
Schedule and Logistics Overview

- Please call into the meeting **5 minutes prior to the start time**, in order to discuss with your group on who will open up the conversation and who will be speaking.

- All times will be **Eastern Standard Time**

- Keep redialing if a busy tone occurs, you will eventually get through

- Calls are scheduled for **15 minutes blocks**. They may end early or go longer, but the time frame remains the same as an in person meeting

- Please provide feedback on how the meeting went in the **Meeting Notes** section of each meeting

- There will be a **help number** listed in the **Talking Points** section to call if you need to get ahold of Prime Advocacy
ME/CFS Advocacy Week 2020

Online Events and Actions

www.MEAdvocacyWeek.com
## Online Events and Actions

### Solve M.E. Advocacy Week 2020 ONLINE: #CongressFight4ME

<table>
<thead>
<tr>
<th>Date</th>
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<th>Time</th>
<th>Platform &amp; Links</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thursday April 16</td>
<td>Solving M.E. Together Advocacy Training</td>
<td>5:00pm – 7:00pm ET</td>
<td>GoToWebinar</td>
<td>Have your mobile device charged and nearby for this training</td>
</tr>
<tr>
<td>Friday April 17</td>
<td>Meeting notices for ME/CFS Advocacy Day sent by email</td>
<td>4:00pm – 9:00pm ET</td>
<td>Zoom Chat (ical)</td>
<td>Zoom is available by computer, tablet, or phone.</td>
</tr>
<tr>
<td>Sunday April 19</td>
<td>Instagram Stories</td>
<td>All Week</td>
<td>Instagram</td>
<td>Check out the GIPHY stickers for ME/CFS and Advocacy Day to add to your story. Stories last 24 hours. Post one a day!</td>
</tr>
<tr>
<td>Monday April 20</td>
<td>2nd Annual EmPOWER M.E. Roundtable</td>
<td>1:00pm – 2:30pm ET</td>
<td>GoToWebinar</td>
<td>&quot;Navigating Public and Private Disability Insurance with ME/CFS&quot;</td>
</tr>
<tr>
<td></td>
<td>EmPOWER M.E. Office Hours</td>
<td>4:00pm – 9:00pm ET</td>
<td>Zoom Chat (ical)</td>
<td>Ask your questions directly to our EmPOWER M.E. experts</td>
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**Sponsored by**: Bateman-Home Center and KANTOR & KANTOR, LLP

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<tr>
<td>Tuesday April 21</td>
<td>SOLVE ME/CFS ADVOCACY DAY!</td>
<td>8:00am – 5:00pm ET</td>
<td>YOUR HOME</td>
<td>Registration required</td>
</tr>
<tr>
<td>Wednesday April 22</td>
<td>Tweet-a-Thanks!</td>
<td>10:00am – 7:00pm ET</td>
<td>Twitter</td>
<td>Say thank you to champions and offices who spoke with us! Don’t forget MEAwarenessHour at 3pm ET.</td>
</tr>
<tr>
<td>Thursday April 23</td>
<td>Can You Hear M.E. Now??</td>
<td>5:00am – 5:00pm ET</td>
<td>Call / Fax</td>
<td>Use the D.C. Remote Advocate Kit to make our message <em>RING</em> true.</td>
</tr>
<tr>
<td>Friday April 24</td>
<td>Friday Facebook Flood</td>
<td>All Day</td>
<td>Facebook</td>
<td>Use the Tweet D.C. Advocate Kit to make an impact online</td>
</tr>
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www.MEAdvocacyWeek.com
EVENTS

Friday April 17th 4:00pm – 9:00pm ET: **Solve M.E. Advocacy Day Office Hours**

Monday April 20th 1:00pm – 2:30pm ET: **2nd Annual EmPOWER M.E. Roundtable**: “Navigating Public and Private Disability Insurance with ME/CFS”

Friday April 17th 4:00pm – 9:00pm ET: **EmPOWER M.E. Office Hours**
The EmPOWER M.E. education program strives to ensure that no family ever has to learn “the hard way” on their journey with M.E.

Join the 2nd Annual EmPOWER M.E. Roundtable on Monday, April 20th at 1pm ET for an online education workshop, “Navigating Public and Private Disability Insurance with ME/CFS.” Welcome back moderator Board Certified Patient Advocate, Sharon Stevenson, DVM, PhD, leading our expert panel of legal and medical experts as they share their advice on applying, appealing, and documenting your case for public and private disability insurance with ME/CFS.

Public disability insurance (Social Security) is a federal program for workers who have worked long enough to become eligible and meets the program’s definition of disabled. Private disability insurance is a contract between the insurance company and the insured, often provided as a benefit by employers or purchased as personal coverage by individuals.
SOLVE ME/CFS ADVOCACY WEEK

ACTIONS

Sunday April 19th – Sunday April 26th: **Instagram Stories** (social media)

Tuesday April 21st 8:00am – 5:00pm ET: **Solve ME/CFS Advocacy Day!** [Pre-registration required]

Wednesday April 22nd 10:00am – 7:00pm ET: **Tweet-a-Thanks!** (social media)

Thursday April 23rd 9:00am – 5:00pm ET: **Can You Hear M.E. Now?!** (call/fax)

Friday April 24th ALL DAY **Friday Facebook Flood** (social media)

www.MEAdvocacyWeek.com
• Remote Action Kit: All three actions with an interactive online portal. Just enter your zipcode and your call actions, social media actions, and email actions are just a few clicks away. In less than 15 minutes, this web portal will guide to take all THREE congressional actions, and fill in the details for you.

• Tweet D.C. Advocate Kit (free PDF download): If you want to show more flare with your social media actions, check out the Tweet D.C. Advocate Kit with customizable graphics and posts; everything you need to support ME/CFS advocacy on social media! (Twitter, Facebook, and Instagram)

• D.C. Remote Advocate Kit (free PDF download): For beginner, intermediate and advanced phone or fax actions, check out the D.C. Remote Advocate Kit. Here, you’ll find everything you need to call or fax your Members of Congress to support ME/CFS advocacy in D.C. from home.
Advocacy Day 2020

ME/CFS & COVID-19

www.MEAdvocacyWeek.com
Why COVID-19? Why Now?

- Unprecedented crisis, moving big money quickly
- System is designed to be slow, rules are now optional
- Fast-moving Opportunity - COVID 4.0
- Congressional Public Health focus
- Plays to our issue strengths
  - Bi-Partisan
  - Concentrated support
  - (Relatively) Low Cost
Our Ask

“Please support research funding for post-viral diseases, specifically ME/CFS, as an urgent COVID-19 response.”
Is ME/CFS research really a COVID-19 concern?
ME/CFS & COVID-19  The Facts

1. ME/CFS is known for afflicting people following viral infections

   • “One area where there is a considerable degree of medical agreement relates to what triggers, or precipitates ME/CFS. Most people with this illness pre-date the onset of their symptoms to an infection – normally viral but sometimes bacterial – from which they ‘fail to recover’”

     – Dr. Charles Shepherd, medical and research expert with ME/CFS

2. COVID-19 patients are exhibiting ME/CFS symptoms (up to 35% of patients)

   • “Some Coronavirus Patients Show Signs of Brain Ailments” The New York Times

   • “Neurological Manifestations of Hospitalized Patients with COVID-19 in Wuhan, China: a retrospective case series study” medRxiv (https://www.medrxiv.org/content/10.1101/2020.02.22.20026500v1)
ME/CFS & COVID-19 The Facts (cont.)

3. Coronaviruses trigger ME/CFS.

• A 2011 study on “chronic post-SARS syndrome” found 17% of SARS survivors were still sick with ME/CFS symptoms TWO YEARS after infection. SARS is the genetic parent of COVID-19*

• Experts are estimating significant surges in ME/CFS cases following the pandemic, up to 3,570,000 new ME/CFS cases**, more than doubling the existing cases in the United States in 36 months.

• If COVID-19 behaves like Epstein-Barr, up to 9% of survivors could be permanently disabled by ME/CFS***

* “Chronic widespread musculoskeletal pain, fatigue, depression and disordered sleep in chronic post-SARS syndrome; a case-controlled study” by Dr. Harvey Moldofsky - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3071317/#B26

** “The other potential coronavirus catastrophe no one is talking about” by Steve Topple https://www.thecanary.co/global/world-analysis/2020/03/15/the-other-potential-coronavirus-catastrophe-no-one-is-talking-about/

*** “Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort study” by Dr. Ian Hickie https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1569956/
ME/CFS & COVID-19  The Facts (cont.)

4. ME/CFS outbreaks have historically followed viral pandemics, such as the current COVID-19 epidemic.
   - “List of ME/CFS Outbreaks”
     https://www.me-pedia.org/wiki/List_of_myalgic_encephalomyelitis_and_chronic_fatigue_syndrome_outbreaks

5. Our frontline responders are not equipped to identify, diagnose, or treat post-viral neuroimmune disease, especially ME/CFS
   - “How Doctor-Delayed and Missed Diagnoses Harm Patients with Chronic and Rare Illnesses” by Sydney Reed
Our mission....

• Make the case: COVID now, ME/CFS later
• Smooth potential opposition
• Communicate severity of ME/CFS
• Emphasize *viral* connections in ME/CFS
• Highlight economic impact of ME/CFS
  • Unemployment / Underemployment
  • Long-term disability cases will surge
  • Increased medical costs
Your tools

• *Key document this year*
  Solve M.E. COVID-19 Congressional Recommendations

• Congressional Education Video

• YOUR Story!!

• Your Support team
  • Scheduling: Prime Advocacy Caroline@primeadvocacy.com
  • Advocacy: Solve M.E. Etaylor@solvecfs.org
  • Social Media and Tech Support: BOTH! solvecfs@solvecfs.org
Your Story

Try to tailor your story for COVID-19 implications. Here’s some ideas:

• How your delayed or misdiagnosis impacted your health
  - Will it be just as hard or worse for a COVID-19 survivor in your area?

• Financial impacts of ME/CFS on you and your family
  - Can your community survive that financial cost if hundreds or thousands have the same experience?

• Your long-term outlook of life with ME/CFS
Focus on...

- Emotional/Human connection
- ME/CFS & COVID-19 facts
  - Refer to the Solve M.E. Recommendations
- Your Story
  - Focus on experiences that may be shared with COVID-19 survivors in the next 6-12 months.
- Need for action
  - (i.e. We need to be prepared now)
Don’t Worry About...

• Numbers and details – refer to your materials or defer question to staff
• ME/CFS field challenges – we know there are many!
• Definitions or acronyms – close enough is great
• Other issues – ME/CFS research is our single focus this year
  • Solve M.E. is supporting non-profit sector support legislation
  • Solve M.E. is supporting paid family leave and sick time provisions
  • Solve M.E. is supporting disability expansions, supplemental income and other supports
  • Solve M.E. is supporting telehealth and remote medicine expansion
  • Solve M.E. is supporting FDA and NIH overhauls to expedite drug development
  • Solve M.E. is supporting legislation addressing medication and supply shortages
One Ask: Three ways to ask it

“Please support research funding for post-viral diseases, specifically ME/CFS, as an urgent COVID-19 response.”

“ME/CFS, or Chronic Fatigue Syndrome is an urgent PUBLIC HEALTH concern, since it can be triggered by coronaviruses and is a predominantly post-viral disease.”

“If unchecked, the current COVID-19 pandemic could drastically increase cases of ME/CFS. We must fund research to find risk factors and educate medical professionals about the risk of ME/CFS in COVID-19 survivors.”
A Note for Team Leads

• Air traffic control vs pilot
• Contact information for your Congressional office
• Giving everyone an opportunity to speak
• Time management
• Wrap up and thanks
  • Thank you (both to staff and fellow participants)
  • Invite any final input
  • Make the ask... One more time
Please support the **RECOMMENDATIONS OF SOLVE M.E.** to provide research funding for post-viral diseases, specifically ME/CFS as an urgent COVID-19 response.
Our Legislative Package

• Authorization and appropriation of at least $15 million a year over 4 years to the Director of the NIH to conduct and support post-viral neuroimmune disease research

• Research focus on diagnosis, treatment, and risk factors of post-viral chronic neuroimmune diseases; specifically ME/CFS, COVID-19 patients exhibiting ME/CFS symptoms, and survivors of COVID-19 with ME/CFS.

NIH implementation will include:
1. post-viral neuroimmune disease data collection and sharing;
2. new and expanded current Collaborative Research Centers to meet COVID-19 goals;
3. launching (or expanding) NIH intramural ME/CFS research to incorporate COVID-19 patients;
4. new ME/CFS and COVID-19 disease specific competitive funding opportunities with set-aside funds, prioritizing new and early career researchers.
COVID-19 and ME/CFS Questions?

www.MEAdvocacyWeek.com