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ImmuneDysfunction.org Applauds Institute of Medicine Report

Press Release

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Last week, the Institute of Medicine released its report establishing new diagnostic criteria for ME/CFS with the new name, Systemic Exertion Intolerance Disease, or S.E.I.D. What began as “Yuppie Flu” in the 80’s, *Chronic Fatigue Syndrome* over the past 30 years and most recently Myalgic Encephalomyelitis, or ME/CFS has been plagued by misunderstanding, misdiagnoses, and dismissive attitudes since its onset. This announcement confirms it to be a disease, not a psychiatric disorder, and to be real, profound, and debilitating. Proposed Diagnostic Criteria for ME/CFS Diagnosis requires that the patient have the following symptoms:

A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and
Post-exertional malaise, and
Unrefreshing sleep. and
Cognitive impairment

ImmuneDysfunction.org, a Vermont based non-profit organization has campaigned for the revised definition for 18 years and applauds these actions. For decades, CFS patients have been denigrated as malingerers, branded as lazy and dismissed by established medical practises. Fatigue is out of the name. The IOM Committee recommended changing the name of the disease, stating the following: *“The term ‘chronic fatigue syndrome’ can result in stigmatization and trivialization and should no longer be used as the name of this illness.”*

The new name proposed by the IOM is Systemic Exertion Intolerance Disease, SEID.

“This new name captures a central characteristic of this disease—the fact that exertion of any sort (physical, cognitive, or emotional)—can adversely affect patients in many organ systems and in many aspects of their lives.”

The report also emphasizes the urgent need for research:

“Remarkably little research funding has been made available to study the cause of ME/CFS, mechanisms associated with the development and progression of the disease, or effective treatment, especially given the number of people affected....Finding the cause of and cure for ME/CFS may also require research on large numbers of ME/CFS patients, from which important subsets can be identified (for example, variations in symptoms, response to physical and cognitive stressors, brain imaging, the microbiome, virology, immune function, and gene expression). Studies assessing the natural history of the disease and its temporal characteristics—onset, duration, severity, recovery, and functional losses—are essential for a better understanding of ME/CFS. The committee stresses that more research is urgently needed.”

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