

To: National Center for Health Statistics, U.S. Centers for Disease Control and Prevention
Subject: Fix the catastrophic lack of ME/CFS case tracking in the U.S!

We have collected the following [redacted] petition signatures from the ME/CFS community in support of the [joint proposal](#) submitted by our seven organizations* calling on the National Center for Health Statistics (NCHS) to fix the coding of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in the US International Classification of Diseases (ICD-10-CM).

Today, 1-2.5 million Americans with ME/CFS are invisible in US mortality and morbidity tracking and in US research using electronic health records. This is the direct result of ICD-10-CM coding because the term ME/CFS, adopted federally and in US clinical guidance, is not listed at all while the term CFS, which most US doctors still use, has the same code as the symptom of “chronic fatigue, unspecified.”

Previous proposals were submitted in 2011, 2012, and 2018 to NCHS to fix this problem. But all three were rejected because of a lack of consensus on how to resolve it, particularly regarding the term “chronic fatigue syndrome.” To avoid having a fourth proposal rejected, the seven organizations have submitted a [new proposal](#) (**) that asked for the most basic changes possible - to add the term ME/CFS and to expand the G93.3 category to encompass non-viral causes.

To the organizations’ proposal, NCHS then recommended [additional ICD-10-CM coding changes](#). These include changes that resulted in previous proposals being rejected because of lack of stakeholder consensus on how to resolve the coding problem. We acknowledge and appreciate the concerns raised about these additional changes. But we are calling on NCHS to at least approve the seven organization’s proposal as submitted (**) even if there’s a lack of consensus on some of the additional coding changes NCHS proposed. **We also call for this change to be done in the April 2022 update if at all possible because we are currently unable to track those patients who develop ME/CFS following COVID-19.**

Especially now with the potential tsunami of new ME/CFS cases that could develop following COVID, it is imperative that we finally fix the ICD coding of ME/CFS. **After 10 years, we must find a way to finally start tracking this devastating disease.**

*The seven organizations include: International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, Open Medicine Foundation, Solve M.E., #MEAction, Massachusetts ME/CFS & FM Association, Minnesota ME/CFS Alliance, and Pandora Org

** The [changes proposed](#) by the seven organizations include:

- Expand the lead term for G93.3, post-viral fatigue syndrome to accommodate non-viral causes of ME/CFS
- Remove “benign” from the term “myalgic encephalomyelitis”
- Provide separate subcodes (G93.3n) for post-viral fatigue syndrome and myalgic encephalomyelitis
 - Per ICD convention, we also proposed a subcode for “other” conditions outside these.
- Add the terms “myalgic encephalomyelitis/chronic fatigue syndrome” and “ME/CFS” as inclusions (essentially a synonym or related condition) of myalgic encephalomyelitis because this is the term adopted in the US
- Revise and add exclusion terms as needed

Petition Signers: