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LONG COVID
ALLIANCE

ADVOCACY WEEK

APRIL 18-24, 2021

Remote Congressional Meeting Training

April 13, 2021

www.MEAdvocacyWeek.com

About Us



Emily Taylor

Director of
Advocacy and
Community
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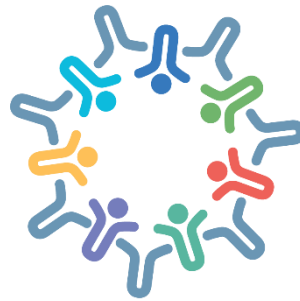
*Solve ME/CFS
Initiative*



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LCA



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APRIL 18-24, 2021

Today's Agenda

YOUR MEETINGS

- What to Expect
- Best Practices
- Tips and Support
- Team Leads

YOUR TOOLS

- Storytelling
- Online Portal
- Meeting Dashboard
- Office Hours

YOUR TALKING POINTS

- The ONE sentence
- The Asks
- Meeting Priorities



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ADVOCACY DAY

APRIL 20, 2021

YOUR MEETINGS

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What to Expect

Every meeting is important

- Congress is back in session for a **very intense period** in which they are negotiating major infrastructure legislation. There is a possibility you will not get to speak with the Member. The COVID-19 situation is very fluid.
- **The staffer** is essential in the life of an office. Be prepared to talk with a 25 year-old who could be making policy decisions for the office. Very important to the process.
- 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 the 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. 25–35% of COVID-19 patients, known as “long haulers,” are experiencing long-term symptoms.
2. All Longhaulers face job loss, disability, and a broken medical care system. According to Dr. Tony Komaroff of Harvard University (citing Harvard economists Larry Summers and David Cutler), "the direct and indirect economic costs of to the US economy from just the chronic illnesses that follow COVID are going to range **over \$4 trillion in the next decade.**"
3. **Please support the COVID-19 Longhaulers Act**, which will be introduced this month by Representative Don Beyer (VA-08).

...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



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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 Advocacy Associates 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 Advocacy Associates 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 real world impacts on healthcare and constituents in the district.
- This will force the Member and staff to listen right from the beginning and shape the conversation.



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Meeting Tips

Speak Plainly

- Solve ME/CFS and the Long COVID Alliance 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.

Meeting Tips

Establish Roles

- Most meeting groups will be about ~5 attendees
 - some as small as 3 -- others big as 12
- Call in **5 minutes prior** to make sure you have identified who will initiate the conversation (the team lead), who is the constituent, who will speak on critical talking points, and/or 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
- If you ever get stuck, go back to the ONE sentence

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 your bill***



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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 her constituents.

Thank them for their time and see if they request any additional information before ending the conversation. *Check out the “Send Thank You Note” button and customize!*

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.

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.

Team Leads: What you need to know

- Call in 10 minutes early
- Start the meeting, make introductions
- State the ONE sentence
- Identify the constituent
- Help everyone find an opportunity to speak
- Time management
- Wrap up and thanks
 - Thank you (both to staff and fellow participants)
 - Invite any final input
 - State the ONE sentence... One more time



Team Lead Checklist

- Call in 10 minutes early
- Introduce yourself at the beginning
- State the ONE sentence
- Introduce & Identify the constituent
- Watch the time
- With 2 minutes left, wrap up
- Invite any final input
- Repeat the ONE sentence
- Thank You! (staff and advocates!)



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YOUR TOOLS

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Your Story

- Stories can **EVOKE** people's **EMOTIONS**
- Feelings and emotions are what **SPUR** people to **ACTION**
- The **POWER** of your story can move people to create **CHANGE**

Your Story

- This affects me personally, as a _____
 - Person with severe ME/CFS for 20 years
 - Caregiver for a loved one with a chronic post viral illness
 - As a person who has Long COVID
- 1-2 specific examples of how this has impacted your life
 - How has a delayed or misdiagnosis impacted your health?
 - What are the financial impacts on you and your family?
 - How has this affected your family and relationships?
 - What does research/medical education mean for your day-to-day life?

Values, Problem, Solution, Action

1. Three Sentence Story
2. Problem you want them to solve
3. Solution you believe in
4. Action you want them to take
5. How that action did, would, or would have helped you
6. Repeat action

Adapted from materials by Opportunity Agenda and sujatha baliga, restorative justice project

Focus on...

- Emotional/Human connection
- Shared experiences with others suffering complex, chronic illnesses
- Post-viral implications
- COVID-19 Longhaulers Act
 - Data-Driven policy solutions
 - How this will help you, and others like you
- Need for action *now!*



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Don't Worry About...

- Numbers and details – refer to your materials or note for our staff to follow-up
- Challenges that this act doesn't fix- this is a stepping stone, not the end!
- Definitions or acronyms – close enough is great
- Saying everything- start with what is most important, in case you run out of time
- Other issues – #StopTheLonghaul is our single focus this year
 - Pass and fund the COVID-19 Longhaulers Act
 - Plug the gaps in post-viral health care delivery

We know many other issues inspire and drive you, but today is about post-viral illness

Self Care

- Honor that this isn't your whole story
- How are you going to take care of yourself **BEFORE?**
- How are you going to take care of yourself **DURING?**
- How are you going to take care of yourself **AFTER?**

Adapted from materials by sujatha baliga, restorative justice project

Your Online Portal



Your Meetings - ME/CFS & Long COVID Virtual Advocacy Day

Tuesday, April 20, 2021

ALL TIMES EASTERN



Sen. Maria Cantwell (D) [WA]

Virtual Meeting: Click for details on how to join. You'll be able to join online or by conference phone number.
Kevin Chang, Legislative Correspondent

03:00 PM



Sen. Alejandro Padilla (D) [CA]

Virtual Meeting: Click for details on how to join. You'll be able to join online or by conference phone number.
Lorenzo Rubalcava, Policy Advisor

04:00 PM



Sen. Dianne Feinstein (D) [CA]

Virtual Meeting: Click for details on how to join. You'll be able to join by conference phone number.
Deanna Segall, Legislative Correspondent

05:00 PM

TBD

ALL TIMES EASTERN



Sen. Patty Murray (D) [WA]

Virtual Meeting: Click for details on how to join.

TBD

Your Meeting Dashboard

Tuesday April 20, 2021 at 03:00 PM Eastern



Sen. Maria Cantwell (D) [WA]

Meeting With: Kevin Chang, Legislative Correspondent

Join Online Meeting

Dial-In: 1-253-215-8782

Access Code / PIN: 638-955-4583#

Important Information:

Meeting is in Eastern Time.

Please DO NOT click the "Join Online Meeting" button until 5 min prior to your specific meeting time, or use that link for anything other than this specific meeting.

Check In

Send Thank You Note

Meeting Report Form

Take Notes

Member Attended

Only Staff Attended

Tweet

Facebook

LinkedIn

▼ Talking Points

Post-viral chronic illnesses are not new. Long COVID patients are experiencing the same symptoms, the same hardships, and the same barriers as other similar illnesses like ME/CFS, POTS, MCAS, EDS, just to name a few.

- Share examples of your symptoms, hardships, or barriers.

THANK YOU for helping to provide \$1.25 billion to the National Institutes of Health to research the long-term effects of COVID-19. But NIH research *alone* cannot meet this "hidden wave" of Long COVID and post-viral illnesses.

Please support the COVID-19 Longhaulers Act, which will be introduced this month by

▼ Documents

COVID-19 Longhaulers Act Bill Summary (PDF)

E-Dear Colleague FY22 (ME-CFS) (PDF)

Feb 25 - Long COVID Alliance Recommendations to NIH (PDF)

▼ Attendees



Emily Taylor



Your tools

- Your Online Portal - [Advocacy Day Online Portal](#)
 - All documents and talking points can be accessed here!
 - **REMEMBER! NO PASSWORD NEEDED! Use the “Send me a sign-in link” button**
- *Key document this year*
[Summary of COVID-19 Longhaulers Act](#)
- YOUR Story!!

Additional Support

Your Support team

Scheduling: Advocacy Associates mestringer@advocacyassociates.com, jrodriguez@advocacyassociates.com

Advocacy: Solve M.E. Etaylor@solvecfs.org, jbrownclark@solvecfs.org

Social Media and Tech Support: Both! advocacy@solvecfs.org

Office Hours

Wednesday, April 14

- [Spoonies, Families, & Friends](#): 11 am PT/ 2 pm ET
- [Team leads](#): 4 pm PT/ 7 pm ET

Thursday, April 15

- [Long COVID](#): 11 am PT/ 2 pm ET
- [Team leads](#): 4 pm PT/ 7 pm ET

Friday, April 16

- [Social Hour](#): 4 pm PT/ 7 pm ET



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YOUR TALKING POINTS

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The ONE sentence

“ Please support the COVID-19 Longhaulers Act. ”

The Talking Points

1. An estimated 25–35% of COVID-19 patients, known as “long haulers,” are experiencing long-term effects of COVID-19 infections
 - According to [Dr. Anthony Fauci](#), Director of the National Institute of Allergy and Infectious Diseases
 - Patient-preferred term is “Long COVID.” Also called “post-acute sequelae of COVID-19” (PASC)
 - Long COVID impacts all ages, races, and sex, regardless of initial infection severity
2. Long COVID may cost the U.S. economy \$4 trillion over next decade
 - Dr. Tony Komaroff of Harvard University (citing Harvard economists Larry Summers and David Cutler) said, "the direct and indirect economic costs of to the US economy from just the chronic illnesses that follow COVID are going to range over \$4 trillion in the next decade."
 - Komaroff, Anthony, and Oved Amitay. Learning from the Past: The Long-Term Consequences of COVID-19, Youtube, 19 Mar. 2021, youtu.be/rPW_rAN32w?t=199. Accessed 12 Apr. 2021.

The Talking Points

3. THANK YOU for helping to provide \$1.25 billion to the National Institutes of Health to research the long-term effects of COVID-19.
4. But NIH research alone cannot meet this “hidden wave” of Long COVID and post-viral illnesses.
5. We need 1) EDUCATION, 2) COMPREHENSIVE CARE, AND 3) TREATMENT EQUITY!

If questions arise about NIH, refer to your handout [“Feb 25 – Long COVID Alliance Recommendations to NIH \(PDF\)”](#)

The ONE sentence

“ Please support the COVID-19 Longhaulers Act. ”

The COVID-19 Longhaulers Act will...

1. Be introduced by Representative Don Beyer shortly,
2. Accelerate research through data harmonization,
3. Improve care by researching Long COVID treatment efficacy, delivery, and disparities
4. Fund medical education and public education programs about Long COVID and related post-viral illnesses
5. **ONLY IF ASKED!**..... cost ~\$95 million for FY22

The ONE sentence: Three ways to say it

“ Please support the COVID-19 Longhaulers Act. ”

“ Can we count on your support to help pass the COVID-19 Longhaulers Act? ”

“ Will you speak to Rep. Beyer about the COVID-19 Longhaulers Act? ”

Our ME/CFS Ask ...for the veterans

“

Representatives Zoe Lofgren and Anna Eshoo are circulating a sign on letter for ME/CFS which is included in your digital packet.

Please co-sign these important appropriations requests to continue and expand existing post-viral research programs already underway. ”



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Questions?

www.MEAdvocacyWeek.com

Quick Access Links

- Information about Advocacy Week – www.MEAdvocacyWeek.com
- Information about Long COVID Alliance – www.LongCOVIDAlliance.org
- COVID-19 Longhaulers Act Summary - <https://solvecfs.org/wp-content/uploads/2021/04/COVID-19-Longhaulers-Act-1pg-Final.pdf>
- *Feb 25 – Long COVID Alliance Recommendations to NIH - <https://solvecfs.org/wp-content/uploads/2021/02/NIH-Long-COVID-Coalition-Recommendations-Letter-Final-for-sign-on.pdf>*