

To the CFSAC:

Epidemic Myalgic Encephalomyelitis: A Demand for Urgent Action and Accountability

The CDC has systematically failed its mission to protect the health of the global community with regard to the uncontrolled spread of the pandemic neurological and multiple systemic disease Myalgic Encephalomyelitis, to prevent the chronic lifelong disability, suffering and needless deaths it has wreaked on the lives of millions of people around the world since the CDC became negatively involved with this infectious disease 25 years ago while in the midst of the AIDS pandemic. The CDC ignored the growing epidemics, the Cheney/Peterson biomarkers and historical evidence by constructing CFS and pretending it was a new condition.

It has failed to educate the public about the 75 year epidemic history of M.E., to educate the medical profession with appropriate guidelines to care for the patients, to fund research and provide treatments for the disease, and critically to ban blood donations and stop the spread of this disease. It has failed its mission and goals, denying the epidemics, focusing wrongly on fatigue and psychosocial factors, pursuing meaningless research studies, and subjecting sufferers to uninformed medical neglect and human rights abuses. Advising doctors not to do the very tests that would confirm the disease? That is CDC policy.

It began with a botched investigation of a major outbreak of M.E. in a tourist village at Lake Tahoe, where the CDC ignored the biomarkers found by Drs Cheney and Peterson which validated the disease, and continuing to the present day with its 25-year marketing exercise in rebranding this serious disease similar to M.S. and Post Polio Syndrome as CFS, renaming and redefining it as a vague fatigue state via the unscientific Fukuda and Holmes definitions and further reducing it to a “stress-related disorder” using the 2005 Reeves “empirical” definition – a subjective questionnaire about “unwellness”. CFS is known as the wastebasket diagnosis - for it describes all states of “chronic fatigue” and has been the subject of intense psychiatric speculation and abuse. Severely affected patients are not believed, and many are so desperate they take their own lives. Sick children have been removed from their families, what kind of society allows this?

The first recorded epidemic was initially described by the U.S. Surgeon General A.G. Gilliam as Atypical Poliomyelitis in 1934. After an epidemic affecting the doctors and nurses at the Royal Free Hospital in 1955, M.E. was named by Sir Donald Acheson in 1956 and described by A.L. Wallis in 1959. The distinguished neurologist Lord Brain included it in the standard textbook of Neurology in 1962. Drs Melvin Ramsay and John Richardson had Benign Myalgic Encephalomyelitis recognised by WHO in ICD-8 at Code 323 under Diseases of the Central Nervous System in the 1969 edition of the WHO-ICD.

Why was M.E. moved to Code G93.3 Other Disorders of the Brain with CFS listed as a synonymous term – can the CDC explain why it is now in this odd category with various unrelated entries? The CFS definition does not describe the neurological disease M.E. and severely undermines its biomedical credibility. The US – in ignorance of the official name and neurological classification of the disease? – then referred to the continuing epidemics as Epidemic Neuromyasthenia until the fateful outbreaks in the 1980s.

In 1978 the Royal Society of Medicine held a symposium on ME at which ME was accepted as a distinct entity and The Ramsay case description was published in 1981. In response to massive outbreaks in the 1980s, the CDC rebranded the disease as CFS, placed it in the National Center for Zoonotic, Vector-Borne, and Enteric Diseases at the Chronic Viral Diseases Branch, designated it for funding status as "A serious legitimate diagnosis CDC PRIORITY 1 disease of public health importance", and then failed to fund it adequately, promoted it as a recoverable fatigue state, and acted to eradicate all knowledge of the M.E. Researchers could not get M.E. research published as they had to abide by the CDC's name and definition.

The CDC did not fulfil its obligation to protect the public, it proceeded on a program of denial, failing to alert the public or the responsible health agencies of this serious public health threat, failing to ban blood donations and contain the disease, and indulging in a funding scandal in which William Reeves was involved. The NIH has also failed its mission to research the disease, hiding it under CFS at the Office of Research into Women's Health (ORWH) with a paltry budget, rather than placing M.E. at the National Institute of Neurological Disorders and Stroke (NINDS) alongside similar diseases as M.S. and Post Polio Syndrome, where it should have a budget on a scale commensurate with the fact that more people are affected by M.E. than M.S. and are just as severely disabled.

The CDC website on CFS continues to ignore the wealth of accumulating evidence: "As yet, there are no diagnostic tests or laboratory markers for CFS, and its pathophysiology remains unknown. ... Various terms are often used interchangeably with CFS. CFS is the preferred term because it has an internationally accepted case definition that is used in research and clinical settings ... The name myalgic encephalomyelitis (ME) was coined in the 1950s to clarify well-documented outbreaks of disease; however, ME is accompanied by neurologic and muscular signs and has a case definition distinct from that of CFS." There is no definition of M.E. that they recognise, not the Ramsay definition or the 2003 Canadian definition, despite the documented M.E. epidemics, testable abnormalities, and compelling evidence of enteroviral contagion and severe neurological and systemic dysfunction.

The CFSAC needs to act firmly, stop acting like a bumbling committee and listen to the expert patient testimony that has been telling them for years of the urgent need to recognise Myalgic Encephalomyelitis and for accountable leadership. The CDC is not leading the world as it claims but has again been caught out in funding abuses; and independent research has had to step in - it is The Chia Enterovirus Foundation, The Whittemore Peterson Institute, MEResearchUK and The (ME)CFS Research Foundation that are unravelling this complex disease. The NIH must also act responsibly and place M.E. at NINDS where researchers can look at the similar etiologies and pathological processes of diseases like M.S. and Post Polio Syndrome.

The unstated objective of the 5-year "CFS" strategic research plan is to continue to study CFS as a stress-related disorder by following the false UK psychiatric model, which produced the dangerously flawed NICE Guidelines for CFS/ME - for vaguely defined "chronic fatigue" patients - and the funding of chronic fatigue clinics which are detrimental to M.E. patients and deprive them of the medical care that they would receive if M.E. was a recognised neurological disease. The vague goals of the Draft Strategic Research Plan General Outline use the keywords favoured by the psychiatric model – psychosocial, psychoneuroendocrinologic, risk factors, management, intervention, and absurdly to move CFS - the wastebasket diagnosis - into the

mainstream of public health concerns. That is the CDC's policy – to focus on a meaningless wastebasket diagnosis instead of the urgent and desperate need for Myalgic Encephalomyelitis research?

A decision 25 years ago to alert the public to the M.E. pandemic as they have done with the recent H1N1 flu outbreak would have been the responsible action of the CDC in this regard, and recognition of the pathological biomarkers discovered in the 1980s should have validated the serious nature of the disease as technological advances did for M.S. in the 1950s. Knowledge of the previous epidemics would have apprised all medical personnel of the parallels with poliomyelitis and enteroviral etiology, enabled early detection in the acute stage of the disease, created demand for a massive injection of funding for research into etiology, pathophysiology and treatments, and the prevention of long term disability. Medical treatments would be approved now to stop the suffering and needless deaths that have been ignored or cruelly stigmatized by warped concepts of fatigue and somatisation.

Given the failure of the CDC to alert the public and contain this pandemic, a Congressional Inquiry into this appalling state of affairs is long overdue and desperately needed - after 25 years the pandemic is still hidden, the numbers of patients neglected by the medical profession are growing and the hidden death rate is steadily climbing. The CDC has had every opportunity to correct this over the last 25 years, and the CFSAC must also correct itself and provide strong leadership now. It is inevitable that private research organizations will unravel the truth about the disease, and patients suffering for decades or diagnosed with M.E. before the CDC intervened with its CFS wastebasket diagnosis - will not give up the quest for the truth about Myalgic Encephalomyelitis.

The CFSAC must respectfully consider how it is contributing to the human rights abuse caused by the CFS construct, and demonstrate that it is forcefully acting in the best interests of these severely ill and neglected patients by becoming the Myalgic Encephalomyelitis Advisory Committee, demanding the reinstatement of Myalgic Encephalomyelitis and the adaptation of a research version of the Canadian Consensus Guidelines, the only medically relevant guidelines with *diagnostic tests* and treatment suggestions.

CFS patient organisations also need to acknowledge their part in promoting the CDC's CFS construct and stop the name game of CFS, CFIDS, ME/CFS, CFS/ME, ME/CFS/PVFS and Myalgic Encephalopathy, all of which feed into the uncertainty and disbelief that discourage medical and public understanding of the disease. Please stop supporting the misinformation, publicise the historical and current medical facts and persistently demand that Myalgic Encephalomyelitis is urgently recognised and on the public agenda.

If anyone wants to quibble about whether the name is technically correct then carefully consider the extensive history of M.E. and how the CFS construct has delayed valuable research and progress, and prolonged the suffering of M.E. patients. Only when thorough research has been conducted on strictly defined and also severely affected M.E. patients can we question whether the name – classified by WHO for 40 years and known around the world for over 50 years – is still medically appropriate, or not.

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