



Solve ME/CFS Initiative

Leading the Fight to cure ME/CFS

Statement by Solve ME/CFS Initiative President and CEO Carol Head on the naming and definition challenges of Myalgic Encephalomyelitis (ME)

October 31, 2018

Several weeks ago, I committed that I would expand on a short tweet our organization sent regarding our stance on the naming and definition of Myalgic Encephalomyelitis (ME), previously known as Chronic Fatigue Syndrome (CFS). We noted that it is difficult to engage in meaningful dialogue on Twitter, especially on issues that are nuanced and about which we all feel so deeply. We at the Solve ME/CFS Initiative (SMCI) are wholly committed to ending the suffering of those with ME/CFS. As a national organization conducting both advocacy and research efforts, we must recognize the complexity and multi-faceted impact of naming and definitions. ME/CFS faces many challenges in those areas.

Regarding the definitions of the disease, we do support the Canadian Consensus Criteria (CCC) and International Consensus Criteria (ICC). We reject The Fukuda Criteria and many other definitions that have been put forward in the past that are either too narrow or too wide. In evaluating research proposals that SMCI selects for funding or other research support mechanisms, the definition criteria of ME used in those proposals is critically important in our decision making process. Our highly experienced and knowledgeable Research Advisory Council, staff, and patient-inclusive peer review processes are well versed in the definition concerns of study protocols. In some instances, we rely on the trusted clinical knowledge of deeply experienced ME/CFS clinicians.

We find the *clinical diagnostic criteria* in the 2015 Institute of Medicine (IOM)/National Academy of Medicine (NAM) report, "[Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#)" to be helpful, although not definitive. The report itself was a key stepping stone to galvanizing improved, though not nearly adequate, federal government response. Looking at the current crisis in ME clinical care in the United States and the vast number of misinformed and under-educated clinicians who see ME patients, the diagnostic criteria in the IOM/NAM can be helpful to THOSE clinicians. **For the many clinicians who lack even basic knowledge, it's good to provide something simple which may actually be used.** The IOM/NAM *clinical* definition, while overly simplistic, fulfills this need. The IOM/NAM clinical guidance is a significant improvement from the common clinical care that most patients receive, which primarily consists of sending people with ME away, telling them they suffer from a psychological problem, or simply ignoring them. We hope the NAM/IOM will continue to be an educational tool in improving clinical care for ME patients.

That being said, we do not consider the IOM/NAM definition appropriate for research use. It was never intended for that purpose.

Regarding the name of the disease, our organization prefers the term Myalgic Encephalomyelitis (ME), but also continues to use the former terminology Chronic Fatigue Syndrome (CFS) and generally uses "ME/CFS" as it is the most common American usage in government, research, and



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the broader community. As a bridge building organization, it is our imperative to embrace the vocabulary common to broad audiences and the general public. We use both terms to be collaborative and inclusive.

For example, we used the term “Chronic Fatigue Syndrome” in our [Times Square advertisement](#) two years ago. We made this decision consciously in order for the advertisement to be effective. Despite our deep disdain for the words “Chronic Fatigue Syndrome,” we need to communicate broadly to people using language that will have meaning to them. Although we disdain it, many people in the United States know only of CFS. So, a billboard labeled ME would have done virtually nothing to change public perceptions of the disease. With such limited resources at our disposal, we need to be EFFECTIVE in communicating to the general public. This ad was effective in doing so.

As an aside, we got a very deep discount on the cost of the Times Square ad and it was borne by a single donor who liked the ad we created. We did not spend any of our other donors’ money on this. We are very careful about being prudent, wise, frugal stewards of our donors’ precious contributions.

Regarding the use of the terms on our website, we again are using terminology with the intention of reaching audiences more broadly. We want the millions of people who still (wrongly!) know this disease as “chronic fatigue syndrome” to **find our site, to get educated**, and find the information they are desperately looking for. Therefore, this is again a communications issue.

Our recent materials, generally use language such as “ME (formerly referred to as CFS)” so that we both help the reader understand the disease we are talking about (CFS) and clearly signal that the CFS label is obsolete.

Regarding the name Systemic Exertion Intolerance Disorder (SEID), we do not generally use it and we prefer the term ME. As SEID relates to the IOM/NAM report, we have not adopted that recommendation of the report. However, we do believe in the core message of the IOM/NAM report – ***That ME is a serious, debilitating chronic physical (not psychological) disease.*** That message from an internal government source was a significant breakthrough for the disease. This primary finding in the IOM/NAM report has been the key factor in changing the minds of powerful individuals (government officials, researchers, clinicians, policymakers) and the report is a powerful tool. Combined with effective, targeted advocacy and improved scientific understanding, the report is a key reason for the advances in ME demonstrated in the last three years.

In conclusion, the issues and complexities surrounding both the name and the definition of ME/CFS are many and continue to have cross-cutting impacts on much of the work we do. But at SMCI, we continue to be focused forward, toward a cure.



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I hope this statement helps explain the position and actions of our organization and illuminates the many ways in which SMCI produces real results for those with ME. Some may not agree, but we are all on the same side in this difficult battle against an insidious disease. SMCI works very hard, in good faith with many partners and continues to educate our public and private collaborators about these many complexities and challenges within ME/CFS. We respect the intent of all in our ME/CFS community to help those who suffer with this disease as we at SMCI work to broaden the understanding, impact, and most importantly funding for ME/CFS research and clinical care.

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About Solve ME/CFS Initiative

SMCI is a non-profit disease organization that accelerates the discovery of safe and effective treatments for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), works aggressively toward expansion of research funds, and engages the ME/CFS community in research, advocacy and patient support. SMCI is the foundational ME/CFS organization, steadily broadening strategic, collaborative relationships with patients, researchers, government officials and other ME organizations across the globe.

www.solvecfs.org