



Solve M.E.

SOLVE ME/CFS
ADVOCACY WEEK



APRIL 19 - 26, 2020

~~WASHINGTON, DC~~

From Home!

SOLVE ME/CFS
ADVOCACY DAY
2020



**WANT TO
DO
MORE?**

**TRY TWEET
D.C. ADVOCATE
SOCIAL MEDIA
ACTIONS**

OR

**D.C. TO M.E.
ADVOCATE
LOCAL AND
DISTRICT
ACTIONS**

D.C. Remote Call-In Action Kit

You can still be a big part of ME/CFS Advocacy Week, April 19 to April 26, 2020, even if you have limited energy. Make your voice heard by phone or fax! Call your members of Congress and tell them to support ME/CFS research.

We want to flood Congress with calls during ME/CFS Advocacy Week, especially on our dedicated “Can you hear M.E. now?” action on Thursday April 23. To make things even easier, try our online REMOTE ACTION KIT at: <https://solvemecfs.wpengine.com/call-in-action-kit/>

ME/CFS ADVOCACY WEEK CALL OR FAX CHECKLIST:

- Get your D.C. REMOTE Advocate Kit
- Review Kit
 - Let us know if you have questions at solvecfs@solvecfs.org
- Pick your method: phone, fax, or both!
- Find contact info for your Members of Congress
 - Visit our online tool [HERE](#), or use www.GOVTRACK.US
 - Identify Washington DC office contact info
 - CHAMPIONS: Check your Contact Cards in your mail package
- Practice your script or draft your fax letter
- Call or fax!
 - Support Advocacy Day – Tuesday April 21
 - Can you hear M.E. now? – Thursday April 23
 - Remember to make **THREE** calls for each action; both your senators and your representative!



FIND CONTACT INFO FOR CONGRESS

Our [ONLINE REMOTE ACTION KIT](#) is your easiest one-stop shop for call and social media actions. Just fill in your zip code and the tool fills in the rest.

If you'd rather craft your own message, no problem!

Find your Senator's phone or fax number here:

Senators: https://www.senate.gov/general/contact_information/senators_cfm.cfm

House of Representatives:

<https://www.house.gov/representatives/find-your-representative>

If you are working "offline," call **(202) 224-3121** for the U.S. Capitol switchboard operator.

CHAMPIONS: Locate this information on your Congressional Contact card in your mailed packet

PHONE CALL POINTERS

Your calls will only take 2-3 minutes each, where you will either speak with a staff member or leave a voicemail. Every call and every voicemail are tallied up and provided to your Member of Congress! The more calls, the attention a member gives to an issue.

If you have the energy, make **THREE** phone calls:

1. Your 1st Senator
2. Your 2nd Senator
3. Your Representative

If you are up for it, you can even call each day during the week and repeat the same important message!

If you are unable to get through to your Senator's DC office or are unable to leave a voicemail, you can always contact a district office.

Beginner advocates: If you are nervous your first try, no problem! Try calling outside of regular office hours and leaving a voicemail, just to get comfortable. You can even leave a voicemail every day - they add up and make a big difference!



Intermediate advocates: Call during business hours to speak directly to a member of the staff. You may have to try several times. You can also ask to leave a voicemail directly for the HEALTH staff.

Advanced advocates: Call during business hours and request to speak to the HEALTH staff regarding a request. Most likely, you will not be able to get through and will leave a message or voicemail. But if you can try several times, you may get a few minutes to share your story and our requests with the HEALTH staff directly.

Use our [REMOTE ACTION KIT](#) online to look up phone numbers, provide call scripts, and tell us how everything went.

WHAT DO I SAY?

In the next pages, you'll find sample call scripts with easy talking points that you can use during your calls. But, for those of you who would rather make your own script – here's the key parts.

Each phone call, will have three parts. The first is IDENTIFYING YOURSELF, the second is IDENTIFYING YOUR ISSUE, and the third is IDENTIFYING YOUR REQUEST.

#1 – Identifying Yourself

When call your member of Congress during business hours, you will likely speak to an intern or member of the DC office staff who answers the phone. The first thing you do, is identify yourself as a person who lives in your member's district. Here's what that looks like:

Hello, my name is _____ (your name) and I am calling from _____ (city), _____ (state). I am a person with ME/CFS; or Chronic Fatigue Syndrome.

If you are leaving a voicemail, this is still the first thing you want to say.

#2 – Identifying Your Issue

Congressional staff take hundreds, even thousands of calls a day. Most offices have electronic cataloging systems to quickly sort calls and messages by SUBJECT, so they go to the correct staffer. You want to be clear that you are calling about a HEALTH issue, ME/CFS or CHRONIC FATIGUE SYNDROME. This is what you can say:



I am calling to ask Senator _____ to please support immediate response measures for ME/CFS in the next COVID-19 response package. ME/CFS, or Chronic Fatigue Syndrome is an urgent HEALTH concern, since it can be triggered by coronaviruses and is a predominantly post-viral disease.

After you identify your issue, this your opportunity to educate Congress! You can do this by providing key facts and concerns or by sharing a personal story. This year, COVID-19 is everyone’s biggest concern – and the facts about its connection to ME/CFS are really vital. Here’s an example of how you can outline those concerns:

- 1. Some COVID-19 patients are exhibiting ME/CFS symptoms (nearly 35% of patients)ⁱ*
- 2. Coronaviruses trigger ME/CFSⁱⁱ. Experts are estimating significant surges in ME/CFS cases following the pandemic, **up to 3,570,000 new ME/CFS cases**ⁱⁱⁱ, 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^{iv}.*
- 4. Our frontline responders are not equipped to identify and diagnosis post-viral neuroimmune disease.*

If you have the energy, you can further explain why the issue is important to you by sharing more about your personal journey with ME/CFS. This is the best part of the conversation to do so. Some ideas for how to share your personal journey:

This affects me personally, as a person with ME for _____ years. (or as a caregiver/family member of a person with ME for _____ years)

3 brief, specific examples/facts about your experiences with ME/CFS:

- How this impacts your career or ability to work*
- How this impacts your family or relationships*
- How this impacts your life during the COVID-19 epidemic*

#3 – Identifying Your Request

Now, you’ve saved the best for last – what your member of Congress can do to help! This year, we are focusing on including ME/CFS research as essential for an effective COVID-19 public health response. Solve M.E. is circulating formal recommendations to Congress. Here’s how you can ask your Member of Congress to help:



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

Solve M.E. recommends:

- *At least \$15 million a year over 4 years to the Director of the NIH to conduct and support post-viral neuroimmune 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.*

After you've stated your need, always say thank you! Some offices may ask for a phone number or email to follow-up with your request. This is optional and entirely up to your personal preference. If you'd like to continue working with your member of Congress, email our team (solvecfs@solvecfs.org) so we can support you!

SAMPLE CALL SCRIPTS

Beginner:

Feel free to put this script in your own words!

Hello, my name is _____ (your name) and I am calling from _____ (city), _____ (state). I am calling to ask (Senator/Congressman) _____ to please support immediate response measures for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in the next COVID-19 response package. This is an urgent HEALTH issue.

*We must equip our frontline responders to identify and diagnosis post-viral neuroimmune disease in COVID-19 patients. **Early diagnosis is key** to prevent long-term disability caused by ME/CFS.*

If unchecked, we believe the current COVID-19 pandemic will 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.

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

Thank you for listening and for your prompt attention to this issue.



Intermediate:

Feel free to put this script in your own words!

Hello, my name is _____ (your name) and I am calling from _____ (city), _____ (state). I am calling to ask (Senator/Congressman) _____ to please support immediate response measures for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in the next COVID-19 response package. This is an urgent HEALTH issue.

Tell your story here!

This affects me personally, as a person with ME for _____ years. (or as a caregiver/family member of a person with ME for _____ years)

3 brief, specific examples/facts about your experiences with ME/CFS:

- How this impacts your career or ability to work*
- How this impacts your family or relationships*
- How this impacts your life during the COVID-19 epidemic*

If unchecked, we believe the current COVID-19 pandemic will 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.

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

Thank you for listening and for your prompt attention to this issue.

Advanced:

Feel free to put this script in your own words!

Hello, my name is _____ (your name) and I am calling from _____ (city), _____ (state). I am calling to ask (Senator/Congressman) _____ to please support immediate response measures for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in the next COVID-19 response package. This is an urgent HEALTH issue.



1. COVID-19 patients are exhibiting ME/CFS symptoms (nearly 35%^v of patients)
2. Coronaviruses trigger ME/CFS^{vi}. Experts are estimating significant surges in ME/CFS cases following the pandemic, up to 3,570,000^{vii} 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 pandemic^{viii}.
4. “Recovered” doesn’t mean a return to health or a return to work. After SARS (parent of COVID-19), 17% of those infected never returned to work because of ME/CFS-like symptoms.

[Tell your story here!](#)

This affects me personally, as a person with ME for _____ years. (or as a caregiver/family member of a person with ME for _____ years)

3 brief, specific examples/facts about your experiences with ME/CFS:

- *How this impacts your career or ability to work*
- *How this impacts your family or relationships*
- *How this impacts your life during the COVID-19 epidemic*

*We must equip our frontline responders to identify and diagnosis post-viral neuroimmune disease in COVID-19 patients. **Early diagnosis is key** to prevent long-term disability caused by ME/CFS.*

If unchecked, we believe the current COVID-19 pandemic will 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.

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

Thank you for listening and for your prompt attention to this issue.



SAMPLE FAX LETTER

Dear _____:

The virus COVID-19 is anticipated to infect as many as 214 million Americans, cause the hospitalization of 21 million people, and 3.5 million Americans may never return to health, resulting in a cost of over *\$48 billion annually for the rest of their lives* in lost productivity and increased medical costs.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is classified as a neurological disease by the World Health Organization^{ix} and is known for afflicting people with viral infections.^x

1. Some COVID-19 patients are exhibiting ME/CFS symptoms (nearly 35% of patients)^{xi}
2. Coronaviruses trigger ME/CFS^{xii}. Experts are estimating significant surges in ME/CFS cases following the pandemic, **up to 3,570,000 new ME/CFS cases**^{xiii}, 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^{xiv}.
4. Our frontline responders are not equipped to identify and diagnosis post-viral neuroimmune disease.

As you know, ME/CFS is a complex, debilitating, predominantly post-viral^{xv} chronic disease afflicting up to 2.5 million Americans of all ages and walks of life^{xvi}. In 2015, 89% of patients reported that they were forced to leave their job because of ME/CFS^{xvii} and, with no FDA approved treatments and extremely low recovery rates, people with ME/CFS mostly suffer for life. These “missing millions” cost their families, the U.S. healthcare system, and our economy \$24 billion annually and are an incredibly high risk population for COVID-19 infection.

ME/CFS is a neuro-immune disease resulting in multi-systemic disruptions, particularly of the immune system, and even organ shut down. People with ME/CFS are incredibly vulnerable to even the most benign infection. While information about COVID-19 impacts on people with ME/CFS is still forthcoming, we urge you to acknowledge this particularly vulnerable population and keep their needs in mind as you craft additional response packages to this pandemic.

In the past 4 years, the National Institutes of Health (NIH) have grown the field of ME/CFS research and built a network of disease experts and scientists at the leading edge of the field of post-viral neuroimmune diagnostics and treatment. Given the clear connection to the COVID-19 crisis, the ME/CFS research community is an untapped scientific resource that will be vital to existing COVID-19 scientific, diagnostic, and treatment efforts.

COVID-19 Response Recommendation from Solve M.E.



Solve ME/CFS Initiative (Solve M.E.) recommends immediate congressional action to enable current NIH ME/CFS research programs to tackle these new neuroimmune related COVID-19 challenges. Solve M.E. calls for the authorization and appropriation of at least \$15 million a year over 4 years to the Director of the NIH to conduct and support research and related activities concerning the 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. In accomplishing this goal, Solve M.E. encourages the NIH to implement 1) post-viral neuroimmune disease data collection and sharing; 2) establishing new and expanding current Collaborative Research Centers to meet COVID-19 goals, 3) launching (or expanding) intramural ME/CFS research to incorporate COVID-19 patients, 4) launch new ME/CFS and COVID-19 disease specific competitive funding opportunities with set-aside funds, prioritizing new and early career researchers.

Thank you for your attention to this critical issue, and we look forward to your response.

Sincerely,

_____ (your name)
_____ (your address)

ⁱ <https://www.theglobeandmail.com/canada/article-scientists-warn-covid-19-could-lead-to-neurological-complications-in/>

ⁱⁱ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3071317/#B26>

ⁱⁱⁱ <https://www.thecanary.co/global/world-analysis/2020/03/15/the-other-potential-coronavirus-catastrophe-no-one-is-talking-about/>

^{iv} <https://ammes.org/outbreaks/>

^v <https://www.theglobeandmail.com/canada/article-scientists-warn-covid-19-could-lead-to-neurological-complications-in/>

^{vi} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3071317/#B26>

^{vii} <https://www.thecanary.co/global/world-analysis/2020/03/15/the-other-potential-coronavirus-catastrophe-no-one-is-talking-about/>

^{viii} <https://ammes.org/outbreaks/>

^{ix} World Health Organization (1969). *International Classification of Diseases (PDF)*. 2 (Eighth revision ed.). Geneva: WHO. p. 173. Encephalomyelitis (chronic), (myalgic, benign) 323

^x <https://www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/symptoms-causes/syc-20360490>

^{xi} <https://www.theglobeandmail.com/canada/article-scientists-warn-covid-19-could-lead-to-neurological-complications-in/>

^{xii} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3071317/#B26>

^{xiii} <https://www.thecanary.co/global/world-analysis/2020/03/15/the-other-potential-coronavirus-catastrophe-no-one-is-talking-about/>

^{xiv} <https://ammes.org/outbreaks/>

^{xv} <https://www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/symptoms-causes/syc-20360490>

^{xvi} <https://www.ncbi.nlm.nih.gov/pubmed/25695122>

^{xvii} <https://www.ncbi.nlm.nih.gov/pubmed/25695122>