

Press Release

FOR IMMEDIATE RELEASE – August 23, 2021

**SEVEN SIGNIFICANT ORGANIZATIONS PROPOSE CRITICAL CODE CHANGE TO
CDC'S ICD-10, ADDRESSING CATASTROPHIC LACK OF ME/CFS CASE TRACKING IN THE U.S.**

Without action, millions of Americans' medical data will continue being mislabeled and lost, especially as Long COVID cases exponentially increase.

LOS ANGELES, C.A. — It's estimated that approximately 2.5 million Americans currently suffer from myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), often a post-infection disease. Yet there's no way for those in the medical system to properly code and track the disease in the U.S., meaning critical data is lost forever.

This affects not only current cases of ME/CFS, but also *millions* of anticipated new cases of Long COVID following COVID-19 infections, many of whom are very similar to ME/CFS. The need for code correction has never been more urgent and now numerous organizations are asking the Centers for Disease Control (CDC) to do just that.

“This is an urgent call to action from our organizations. with this important new proposal,” said Oved Amitay, President and CEO of Solve M.E. “This collective effort demonstrates consensus and expedience. If the CDC doesn't fix this code, we'll be in dire straits as COVID-19 triggers millions of additional ME/CFS cases.”

Here's why.

The United States, and much of the world, uses a standardized system called the International Classification of Diseases (ICD) to code all diseases in medical records. This allows mortality and morbidity data to be consistently coded and tracked. While the World Health Organization recently released an updated version of its ICD, the U.S. and most countries still use ICD-10.

The CDC's version of ICD-10 (ICD-10-CM) doesn't have a code for ME/CFS, even though U.S. federal agencies and numerous medical education providers have widely adopted it. In the absence of a code for ME/CFS, there's no way to track its mortality and morbidity or *its*

relationship to Long COVID cases. Instead, since 2015, U.S. doctors have been forced to diagnose *either* CFS or ME - and they invariably choose chronic fatigue syndrome. In the US, CFS is equated to the symptom of chronic fatigue, further obscuring vital prevalence data.

“This issue is a moral imperative. America is the only country in the world that doesn’t properly classify this disease,” said Dr. Lily Chu, Vice President of the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. “As we now see an explosion of new ME/CFS cases linked to COVID-19 and Long COVID, we must correct this before critical data is lost forever.”

Not only is it impossible to track and report on the mortality and morbidity of ME/CFS, but the codes impact insurance reimbursement, use of electronic health records in retrospective research, generating statistics on disease burden and outcomes, and the medical perception of ME/CFS.

Seven highly influential advocacy, education, and research organizations banded together and are urgently demanding change. They submitted a joint proposal to the CDC requesting the following:

1. Add ME/CFS to the neurological chapter of ICD-10-CM as an inclusion of ME
2. Expand the lead term “postviral fatigue syndrome” to allow for non-viral triggers
3. Add a subcode for postviral fatigue syndrome that is separate from that for ME, because ME is not always post viral

What’s next?

On September 14-15, 2021, the CDC’s National Center for Health Statistics will consider the joint proposal. All seven organizations strongly urge the CDC to adopt these proposed coding changes.

The seven organizations are:

1. [International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis](#)
2. [Massachusetts ME/CFS & FM Association](#)
3. [#MEAction](#)
4. [Minnesota ME/CFS Alliance](#)
5. [Open Medicine Foundation](#)
6. [Pandora Org](#)
7. [Solve M.E.](#)

What is ME/CFS?

ME/CFS is a chronic, complex, disease that profoundly limits the health and productivity of patients. It causes neurological, immune, autonomic, and energy metabolism impairment. Symptoms can include extreme exhaustion at the cellular level (exacerbated by activity), an intolerance to exertion, problems being upright, pain, cognitive impairment and extreme sensitivity to light and sound. As many as 75% can't work and an estimated 25% are homebound or bedbound. There is no cure, nor are there any FDA-approved drugs or treatments.

MEDIA INQUIRIES ONLY CONTACT

Stephanie Worrell

Sedulo Communications on behalf of Solve M.E.

Direct: 208.484.9470

Email: stephworrell@thinksedulo.com

More About the Seven Organizations:

This coalition of seven organizations works with people with ME/CFS and Long Covid and is composed of influential ME/CFS patient-advocates, medical providers, and scientists.