



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 D.C.
REMOTE
ADVOCATE**
CALL AND FAX
ACTIONS

OR

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

Tweet D.C. Social Media Kit

Thanks for joining thousands of ME/CFS research, patient, and advocacy community members in standing together in one voice for ME/CFS research and education. Follow these easy steps to join our efforts on SOCIAL MEDIA. You will need a [FACEBOOK](#), [TWITTER](#), and/or [INSTAGRAM](#) account. Use the worksheets to help plan when you are feeling well – to help manage your energy during ME/CFS Advocacy week: April 19 – April 26, 2020.

ME/CFS Advocacy Week SOCIAL MEDIA Checklist:

- Get your Tweet D.C. Advocate Kit
- Review Kit and follow Solve M.E. online
 - Facebook: [@SolveMECFSInitiative](#)
 - Twitter: [@PlzSolveCFS](#)
 - Instagram: [@Solve_CFS](#)
- Pick your photos to FRAME or graphics to share
 - Download graphics [here](#), or visit: www.MEAdvocacyWeek.com
 - Download the [frame digitally](#) and combine with your picture, or
 - CHAMPIONS: Use your Advocacy Week magnet frame with a printed photo and take a picture with your phone!
- Find your Members of Congress on social media
 - Visit our online tool [HERE](#), or use www.GOVTRACK.US
 - CHAMPIONS: Check your Contact Cards in your mail package
- Draft or pick your message
- POST, POST, POST!
 - INSTAGRAM – Start Sunday April 19, post 1 story and 1 post
 - ALL PLATFORMS – Support Advocacy Day – Tuesday April 21
 - TWITTER - Tweet-A-Thanks – Wednesday April 22
 - FACEBOOK – Friday Facebook Flood – Friday April 24



Pick your photos to FRAME or graphics to share

A picture is worth a thousand words...Make sure to select your favorite photos or graphics to share for your online actions. Here's a few samples you can use for your photos:



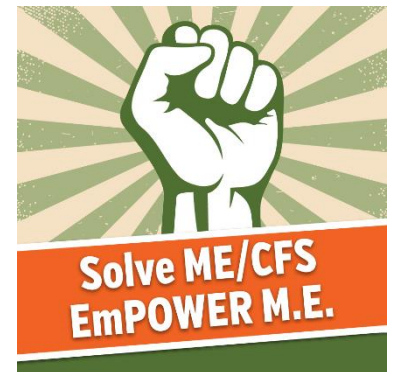
Solve M.E.

Facts about ME/CFS

For Advocates:

1. ME/CFS devastates the lives of up to 2.5 million Americans
2. Costs the U.S. economy an estimated \$24 billion each year
3. 69% of people with ME/CFS are unable to work and 89% lost their job due to ME/CFS
4. People with ME/CFS have the lowest quality of life scores of any disease measured
5. There is no FDA Approved treatment for ME/CFS and people often suffer for life

#CongressFight4ME www.SolveME.com



Use this frame around your favorite advocacy memories to share!

I called Capitol Hill today to tell them ME is an issue they need to care about!

Your turn! Call your member of Congress and tell them to Fight for ME.

#CongressFight4ME #StormDC4ME

Now more than ever I need you to advocate for ME/CFS.

Research shows that Coronaviruses trigger ME/CFS, we can expect people who "recover" from COVID-19 to have ME/CFS within a year.

#CongressFight4ME #StormDC4ME

I saw dozens of doctors, from homeopaths to tropical disease specialists, grueling visits, spending tens of thousands of dollars.

I realized that I had severe ME/CFS and after a fruitless week in a Houston diagnostic hospital five years ago, I made the decision that I was not going to subject myself to any more torturous tests or dismissive physicians. I knew in my heart I was neither crazy, "clinically depressed" or trying to garner attention.

Who would choose this disease?

HUMANS OF ME/CFS
- STEPHANIE S.

Imagine waking up and barely being able to move. Barely being able to keep your eyes open. Unable to bear the quietest sound or the dullest light. Unable to carry out the simplest tasks. Unable to focus. Unable to structure your thoughts.

Then imagine being told that there's nothing wrong with you. That's what millions of people, including myself, are suffering with every day. ME/CFS is like a leech. It sucks out all the positives from your life.

HUMANS OF ME/CFS
- TOM P.

Visit <https://www.facebook.com/pg/SolveMECFSInitiative/photos/> to see more graphics you can use for free!



Find your Members of Congress on social media

CHAMPIONS: Use your congressional Contact Card in your package to complete your Planning Worksheet.

- Solve M.E. Remote Action Kit: <https://solvemecfs.wpengine.com/call-in-action-kit/>
- Enter your address at: <https://www.govtrack.us/congress/members>

Tag your Members of Congress by adding their social media handle in your message with an “@”. You can use your Worksheets, included on the following pages.

Draft or Pick your Message

Draft a message that expresses your feelings or shares important information. Remember a post for your friends or family should look different than a post you send to your Member of Congress.

Post Suggestions For Friends and Family:

- Encourage friends and family to take action too!
- Educate them about how your life has changed because of ME/CFS
- Share real experiences of your ME/CFS
- Share gratitude for your support network
- Be sure to share our ME/CFS Advocacy Week Action links!
 - Email action: <https://sforce.co/3ckQ11T>
 - Remote Action Kit: <https://solvemecfs.wpengine.com/call-in-action-kit/>

Here's some sample posts for friends or family:

- Join me and take this 2 min action today to ask members of Congress to fund vital research about #MECFS and the long-term impacts of #COVID-19. <https://sforce.co/3ckQ11T> THANK YOU for your #advocacy!
#CongressFight4ME #SolveME #ontheHillfromHome
- It's #MECFS #Advocacy Week! Thousands of #pwME are joining together and you can to! Join the fight!
<https://solvemecfs.wpengine.com/call-in-action-kit/> #CongressFight4ME #SolveME #ontheHillfromHome
- I'm an #MECFS advocate so that no other family has to experience what mine has. Will you stand with me? Help @PlzSolveCFS call upon congress to increase #research funding. It only takes 2 minutes. <https://sforce.co/3ckQ11T>
#CongressFight4ME #SolveME #ontheHillfromHome
- Did you know that #coronavirus can trigger #MECFS? Our #healthcare workers deserve the best education and science! Tell Congress to increase research and education funding to #SolveME #CongressFight4ME
#ontheHillfromHome <https://solvemecfs.wpengine.com/call-in-action-kit/>



Make sure to make the most of your social media actions by tagging and messaging your MEMBERS OF CONGRESS through their social media channels. You can take the same message maximize your reach by posting and tagging your Member of Congress on TWITTER, FACEBOOK, and INSTAGRAM.

Post Suggestions For Members of Congress:

- You can post publicly (with a tag) so friends and family can see also
- Or direct message your Member of Congress if you do not wish others to see your post.
- Share important facts or quotes to educate them
 - Tag multiple members in a single post
 - Share gratitude for their past support, if you know they've helped ME/CFS before.
 - Be sure to share our ME/CFS Advocacy Week Action links!
 - Congressional Education Video: coming soon!
 - Congressional Thank you video: coming soon!

Here's some sample posts for Members of Congress:

- I'm calling on [@legislator] to be my voice in Congress in the fight against myalgic encephalomyelitis (ME), commonly referred to as chronic fatigue syndrome (CFS). Please support and fund NIH research into new neuroimmune related #COVID19 challenges #CongressFight4ME #SolveMECFS
- The current #coronavirus and #COVID19 may lead to an increase in cases of ME/CFS in those who recover. We need action from [@legislator] to support and fund NIH research into new neuroimmune related #COVID19 challenges #CongressFight4ME #SolveMECFS
- [@legislator]: Did you know that Up to 69% of people with ME/CFS are unemployed and up to 89% lost their job? I'm asking you to support and fund NIH research into new neuroimmune related #COVID19 challenges #CongressFight4ME #SolveMECFS
- ME/CFS is significantly more prevalent than multiple sclerosis, cerebral palsy and muscular dystrophy combined. We need leaders like [@legislator] to support and fund NIH research into new neuroimmune related #COVID19 challenges #CongressFight4ME #SolveMECFS
- The US economic burden from ME/CFS is \$17-\$24 billion in medical expenses and lost productivity due to patients' inability to work. I'm asking [@legislator] to support and fund NIH research into new neuroimmune related #COVID19 challenges #CongressFight4ME #SolveMECFS
- People with ME/CFS have the lowest quality of life scores of any disease. Lower than stroke, heart attack, lung cancer, and renal failure. That's we need [@legislator] to support and fund NIH research into new neuroimmune related #COVID19 challenges #CongressFight4ME #SolveMECFS
- I want [@legislator] to know that ME/CFS is a devastating multi-system disease that causes energy depletion on a cellular level and severe physical & cognitive limitations. I'm asking for support to fight ME/CFS by supporting and funding NIH research #CongressFight4ME #SolveMECFS



Tweet D.C. Advocate and Champions Instagram Worksheet

Photos or graphics I'd like to use:
(Copy links, photo or write file
location/name here)

My Representative's Instagram:

My Jr. Senator's Instagram:

My Sr. Senator's Instagram:

Other Member of Congress or person to tag:

USE HASHTAGS: #SolveME #SolveMECFS #CongressFight4ME #StormDC4ME #invisibleillness #chronicillness #ME / #MECFS / #MyalgicE #advocacy #SolveME #ontheHillfromHome #ontheHillatHome #pwME #MEResearch #scienceforME #investinME #GoodScience #researchers #science #scientists #genetics #EndMECFS #chronicfatigue #spoonie #chronicillnesswarrior #invisibleillness #CFSME #severeME #myalgicencephalomyelitis #highriskcovid19

My Post Instagram Story – How Does ME/CFS Impact your life?: (Sunday April 19):
Try out the [ME/CFS Impact Tool](#) as part of the [You + M.E. Registry](#)

My Post Supporting ME/CFS Advocacy Day (Tuesday April 21):



Tweet D.C. Advocate and Champions Facebook Worksheet

Photos I'd like to use:
(Copy links, photo or write file
location/name here)

My Representative's Facebook:

My Jr. Senator's Facebook:

My Sr. Senator's Facebook:

Other Member of Congress or person to tag:

USE HASHTAGS: #SolveME #SolveMECFS #CongressFight4ME #MECFS #ME
#Advocacy #pwME #invisibleillness #chronicillness #highriskcovid19

My Post Supporting ME/CFS Advocacy Day (Tuesday April 21):

My Post Friday Facebook Flood (Friday April 24):



Tweet D.C. Advocate and Champions Twitter Worksheet

Photos I'd like to use:
(Copy links, photo or write file
location/name here)

My Representative's Twitter handle:
(begins with @)

My Jr. Senator's Twitter handle:
(begins with @)

My Sr. Senator's Twitter handle:
(begins with @)

Other Member of Congress or person to tag:

USE HASHTAGS: #SolveME #SolveMECFE #CongressFight4ME #invisibleillness
#chronicillness #pwME #MECFE #pots #fibro #Covid19 #HighRiskCovid19

My Post Supporting ME/CFE Advocacy Day (Tuesday April 21):

My Post Tweet-A-Thanks (Wednesday April 22):