



POSITION PAPER ME INTERNATIONAL

Myalgic Encephalomyelitis is a Distinct Neurological Disease

ME International Supports Adoption of the #MEICC¹ & #MEICPrimer²

Introduction

Much has been written^{3,4,5} and discussed about diagnosing myalgic encephalomyelitis (ME), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), chronic fatigue syndrome (CFS) and systemic exertion intolerance disease (SEID aka ME/CFS).

Here we clarify ME International’s position on whether ME, CFS, CFS/ME, ME/CFS, and ME/CFS-SEID are the same disease and whether the diagnostic criteria for ME, CFS, CFS/ME, ME/CFS, and ME/CFS-SEID select the same group of patients. The non-standardized and overlapping definitions in the USA and other countries have resulted in an inability to compare results of multiple studies because those suffering from chronic fatigue unspecified (ICD code R53.82) and other vague criteria are mixed in with those suffering from ME (ICD G93.3).⁶

Background

ME, CFS, ME/CFS, and ME/CFS-SEID are the recognized diagnostic criteria in the USA⁷:

1988	CFS	Holmes, CDC
1994	CFS	Fukuda, CDC
2003	ME/CFS	Canadian Consensus Criteria (CCC)
2011	ME	International Consensus Criteria (ICC)
2015	SEID (uses ME/CFS label)	Institute of Medicine (IOM) (Now NAM)

As stated in the 2012 ME IC Primer, the ICC advances the successful strategy of the CCC of grouping coordinated patterns of symptom clusters that identify areas of pathology. CCC is the precursor to the ICC and is closely aligned with the definition of ME as a distinct neurological disease separate from CFS and ME/CFS-SEID.

The IC Primer defines ME as:
“Profound dysfunction/dysregulation of the neurological control system results in faulty communication and interaction between the CNS and major body systems, notably the immune and endocrine systems, dysfunction of cellular energy metabolism and ion transport, and cardiac impairments.” (International Consensus Primer pg.1).



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In 2011, the International Consensus Criteria panel consisted of clinicians, research investigators, teaching faculty, and an independent educator. They represented diverse backgrounds, medical specialties and worldwide geographical regions. Collectively, the members of the panel diagnosed and/or treated more than 50,000 ME patients and their expertise represents more than 500 years of clinical experience. (IC Primer pg. ii)

In 2015, against the requests of experts, patients and stakeholders⁸, the Institute of Medicine (IOM renamed as National Academy of Medicine) convened a committee that led to a broad criteria based on research focused on CFS studies from approximately 2004 to 2014.⁹ This narrow focus resulted in a lack of recognition for the cause of symptoms seen in patients who fit an ME criteria. This IOM report proposed new diagnostic criteria that they determined would facilitate a simplified diagnosis of those who fit this broad criteria and recommended renaming this combined group of ME and CFS patients as having systemic exertion intolerance disease (SEID). MEadvocacy.org compared the ICC to the IOM criteria in a chart which shows the inadequacy of using the IOM diagnosis for ME patients.¹⁰

ME International's Position

- ME is a distinct neurological disease separate from CFS, CFS/ME, ME/CFS or SEID.
- ME is defined accurately in the ICC.
- The ME IC Primer provides step wise guidance for diagnosing and treating myalgic encephalomyelitis.
- In view of research and clinical experience that strongly points to widespread brain and spine inflammation and multisystemic causes, it is more appropriate and accurate to use the term myalgic encephalomyelitis.
- Research into ME needs to select a more homogenous patient population using the ICC with diagnostic methods found in the IC Primer.
- ME International supports this statement: *"Patients diagnosed using broader or other criteria for CFS or its hybrids (Oxford, Reeves, London, Fukuda, CCC, etc.) should be reassessed with the ICC."* (IC Primer pg ii).
- In addition, ME International supports recognition of the original description by Dr. Ramsay, research into the multiple outbreaks, as well as recognition of the possible connection to enteroviruses (polio) and/or retroviruses.

Conclusion

ME International's position is that myalgic encephalomyelitis is a complex, acquired multi-systemic disease apart from CFS and ME/CFS, that all patients need to be screened for ME in accordance with the IC Primer, and all research labeled "ME" use the ICC.



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More detailed information can be found on our website at ME-International.org

1. Myalgic encephalomyelitis: International Consensus Criteria
<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x>
2. Myalgic Encephalomyelitis Adult & Paedatric: International Consensus Primer for Medical Practitioners
<https://www.me-international.org/primercheat-sheets.html>
3. Lim EJ, Son CG. Review of case definitions for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). J Transl Med. 2020 Jul 29;18(1):289. doi: 10.1186/s12967-020-02455-0. PMID: 32727489; PMCID: PMC7391812.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7391812/>
4. Twisk, F. Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, and Systemic Exertion Intolerance Disease: Three Distinct Clinical Entities. Apr 13, 2018; ME-de-patiënten Foundation, Zonedauw 15, 1906 HB Limmen, The Netherlands
<https://www.mdpi.com/2075-4418/9/1/1/htm>
5. Bruce M. Carruthers, Anil Kumar Jain, Kenny L. De Meirleir, Daniel L. Peterson, Nancy G. Klimas, A. Martin Lerner, Alison C. Basted, Pierre Flor-Henry, Pradip Joshi, A. C. Peter Powles, Jeffrey A. Sherkey & Marjorie I. van de Sande (2003) Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinical Working Case Definition, Diagnostic and Treatment Protocols - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Journal of Chronic Fatigue Syndrome, 11:1, 7-115
https://www.tandfonline.com/doi/abs/10.1300/J092v11n01_02
6. 2021 ICD-10-CM Diagnosis Code G93.3
<https://www.icd10data.com/ICD10CM/Codes/G00-G99/G89-G99/G93-/G93.3>
NOTE: World Health Organization combines ME and CFS under one code. Current WHO code is G93.3 and will become 8E49 in future update.
7. Criteria information with links: <https://www.me-international.org/criteria.html>
8. An open letter to the honorable Kathleen Sebelius, U.S. Secretary of Health and Human Services, September 23, 2013: https://drive.google.com/file/d/1Ao1Kjve-pcBJQld_tnZ9JrbvX03i-10c/view?usp=sharing
9. Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington (DC): National Academies Press (US); 2015 Feb 10; doi: 10.17226/19012
<https://www.ncbi.nlm.nih.gov/books/NBK274235/>
10. ICC_compared_to_IOM.pdf chart (MEadvocacy.org):
https://d3n8a8pro7vhmx.cloudfront.net/meadvocacy/pages/22/attachments/original/1531592663/ICC_compared_to_IOM.pdf?1531592663