



# Solve ME/CFS Initiative

Leading the Fight to cure ME/CFS

## ME/CFS Advocacy Week Local and Online Toolkit 2018

May 8, 2018

Dear ME/CFS Advocate,

Thank you for generously giving your energy and time to join our second annual ME/CFS Advocacy Week from your local district. We truly cannot do this without you – your stories, your gifts, and your voice drive everything we do here at SMCI.

The goal of SMCI Advocacy Week in 2018 is to:

- Solidify funding requests from SMCI's efforts in March
- Create momentum and “buzz” for ME/CFS on Capitol Hill
- Educate legislators and staff on ME/CFS
- Build relationships for future actions
- Secure support for current “asks”

This toolkit was created to help guide you, step by step, to support our advocacy efforts in Washington DC. Here you will find a summary of Advocacy Week, links, checklists, and sample letters to guide your efforts. If you have any questions, don't hesitate to contact me.

Together, we will win this fight!

Thank you for all your support,



Emily Taylor ([etaylor@solvecfs.org](mailto:etaylor@solvecfs.org))  
Director of Advocacy and Communications  
Solve ME/CFS Initiative (SMCI)  
(704) 364-0016 x209

## Advocacy Checklist – ME/CFS Advocacy Week

- Take Action online with SMCI's 2-minute congressional messaging tool
  - Remember the “Prefix” dropdown menu must be completed to submit the form
  - Take action for the Senate here –  
[https://solvecfs.secure.force.com/actions/kwac\\_takeaction?actionId=AR00034](https://solvecfs.secure.force.com/actions/kwac_takeaction?actionId=AR00034)
- Share the online action with your friends and family
  - See the **Sample E-mail** on page 4
- Post on social media to raise awareness
  - See **Social Media Guide** on page 4
- Call your Senators (both of them)
  - See the **Senate Action Guide** on page 5
- Call your Representative
  - See the **House Action Guide** on page 9
- Send a fax with your written request
  - FIND the fax number of your SENATORS and US REPRESENTATIVE:  
<https://www.house.gov/representatives/find-your-representative>
  - Use the House and/or Senate “Advanced Advocacy” action guide to write a fax letter to your member of congress
  - Write your own personal story and comments on a cover page for your fax
- Be a local leader! District meetings, local proclamations, #MillionsMissing and more
  - See **Local Advocacy Guide** on page 14

*\*\*Don't forget to let us know how your advocacy went by using this easy report form:*

<https://solvemecfs.wufoo.com/forms/p3b8bge0oi52u6/> \*\*

### Other Helpful Items:

Key Talking Points – Page 3

Draft Senate Resolution – Pages 7-8

Sample Hearing Request Letter – Pages 11-13

Additional Resources – Page 18

# ME/CFS Advocacy Week – Key Talking Points

## Our Request - Senate

Senator Ed Markey is leading a Senate Resolution on ME/CFS. Ask your Senator to co-sponsor and support this resolution (draft resolution language on pages 7-8).

## Our Request - House

- 1) Please support our FY19 Appropriations requests and committee report language for ME/CFS as communicated in a 44 member sign-on letter on March 19, 2018. (see letter at: <https://solvecfs.org/wp-content/uploads/2018/05/FY19-ME-CFS-Research-FINAL-SIGNED.pdf>)
- 2) Please send a letter to the Energy and Commerce Subcommittee on Health requesting a hearing on the clinical care crisis of Americans with ME/CFS. (draft letter on pages 11-13)

## The Issue

MYALGIC ENCEPHALOMYELITIS (ME) ALSO KNOWN AS CHRONIC FATIGUE SYNDROME (CFS)

ME/CFS is a devastating multi-system disease that causes energy depletion on a cellular level and severe physical and cognitive limitations. The hallmark symptom is post-exertional malaise (a worsening of symptoms after activity), accompanied by cognitive dysfunction, unrestorative sleep, difficulty maintaining upright posture, profound cellular exhaustion or widespread chronic pain all made worse by exertion of any sort.

- ME/CFS is a chronic, complex, multi-systemic disease that profoundly limits your health and quality of life.
- The causes of ME/CFS are unknown
- ME/CFS can be fatal
- National Academy of Medicine in 2015 called “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.” This report created a new diagnostic criteria for ME/CFS and concluded that:
  - 1) ME/CFS is a serious physiological disease – not a mental health condition,
  - 2) “remarkably little research funding has been made available to study ME/CFS,”
  - 3) ME/CFS affects people from all ages, backgrounds, and ethnicities, and
  - 4) Women are 4x as likely to have ME/CFS.
- The US economic burden is \$17-\$24 billion in medical expenses and lost productivity due to patients’ inability to work.
- Up to 69% of people with ME/CFS are unemployed and up to 89% lost their job due to ME/CFS.
- 25% of people with ME/CFS are severe. Severe patients are often bed-bound and unable to do basic activities like eat, shower, or even stand on their own.
- People with ME/CFS have the lowest quality of life scores of any disease tested. Lower than stroke, heart attack, lung cancer, and renal failure.
- ME/CFS is “clinically indistinguishable from Gulf War Illness (GWI)...We hypothesize that GWI is a subset of CFS” – Dr. Nancy Klimas, Institute of Neuro Immune Medicine, leading ME/CFS and GWI researcher

## Sample E-mail: Sharing the online actions

Dear Family and friends –

As you know, I am passionate about fighting for ME/CFS research and awareness. The week of May 12<sup>th</sup> is ME/CFS Advocacy Week and hundreds of people with ME/CFS and their family and caregivers are traveling to Washington DC to demand action for ME/CFS.

I hope you will take 2 minutes to support this effort.

- Click here to [ask your Senators to take action.](#)

If you'd like to learn more about how you can be a part of ME/CFS Advocacy week – visit: <https://solvecfs.org/2nd-annual-cfs-advocacy-week/>

Sincerely,

{Your Name}

## Social Media Posts and Hashtags

- I support #MECFS patients on their Day of Awareness. Learn more about ME/CFS at [www.solvecfs.org](http://www.solvecfs.org)
- May is #MECFS Awareness Month. Up to 2.5 million Americans suffer with this awful disease. Learn more at [www.solvecfs.org](http://www.solvecfs.org)
- Take action to #MakeMayMatter4ME this #MECFS Awareness Month! Write to your senator <https://bit.ly/2KHixOm>
- Over 100 people with #MECFS and their loved ones are heading to Capitol Hill. I stand with them. Let's #MakeMayMatter4ME. You can take action to with this online tool <https://bit.ly/2KHixOm>
- [\[\[Find your congressman's twitter\]\]](#) May is #MECFS awareness month. Stand with people with ME in [{{YOUR STATE}}](#). #FundMECFSResearch

### Hashtags,

#MECFS  
#pwme  
#MakeMayMatter4ME  
#SolveMECFS  
#SeeMEnow  
#MillionsMissing  
#CanYouSeeMEnow

### Twitter tags,

@PlzSolveCFS  
@MEActNet

### and Links:

2-minute congressional action tool:  
<https://bit.ly/2KHixOm>

More information about ME/CFS Advocacy Week:  
<https://solvecfs.org/2nd-annual-cfs-advocacy-week/>

ME/CFS Advocacy Day Press Kit: [Click Here](#)

Visit the MillionsMissing social media tool kit at: <https://thesocialpresskit.com/meaction>

# ME/CFS Advocacy Week - Senate Action Guide

## Our Request - Senate

Senator Ed Markey is leading a Senate Resolution on ME/CFS. Ask your Senator to co-sponsor and support this resolution (draft resolution language on pages 7-8).

## Making a call to voice your support (Basic Advocacy)

1. Call the Capitol switchboard at 202-224-3121 to be connected to your Senator's office
  - \*Remember\* You have two senators so you will need to make this call twice.
2. Use the script below to make your request

Hello, my name is {your name} and I live in {City and State}.

I am calling to ask the Senator to co-sponsor Senator Markey's Resolution for myalgic encephalomyelitis, often called chronic fatigue syndrome, or ME/CFS.

ME/CFS is a devastating chronic illness. I have suffered (or my loved one has suffered) for XX of years. {Share your story in 15 seconds here!}

This resolution is key to raising awareness and spearheading action. I am asking Senator {Name} to please stand with us and become a co-sponsor of this resolution.

Please have your health staff contact Nikki Hurt in the office of Senator Ed Markey for more information.

3. Let us know how it went! Fill out this easy form at:  
<https://solvemecfs.wufoo.com/forms/p3b8bge0oi52u6/>

## Seeking out and/or E-mailing the Health Staff (Advanced Advocacy)

1. Call the Capitol switchboard at 202-224-3121 to be connected to your Senators
  - \*Remember\* You have two senators so you will need to make this call twice.
2. Ask who is the appropriate staff to speak to about health issues
  - Write down this person's name

3. Tell the staffer you have a health-related request and would like to speak this individual (they will likely offer a voicemail or to take a message) or, if possible, ask for their e-mail address to send your request.
4. If you leave a voicemail – see the script for Basic Advocacy above
5. If you get an e-mail address, see sample e-mail below.  
\*\*Don't forget to include the draft senate resolution language on pages 7-8 \*\*

Dear Mr./Ms. {Staffer's Last Name},

My name is {YOUR NAME} and I am a constituent of Senator {Senator's Last Name} from {City}. I (or my loved one) suffers from ME/CFS, a devastating chronic illness called myalgic encephalomyelitis, also known as chronic fatigue syndrome or ME/CFS.

{Share your story with ME/CFS here. 3-4 sentences}

Senator Ed Markey of Massachusetts is leading a Senate resolution about ME/CFS. I am asking Senator {Senator Last Name} to consider becoming a co-sponsor of this resolution.

You can find the draft language under consideration for this Resolution included in this e-mail.

For more information about the Resolution, please contact Niki Hurt in the office of Senator Markey at [Nikki\\_Hurt@markey.senate.gov](mailto:Nikki_Hurt@markey.senate.gov).

If you have questions about ME/CFS, you can reach the Solve ME/CFS Initiative's Director of Advocacy and Communications, Emily Taylor, at [etaylor@solvecfs.org](mailto:etaylor@solvecfs.org) or (704) 364 – 0016 x 209.

Thank you in advance for your consideration and support,

{Your Name}

**\*\*INCLUDE DRAFT LANGUAGE from Pages 7-8 HERE\*\***

6. Let us know how it went! Fill out this easy form at:  
<https://solvemecfs.wufoo.com/forms/p3b8bge0oi52u6/>  
or cc Emily Taylor ([etaylor@solvecfs.org](mailto:etaylor@solvecfs.org)) on your e-mail correspondence

## ME/CFS Advocacy Week – Draft Senate Resolution

### Supporting the goals of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome International Awareness Day.

Whereas the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine (referred to in this preamble as “HMD”), formerly known as the Institute of Medicine, has found Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (referred to in this preamble as “ME/CFS”) to be “a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients”;

Whereas between 836,000 and 2,500,000 individuals of all ages, races, and sexes in the United States are believed to be afflicted with ME/CFS, with millions more afflicted by ME/CFS worldwide, and the vast majority of individuals with ME/CFS are undiagnosed or misdiagnosed;

Whereas ME/CFS is approximately 4 times more prevalent in women than in men;

Whereas ME/CFS is a chronic disease that persists for decades and leaves 1/4 of individuals with ME/CFS housebound or bedbound, often for years;

Whereas 50 to 75 percent of individuals with ME/CFS cannot work or attend school;

Whereas medical expenses and lost productivity related to ME/CFS cost the economy of the United States \$17,000,000,000 to \$24,000,000,000 annually;

Whereas, in a recent study, individuals with ME/CFS scored more poorly in health-related quality of life surveys than individuals with any other disease measured;

Whereas individuals with ME/CFS have been found to be more functionally impaired than individuals with other disabling illnesses, including type 2 diabetes mellitus, congestive heart failure, hypertension, depression, multiple sclerosis, and end-stage renal disease;

Whereas the cause of ME/CFS is unknown, there is no diagnostic test for ME/CFS, and there is no treatment for ME/CFS that is approved by the Food and Drug Administration;

Whereas HMD has noted a “paucity of research” on ME/ CFS and that “more research is essential”;

Whereas individuals with ME/CFS struggle to find doctors who are willing and able to care for them and ME/CFS is included in less than 1/3 of medical curricula;

Whereas, in recognition of the dearth of research on ME/CFS and the profound impact that the disease has on individuals with ME/CFS and their loved ones and caretakers, the National Institutes of Health (referred to in this preamble as “NIH”) is “committed to unraveling the underlying biologic cause(s) of ME/CFS as swiftly as possible, and promoting

research that will inform the development of effective strategies for treatment and prevention of this devastating condition”;

Whereas, in 2017, eleven Institutes at NIH, that also participate in the Trans-NIH Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Working Group, in collaboration with the Office of the Director contributed more than \$7,000,000 in grants to assist in establishing Collaborative Research Centers and a Data Management Coordinating Center to improve the coordination of ME/CFS research and help accelerate understanding of ME/CFS; and

Whereas, in 2018, May 12 is recognized as International Awareness Day for ME/CFS and other neurological conditions: Now, therefore, be it

Resolved, That the Senate—

(1) supports the goals of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome International Awareness Day;

(2) recognizes and affirms the commitment of the United States to— (A) discovering the cause of, and a cure for, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; and (B) improving the availability and quality of medical care for individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; and

(3) encourages— (A) the National Institutes of Health and other Federal agencies to work with experts, stakeholders, and individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome to— (i) consider the recommendations of the National Academies of Sciences, Engineering, and Medicine relating to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; and (ii) support research to discover the cause of, and a cure for, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; and (B) the medical community to enhance practitioner training to provide appropriate and accessible care for individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.



# ME/CFS Advocacy Week - House Action Guide

## Our Request - House

- 1) Please support our FY19 Appropriations requests and committee report language for ME/CFS as communicated in a 44 member sign-on letter on March 19, 2018. (see this letter at: <https://solvecfs.org/wp-content/uploads/2018/05/FY19-ME-CFS-Research-FINAL-SIGNED.pdf> )
- 2) Please send a letter to the Energy and Commerce Subcommittee on Health requesting a hearing on the clinical care crisis of Americans with ME/CFS. (draft letter on pages 11-13)

## Making a call to voice your support (Basic Advocacy)

1. Call the Capitol switchboard at 202-224-3121 to be connected to your Representative's office
2. Use the script below to make your request

Hello, my name is {your name} and I live in {City and State}.

I am calling to ask Representative {Rep's last name} to help fight myalgic encephalomyelitis, often called chronic fatigue syndrome, or ME/CFS.

ME/CFS is a devastating chronic illness. I have suffered (or my loved one has suffered) for XX of years.

{Share your story in 15 seconds here!}

We greatly appreciate any support the Congressman can give during this year's appropriations process to support funding for ME/CFS research and programs.

Also, I am requesting that the Congressman write to the Energy and Commerce Subcommittee on Health and ask for a hearing on ME/CFS. There are fewer than 12 clinical care specialists with expertise in ME/CFS in the entire country to serve between 1 and 2.5 million people with this terrible disease. This is a clinical care crisis that must be addressed by the Health subcommittee.

3. Let us know how it went! Fill out this easy form at: <https://solvemecfs.wufoo.com/forms/p3b8bge0oi52u6/>

## Seeking out and/or E-mailing the Health Staff (Advanced Advocacy)

1. Call the Capitol switchboard at 202-224-3121 to be connected to your Representative
2. Ask who is the appropriate staff to speak to about health issues
  - Write down this person's name
3. Tell the staffer you have a health-related request and would like to speak this individual (they will likely offer a voicemail or to take a message) or, if possible, ask for their e-mail address to send your request.
4. If you leave a voicemail – see the script for Basic Advocacy above.
5. If you get an e-mail address, see sample e-mail below.

**\*\*Don't forget to include the sample request letter language on pages 11-13 \*\***

Dear Mr./Ms. {Staffer's Last Name},

My name is {YOUR NAME} and I am a constituent of Congressman {Representative's Last Name} from {City}.

I (or my loved one) suffers from ME/CFS, a devastating chronic illness called myalgic encephalomyelitis, also known as chronic fatigue syndrome or ME/CFS. {Share your story with ME/CFS here. 3-4 sentences}

Also, I am requesting that the Congressman write to the Energy and Commerce Subcommittee on Health and ask for a hearing on ME/CFS. There are fewer than 12 clinical care specialists with expertise in ME/CFS in the entire country to serve between 1 and 2.5 million people with this terrible disease. This is a clinical care crisis that must be addressed by the Health subcommittee.

You can find a sample letter for this request included with this e-mail.

If you have questions about ME/CFS, you can reach the Solve ME/CFS Initiative's Director of Advocacy and Communications, Emily Taylor, at [etaylor@solvecfs.org](mailto:etaylor@solvecfs.org) or (704) 364 – 0016 x 209.

Thank you in advance for your consideration and support,

{Your Name}

**\*\*INCLUDE SAMPLE LANGUAGE from Pages 11-13 HERE\*\***

6. Let us know how it went! Fill out this easy form at:  
<https://solvemecfs.wufoo.com/forms/p3b8bge0oi52u6/>  
or cc Emily Taylor ([etaylor@solvecfs.org](mailto:etaylor@solvecfs.org)) on your e-mail correspondence

# ME/CFS Advocacy Week – Sample Hearing Request Letter

May XX, 2018

The Honorable Michael Burgess  
Chairman  
Energy and Commerce Subcommittee on  
Health  
2125 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Gene Green  
Ranking Member  
Energy and Commerce Subcommittee on  
Health  
2125 Rayburn House Office Building  
Washington, D.C. 20515

Dear Chairman Burgess and Ranking Member Green:

I write to you today to request that the Energy and Commerce Subcommittee on Health hold a hearing to examine the clinical care crisis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). I ask this committee to review current agency efforts to combat this health crisis, hear first-hand from patients and their caregivers about the challenges and difficulties of living with this life-long chronic illness, and evaluate the crisis in clinical care for ME/CFS.

As you may know, ME/CFS is a complex, multi-system disease with no diagnostic tool, FDA-approved treatment, or cure. A 2015 report by the National Academy of Medicine estimated that ME/CFS disables between 836,000 and 2.5 million people in the United States, more than HIV/AIDs and Multiple Sclerosis (MS) combined.<sup>1</sup> Recovery is rare, estimated at 5-10%, and most patients suffer for life.

People with ME/CFS are more functionally impaired than those with congestive heart failure, stroke, and end-stage renal disease.<sup>2</sup> An estimated 54-69% are unable to work, at an economic cost to our country of \$17-\$24 billion per year.<sup>3</sup> The effects of ME/CFS include severe mobility impairment, widespread pain, cognitive deficiency, sleep disturbance, and post-exertional malaise. The causes of ME/CFS are unknown but have been linked to infection, physical trauma, and environmental factors such as neurotoxins.

The vast majority of the medical community globally knows nothing about the disease,<sup>4</sup> and millions of patients struggle to access medical care or they receive inappropriate care that can cause harm. An estimated 84-91% of ME/CFS patients have not yet been diagnosed. About 75% report that it took longer than 1 year to receive a diagnosis, and 25% said that it took more than 5 years.<sup>5</sup>

Unfortunately, a number of key policy deficiencies have contributed to this clinical care crisis. The Department of Health and Human Services (HHS), despite many requests and recommendations, has not developed a plan for addressing ME/CFS or incorporated ME/CFS into its existing planning processes. From 2014 - 2017, only approximately 7% of Chronic Fatigue Syndrome Advisory Committee recommendations

to the Secretary of HHS were implemented. The following points illustrate why your Committee's review and examination is critical:

- There are only about a dozen clinicians with expertise in treating ME/CFS in the United States, and many of them are nearing retirement. Their waiting lists are years long or have been closed. Most charge extremely high fees and do not accept insurance. Accordingly, very few patients -- and only the wealthy, well-connected, and those not too ill to travel -- receive medical care.
- Lack of an appropriate ICD/billing code impedes reimbursement and disease tracking.<sup>6</sup> This creates challenges for insurance coverage and reimbursement because this disease has been equated to the symptom of "chronic fatigue" in the United States. (Note: The World Health Organization classifies CFS as a neurological disease.<sup>7</sup>)
- Because ME/CFS is a multi-system disease, no medical specialty has taken responsibility for ME/CFS (e.g. rheumatologists). There is no clinical specialty working to provide guidance to health care providers with appropriate treatment recommendations.
- The National Academy of Medicine reported that doctors recommend treatments that can exacerbate symptoms and treat patients with hostility; the main barrier to disseminating updated diagnostic guidelines is medical provider attitude.<sup>8</sup>
- Even prestigious medical organizations (e.g. the Mayo Clinic, UCSF, and Kaiser) have no treatment programs and often do not recognize ME/CFS as a physical disease. Major medical associations typically either neglect the disease or provide inaccurate information.
- Private and government disability and accommodations in schools are difficult to obtain. The Social Security Administration reports that less than 14,000 people receive ME/CFS disability -- out of 836,000 to 2.5 million Americans with ME/CFS, most of whom cannot work.<sup>9</sup> Patients report similar challenges with private disability. Parents have reported difficulties obtaining school accommodations. Although the Centers for Disease Control (CDC) and Department of Education have developed information for school systems; general misinformation and false narratives about the disease remain.<sup>10</sup>

This year marks the 30th anniversary of the first published Chronic Fatigue Syndrome case definition in the United States.<sup>11</sup> This is a key opportunity for the Committee to review the state of what the CDC has labeled "America's Hidden Health Crisis" and call for an accelerated federal response and formalized plan to address the crisis. Given the suffering and bleak outlook for millions of Americans with ME/CFS -- and this Committee's jurisdiction over private and public insurance, biomedical research and development, and the agencies of HHS, including the NIH and CDC -- an oversight hearing should be called to examine progress, patient experience, and clinical care needs for this vulnerable population and to identify the timeline for delivering needed diagnostics, treatments, and appropriate clinical care.

Sincerely,

[Your member of congress]

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<sup>1</sup> “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” National Academy of Medicine (Institute of Medicine of the National Academies, IOM) Final report May 2015, <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>, p. 1

<sup>2</sup> Falk Hvidberg M, Brinth LS, Olesen AV, Petersen KD, Ehlers L (2015) The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). PLoS ONE 10(7): e0132421. <https://doi.org/10.1371/journal.pone.0132421>

<sup>3</sup> “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” National Academy of Medicine (Institute of Medicine of the National Academies, IOM) Final report May 2015, <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx> p 1

<sup>4</sup> “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” National Academy of Medicine (Institute of Medicine of the National Academies, IOM) Final report May 2015, <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>, p. 16, 30, 233-234, NIH P2P Workshop report, p.4

<sup>5</sup> ibid

<sup>6</sup> IACFS/ME Proposal to Change the ICD code for CFS. <http://iacfsme.org/PDFS/2017AugustNewsletter/Proposal-for-modifications-to-ICD-10-IACFSME-July.aspx>

<sup>7</sup> IACFS/ME Proposal to Change the ICD code for CFS. <http://iacfsme.org/PDFS/2017AugustNewsletter/Proposal-for-modifications-to-ICD-10-IACFSME-July.aspx>

<sup>8</sup> “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” National Academy of Medicine (Institute of Medicine of the National Academies, IOM) Final report May 2015, <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>, p. 16, 29, 30, 233-234, NIH P2P Workshop report, p.4

<sup>9</sup> At the December 2015 CFS Advisory Committee (CFSAC), Social Security Administration staff said that less than 14,000 people have SSA disability for CFS

<sup>10</sup> CFSAC June 2017 report on Pediatric Needs of ME/CFS Student. <https://www.hhs.gov/sites/default/files/2017-06-cfsac-meeting-presentation-supporting-pediatric-needs.pdf>

<sup>11</sup> “Chronic Fatigue Syndrome: A Working Case Definition” HOLMES, GARY P.; KAPLAN, JONATHAN E. *Annals of Internal Medicine*, The American College of Physicians. Mar 1, 1988

## ME/CFS Advocacy Week – Local Advocacy Guide

If you are interested in leading advocacy work in your local area, there's many opportunities to connect your neighborhood, city, county, or state efforts to the work of ME/CFS Advocacy Week and the national efforts in Washington DC.

### Holding a Congressional Meeting at the District Level:

Check out last year's ME/CFS Advocacy Week's local training videos for a step-by-step guide to scheduling and conducting a district-level meeting.

The first video training includes instructions and samples for making a meeting request, scheduling your meeting, preparing for your meeting, and telling your story.

- Webinar – How to plan your local advocacy District Training: <https://youtu.be/awLjiYhexQ>
- Webinar Slides: How to plan your local advocacy District Training [DOWNLOAD HERE](#)

The second video training focuses on how to conduct your meeting with sample outlines, best practices, conversation tips, and more. Please review the asks and key talking points for this year's ME/CFS Advocacy week on Page 3.

- Webinar – How to conduct your local advocacy: <https://youtu.be/ba5zgzklexP8>
- Webinar Slides: How to conduct your local advocacy District Training: [DOWNLOAD HERE](#)

### Requesting a City or State Proclamation for ME/CFS Awareness:

Local governments across the United States are standing up to recognize, and raise awareness for, ME/CFS. Here's a guide to securing a proclamation in your city or state. You can also view this guide at: <https://solvecfs.org/mecfs-city-or-county-proclamation-guide-2/>

May 12 is a great opportunity to get recognition of ME/CFS in honor of International ME/CFS Awareness Day. You can also request a proclamation for August 8 which is Severe ME Understanding and Remembrance Day. Both are great opportunities to get your city, county, parish, or state to join the cause!

#### Step 1: Identify your targets

First, you'll need to identify who you need to contact. For city proclamations, you will want to target your mayor and the members of your city council. For county-level proclamations, you will want to target your county administrator (which may go by other names, such as "chief executive," "county manager," or "administrative services director") and your local board of supervisors. For a State level proclamation, you'll need to seek out your Governor.

A quick Google search of your city/county/state name plus the relevant office should get you to the correct information.

## **Step 2: Send in your request**

Use the sample letter and sample proclamation below to draft your request. The more personal you can make it, the better. You can estimate the number of ME/CFS patients in your city or county by taking the total population of your area and dividing it by 200.

### ***Sample Proclamation Request***

[Date]

Honorable [Name]

[Official Title]

[Mailing Address]

Dear [Name]:

August 8 is Understanding and Remembrance Day for Severe Myalgic Encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS). This day provides an excellent opportunity for our [city/county/state] to demonstrate its support in raising awareness of this devastating disease and of the numerous patients who are among us. Moreover, it is a wonderful opportunity to educate the public on the seriousness of ME/CFS and the prevalence of this devastating disease in our community.

I would be honored if you would sponsor an official proclamation to recognize August 8 as Understanding and Remembrance Day for Severe Myalgic Encephalomyelitis. Your proclamation would lend official recognition to the important work of educating the public on ME/CFS as well as emphasize your personal commitment to ending this disease. I have enclosed a sample proclamation that may help your office compose the appropriate proclamation for our [city/county/state].

[Write a short paragraph about how ME/CFS has impacted your life.]

If you or your staff have any questions concerning the request, the sample proclamation, or ME/CFS, please visit [www.solvecfs.org](http://www.solvecfs.org) or call me at [telephone number]. I will follow-up with your office on this request in the next few days. As always, we appreciate your support of ME/CFS and our community.

Thank you for your consideration on this special request.

Sincerely,

{Your Name and Contact information}

Enclosure (1) – Sample Proclamation

***Sample Proclamation Language – To Enclose with Request***

Certificate of Recognition (or Proclamation, or....)

is hereby presented to (for)

Myalgic Encephalomyelitis, Chronic Fatigue Syndrome Awareness Day (or Understanding and Remembrance Day for Severe Myalgic Encephalomyelitis)

WHEREAS, Myalgic Encephalomyelitis (ME), sometimes called Chronic Fatigue Syndrome (ME/CFS) is a neurological and/or neuroimmune disease characterized by overwhelming fatigue, “brain fog,” pain, post-exertional malaise, headaches, cardiac symptoms, immune disorders, dizziness, balance problems, increased morbidity, and eventually high suicide rates due to neglect, and it is perhaps the most common chronic disease causing students to drop out of high schools and colleges, sometimes indefinitely; and

WHEREAS, these illnesses affect men, women, and children of all backgrounds. Once diagnosed one is often ill for years or a lifetime, and most never recover fully; and

WHEREAS, over 20 million individuals worldwide, 2 million in the US, perhaps [population / 200] in **city (state, county, parish...)**, are afflicted by the above chronic neuroinflammatory illnesses; and

WHEREAS, the economic impact of ME/CFS is estimated to be approximately \$20-50 billion dollars per year (CDC Feb 2016, Grand Rounds); and

WHEREAS, awareness will lead to increased NIH and private funds for R&D and necessary services to end the decades of misplaced stigma and discrimination that accompanies these medical diseases:



NOW, THEREFORE, I, [Mayor, City Council, Chief Executive... name], mayor of the city of [City name], do hereby proclaim May 12, 2018, Myalgic Encephalomyelitis, Chronic Fatigue Syndrome Awareness Day (or Understanding and Remembrance Day for Severe Myalgic Encephalomyelitis) in order to help spread awareness of the disease and the need for early diagnosis and to support individuals living with Myalgic Encephalomyelitis, Chronic Fatigue Syndrome.

### **Step 3: Follow up with your contacts**

After you submit your letter and sample proclamation, you should make a follow-up phone call with the office to confirm they have received your submission. Often, they will have misplaced it and you will have to send it again. Once you have confirmed they have received the request, follow up with a respectful request for the status of your request about once a week. Eventually, your request will be denied, scheduled, or granted. The administrator will give you appropriate guidance about picking up your proclamation.

If you or fellow advocates feel well enough, you can also schedule to have the proclamation presented to you at a city council (or similar) meeting to gain added exposure to the full city council and their audience. Ask to schedule this, and see if you can perhaps have a few minutes to tell attendees how this disease has personally affected you or people you know. If possible, have someone take a photo.

### **Step 4: Let us know you were successful**

Once you have successfully secured your city or county proclamation, please contact Emily Taylor of Solve ME/CFS Initiative at the email address above to let us know about your success! Send us a picture of your proclamation (or a PDF), and we will add your city to a growing list of cities and counties that are joining the cause.

You can see a list of current cities here: [http://me-pedia.org/wiki/United\\_States\\_proclamations](http://me-pedia.org/wiki/United_States_proclamations).

### **Connect with a Local #MillionsMissing Action:**

This May 12th, patients, families, and allies will gather around the globe to demand action for people living with ME. #MEAction #MillionsMissing visibility actions will inundate social media. Key figures and organizations from ally communities, such as disability rights and chronic illness, will join our fight and bolster our message at in-person events and on social media. Find a local action near you and learn more at:

<https://millionsmissing.meaction.net/>

#MEAction is a global health network for people with Myalgic Encephalomyelitis, also known as chronic fatigue syndrome.

## Create a Regional Resource Guide for people with ME/CFS:

As you know, there are remarkably few resources available for patients with ME/CFS. You can help by creating a regional resource guide with a variety of sources that may prove helpful to patients including medical services, doctors, disability assistance groups, chronic illness support groups, in-home support services and more. We'd like to see these guides be everything a newly diagnosed patient in your area needs to help them find the best care and support possible on their journey with ME/CFS.

You can learn more at: <https://solvecfs.org/wp-content/uploads/2018/02/3.-Join-our-Team-POSITION-DESCRIPTION-Resource-Researcher.pdf>

## Additional Resources:

- *One page summary about ME/CFS (PDF)*  
This one page infographic about ME/CFS highlights the key statistics about the disease – it can be helpful to send to new contacts who are not familiar with ME/CFS
  - [https://solvecfs.org/wp-content/uploads/2018/01/SMCI\\_infographic-Dec2017.pdf](https://solvecfs.org/wp-content/uploads/2018/01/SMCI_infographic-Dec2017.pdf)
- *About SMCI 1-Page Summary (PDF)*  
A simple one page handout that summarizes the work of the Solve ME/CFS Initiative
  - [https://solvecfs.org/wp-content/uploads/2018/05/SMCI\\_TWO\\_PAGER\\_041618\\_PRINT.pdf](https://solvecfs.org/wp-content/uploads/2018/05/SMCI_TWO_PAGER_041618_PRINT.pdf)
- *State and District ME/CFS Data (Google Drive)*  
This link brings you to a data-set where you can look up the estimated prevalence rates of ME/CFS for each state and district. This information may be helpful when making your request.
  - <https://docs.google.com/spreadsheets/d/1QX4fxZtL2BPPD-i3WsqLogisyU2b35SyiBVshs1Q858/>
- *[Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.](#)*  
February, 2015. One of the most comprehensive reports regarding ME/CFS, this report was published by the National Academy of Medicine and includes a diagnostic criteria, clinicians guide, and comprehensive literature review.
  - [Report Summary](#) (PDF)
  - [Report Key Facts](#) (PDF)
- *Signed March 2018 House Appropriations Letter – 43 Representatives Joined*  
This is the full FY 19 appropriations request letter in the House of Representatives signed by 43 members requesting funding restoration for ME/CFS and committee report language favorable to ME/CFS research, clinical care, and awareness.
  - <https://solvecfs.org/wp-content/uploads/2018/05/FY19-ME-CFS-Research-FINAL-SIGNED.pdf>

- *Faces of ME/CFS (PDF)*

This shares four stories of people with ME/CFS to highlight the devastating impact of the disease – It can be helpful to send to new contacts who are not familiar with ME/CFS

- [https://solvecfs.org/wp-content/uploads/2018/05/Faces\\_MECFS\\_Printer\\_042618.pdf](https://solvecfs.org/wp-content/uploads/2018/05/Faces_MECFS_Printer_042618.pdf)

- *ME/CFS Advocacy Day Capitol Hill Reception Invitation (PDF)*

A formal invitation to the ME/CFS Capitol Hill reception on May 15<sup>th</sup> – Great item to share with staff or members when contacting prior to the event.

- <https://solvecfs.org/wp-content/uploads/2018/05/MECFS-Reception-Invite.pdf>