



congress@meaction.net

## **URGENT ADVOCACY REQUEST/ CALL TO ACTION**

We are proud to announce that U.S. Representatives Zoe Lofgren (CA-19) and Anna Eshoo (CA-18) have agreed to co-sponsor a U.S. House of Representatives letter to National Institutes of Health (NIH) Director Francis Collins. The letter solicits information about the NIH's current and future ME/CFS program and encourages the NIH to strengthen ME/CFS biomedical research efforts (ME/CFS is the Representatives' preferred terminology). The language in the letter was drafted by the two Congresswomen's offices and is NOT subject to change.

The letter is currently being circulated for additional signatures in the U.S. House of Representatives.

We need your help to add your representative's signature to the letter. We are running on a deadline of representatives' sign-on due by this Wed, Sep. 7th, and need you to contact your representative **ASAP**.

### **Steps:**

- 1) Identify your U.S. House of Representatives Member**
- 2) Call your U.S. House of Representatives Member**
- 3) Email your U.S. House of Representatives Member**

## Step 1: Find your House of Representatives Member:

To find your U.S. House of Representatives member, you may visit <http://www.house.gov/representatives/find/>

Please note that this action is for REPRESENTATIVES ONLY, **NOT** SENATORS. **Please do NOT contact your senator about this letter. We hope to have another letter available for senators to sign at a later date.**

## Step 2: Call your House of Representatives Member:

**NOTE:** You may be asked for your exact address -- including zip+4 – to determine whether or not you are a constituent. You can get your zip +4 at: [https://tools.usps.com/go/ZipLookupAction\\_input](https://tools.usps.com/go/ZipLookupAction_input))

Use this script:

My name is \_\_\_\_\_. I'm a constituent in \_\_\_(city)\_\_\_ and a volunteer with MEAction. I am calling with an urgent request for Representative \_\_\_\_\_ to sign on to a letter to the National Institutes of Health, sponsored by Representatives Lofgren and Eshoo of California. The letter supports the 1 to 2.5 million Americans like me [my sister/friend/etc] who are afflicted with the disabling, and costly disease Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome or ME/CFS. ME/CFS has no known cure or FDA-approved treatment, even though it can leave patients bedridden for decades.

May I be connected to your health legislative assistant?

[Click here if they say YES](#)

[Click here if they say NO](#)

If no:

**Leave a message with the intern or staff member.** FEEL FREE TO BRIEFLY DESCRIBE YOUR OWN STORY. REGARDLESS, YOU SHOULD ADD:

The deadline for signing on to Representatives Lofgren and Eshoo's letter to the NIH is Sep. 7. I will email (or fax) your office [the letter](#) and a [fact sheet](#) explaining why the letter is so critical. You may contact **Angela Ebner**, Legislative Assistant for Congresswoman Lofgren, at Angela.Ebner@mail.house.gov or (202) 225-3072 to coordinate your participation.

It would mean the world to me, my family, and other ME/CFS patients in our district to have Representative \_\_\_\_'s support. May I call back tomorrow to find out if Representative \_\_\_\_ will sign this letter?

If yes:

[If the legislative health aide picks up, read on or click here.](#)

[If you get the answering machine, click here.](#)

Use the same script with the legislative health aide:

My name is \_\_\_\_\_. I'm a constituent in     (city)     and a volunteer with MEAction. I am calling with an urgent request for Representative \_\_\_\_\_ to sign on to a letter to the National Institutes of Health, sponsored by Representatives Lofgren and Eshoo of California. The letter supports the 1 to 2.5 million Americans like me [my sister/friend/etc] who are afflicted with the disabling, and costly disease Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome or ME/CFS. ME/CFS has no known cure or FDA-approved treatment, even though it can leave patients bedridden for decades.

*You may also use the talking points on the [#MEAction Fact Sheet](#) for a short meeting.*

The legislative aide does not pick up.

**Leave a brief voicemail for the Health Legislative Assistant.**

Use this script:

My name is \_\_\_\_\_, and I am constituent and volunteer with MEAction. (I /my loved one suffer(s)) from the debilitating disease Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome or ME/CFS, which has no known treatment, or cure. I would like Representative \_\_\_\_\_ to sign on to a letter addressing NIH Director Francis Collins, in support of ME/CFS patients and research. The letter is sponsored by Representatives Lofgren and Eshoo of California. The deadline for signing on to the letter is Sep. 7. Please call me back at \_\_\_\_\_. I will also email your office a draft of the letter, and will call back tomorrow to confirm that you received it. Thank you, and have a wonderful day.

### **Step 3: Write your House of Representatives Member:**

If you are provided with an email address, you may use the email draft below and attach the Fact Sheet, [which you can access by clicking here](#). If not, you can use the Representative's website form to send the draft email.<sup>1</sup>

#### **EMAIL BLAST**

Dear [Staffer's Name],

I'm emailing with an urgent request regarding the disabling neuro-immune disease Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome or ME/CFS. Representatives Lofgren and Eshoo of California are sponsoring a letter to NIH Director Francis Collins in support of ME/CFS patients and research. ME/CFS costs the U.S. economy \$17-24 billion annually; leaves its patients with lower quality of life scores than lung cancer, stroke, and rheumatoid arthritis; and has no known FDA-approved treatment or cure. Would you please support me and the 1 to 2.5

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<sup>1</sup> If you have called your representative previously, please keep your name consistent. For example, if you have used a nickname in the past, continue to do so.

million Americans suffering from this disabling disease, by signing this letter? It would mean the world to me, my family, and other ME/CFS patients in our district to have your support.

The final language for the letter to Director Collins is attached, as is a short fact sheet explaining why the letter is so critical. Please contact Angela Ebner, Legislative Assistant for Rep. Zoe Lofgren (CA-19) at [Angela.Ebner@mail.house.gov](mailto:Angela.Ebner@mail.house.gov) or (202) 225-3072 to coordinate your participation. The letter's deadline is 9/7.

Thank you so very much for your support on this critical action. I look forward to your reply on this request at your earliest convenience.

Warmest Regards,

[Your Name]

[Your Contact Info, Including address and +4 zip]

Access the [letter to NIH Director Francis Collins by clicking here](#) and send along with the above.

You can also access the [fact sheet by clicking here](#).

**Thank you for all your hard work – we can make a difference by fighting in small but significant ways for better treatment, better funding, and better medical education for ME/CFS patients.**