Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
Redefining an Illness

Between 836,000 and 2.5 million Americans suffer from myalgic encephalomyelitis/chronic fatigue syndrome—commonly referred to as ME/CFS. This disease is characterized by profound fatigue, cognitive dysfunction, sleep abnormalities, autonomic manifestations, pain, and other symptoms that are made worse by exertion of any sort. ME/CFS can severely impair patients’ ability to conduct their normal lives. Yet many people struggle with symptoms for years before receiving a diagnosis. Fewer than one-third of medical school curricula and less than half of medical textbooks include information about ME/CFS. Although many health care providers are aware of ME/CFS, they may misunderstand the disease or lack knowledge about how to diagnose and treat it. Such gaps in understanding lead to delayed diagnoses and inappropriate management of patients’ symptoms.

The Department of Health and Human Services (HHS), the National Institutes of Health, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Food and Drug Administration, and the Social Security Administration asked the Institute of Medicine (IOM) to convene an expert committee to examine the evidence base for ME/CFS. In Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness, the committee proposes new diagnostic criteria that will facilitate timely diagnosis and care and enhance understanding among health care providers and the public. In addition, the committee recommends that the name of the disease be changed—from ME/CFS to systemic exertion intolerance disease (SEID)—to more accurately capture the central characteristics of the illness.

Understanding ME/CFS

The primary message of the committee’s report is that ME/CFS is a serious, chronic, complex, systemic disease that often can profoundly affect the lives of
patients. Many people with ME/CFS report difficulty completing everyday tasks, and at least one-quarter have been home- or bed-bound at some point as a result of their illness. The total economic costs of ME/CFS are estimated at $17 to $24 billion annually.

Many health care providers are skeptical about the seriousness of ME/CFS, mistake it for a mental health condition, or consider it a figment of the patient’s imagination. Misconceptions or dismissive attitudes on the part of health care providers make the path to diagnosis long and frustrating for many patients. The committee stresses that health care providers should acknowledge ME/CFS as a serious illness that requires timely diagnosis and appropriate care.

**New Diagnostic Criteria for ME/CFS**

On the basis of a comprehensive literature review and input from patient, advocacy, and research communities, the committee presents new diagnostic criteria for ME/CFS focused on the central symptoms of the disease (see Box). To reach consensus on these criteria, the committee weighed (1) the frequency and severity with which symptoms are experienced by patients; (2) the strength of the scientific literature; and (3) the availability of objective measures supporting a link between particular symptoms and an ME/CFS diagnosis.

Impaired day-to-day function, post-exertional malaise (the worsening of symptoms after physical, cognitive, or emotional activity), and unrefreshing sleep are almost universally present in ME/CFS patients. Therefore, the committee considers these to be the three core symptoms of the disease. Because cognitive impairment and orthostatic intolerance (onset of symptoms when standing upright that are improved by lying back down) are also frequently found in ME/CFS patients, the committee concludes that one of these symptoms must also be present for an ME/CFS diagnosis. Finally, symptoms should persist for at least 6 months and be present at least half the time with moderate, substantial, or severe intensity to distinguish ME/CFS from other diseases. The application of these new criteria will allow a large percentage of currently undiagnosed patients to receive an accurate diagnosis and appropriate care.

The committee recommends that physicians diagnose ME/CFS, in both children and adults, if the new diagnostic criteria are met after conduct-
committee’s efforts to determine whether ME/CFS has subtypes or is instead a collection of potentially distinguishable disorders. Large studies that include individuals with diverse symptoms are needed to fill these knowledge gaps. Almost all studies conducted to date have compared ME/CFS patients to healthy control groups, rather than to patients with other complex fatiguing diseases. As a result, there are very few data to guide clinicians in distinguishing ME/CFS from other disorders—a major impediment to progress in diagnosing and treating the disease.

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. However, the committee notes that some progress is being made in studying ME/CFS using physiologic and molecular methods. This and future research could lead to findings that refine the diagnostic criteria and understanding of ME/CFS subtypes. Therefore, the committee recommends that a multidisciplinary group reexamine its proposed criteria after 5 years or sooner if firm evidence supports the need for modification.

**A New Name for ME/CFS**

Many ME/CFS patients believe that the term “chronic fatigue syndrome” perpetuates misun-
Understanding of the illness and dismissive attitudes from health care providers and the public. The committee agrees that this term does not serve ME/CFS patients well. Furthermore, the committee concludes that the term “myalgic encephalo-myelitis” is inappropriate because there is a lack of evidence for encephalomyelitis (brain inflammation) in ME/CFS patients, and myalgia (muscle pain) is not a core symptom of the disease.

To replace ME/CFS, the committee proposes the name systemic exertion intolerance disease, or SEID. This name captures a central characteristic of the 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 committee believes systemic exertion intolerance disease appropriately captures the complexity and severity of the illness. Therefore, it recommends that patients who meet the proposed diagnostic criteria, whether or not they have already been diagnosed with ME/CFS, should henceforth be diagnosed with SEID.

**Conclusion**

In *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*, the committee proposes clear and concise diagnostic criteria that will facilitate diagnosis and care for the patients affected by this often-debilitating disease. Broad dissemination and use of these criteria is essential to improve understanding of the disease among health care providers and the public and provide a firm foundation for future improvements in diagnosis and treatment of these patients.