

### The Disease of a Thousand Names

Some of the many names for the illness Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy/Myalgic Encephalomyelitis (CFS/CFIDS/ME) over more than 100 years are:

atypical poliomyelitis, Iceland disease, Akureyi disease, Coventry disease, Tapanui flu, Otago mystery disease, Royal Free disease, Lake Tahoe mystery disease, Lyndonville chronic mononucleosis, the English disease, neuromyasthenia, neurasthenia, epidemic neuromyasthenia, myalgic encephalomyelitis, muscular rheumatism, Da Costa's syndrome, Beard's disease, Ramsey's disease, chronic fatigue syndrome, *La Spasmophilie*, Raggedy Ann Syndrome, post-viral fatigue syndrome, persistent viral fatigue syndrome, chronic immune activation syndrome, chronic immune dysfunction syndrome, low natural killer cell syndrome, allergic fatigue syndrome, chronic fatigue and immune dysfunction syndrome, Naxalone-reversible monocyte dysfunction syndrome, chronic Epstein-Barr virus syndrome, chronic mononucleosis-like syndrome, Yuppie flu, Yuppie plague.

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### Early History

Possibly the earliest "modern" mention of the illness was by Thomas Sydenham, the father of English medicine, in 1681. (Some people claim the first mention of the illness in the medical literature goes back to the time of Hammurabi in Ancient Babylon.) He called it Muscular Rheumatism. The earliest mentions of CFS/CFIDS/ME in the more modern medical literature were in the 19<sup>th</sup> century under the names *neurasthenia*, *neuromyasthenia* and *Beard's disease*. While neurasthenia was commonly considered to be a psychosomatic disorder, some descriptions of it indicate real physical symptoms and an origin after a bacterial or viral illness that strongly resembles what is now known as CFS/CFIDS/ME.

### Early 20th Century History

This organic syndrome has also had a recent epidemiological history in other parts of the world, often in epidemic form. The first modern reported U.S. outbreak occurred in 1934 in Los Angeles County General Hospital. Another major outbreak was investigated in 1958 by Dr. Donald A. Henderson of the U.S. Centers for Disease Control and Prevention (who was renowned for his work in polio and won a Medal of Freedom in 2002 for his long-term work directing the World Health Organization's smallpox eradication campaign). In between 1934 and 1958, there were at least twenty-three epidemic outbreaks of what mimicked CFS/CFIDS/ME during polio outbreaks. A number of researchers and clinicians in other nations had direct clinical experience with these cluster outbreaks. Some of these investigators were able to

identify an illness of multiple symptom-complexes across a number of physiological systems and to define the illness as a coherent medical syndrome. These outbreaks occurred in the U.S., England, Iceland, Denmark, Germany, Australia, Greece and South Africa.

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### **Origin of The Name M.E.**

As a result of investigations from the 1950s to the present, particularly in Canada, European countries, Australia and New Zealand, the illness in these countries became known as Myalgic Encephalomyelitis or Myalgic Encephalopathy (ME) as well as benign epidemic neuromyasthenia, neuromyasthenia, or post-viral fatigue syndrome.

The first article attempting to clarify the various outbreaks was published in the *Lancet* in 1956 and was further discussed in an article in the *American Journal of Medicine* in 1959. This line of research came from observant clinicians, including the pioneer, Dr. Melvin Ramsay, who understood the development and proliferation of a coherent disease syndrome. Hence, the definition of the illness and its name were more directly connected to the clear physical nature of the illness. In 1988, Ramsay stated, "ME is an endemic illness which is subject to periodic epidemics." In 1994, Dr. Dowsett, a colleague of Ramsay in Britain, developed the London Criteria for ME, which was a summation of the extensive previous work.

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### **Origin of the Name CFS—1988 Case Definition**

In 1984 there was an outbreak of ME in Tapanui, New Zealand. This was followed by outbreaks in Lyndonville, NY amongst Dr. David Bell's patients (1984-1987) after a possible retrovirus infection, and in the Lake Tahoe, Nevada area (1984-1987) amongst Drs. Paul Cheney and David Peterson's patients of what was initially characterized as chronic Epstein-Barr virus. The Centers for Disease Control & Prevention (CDC) investigated the latter outbreak. Eventually a committee was formed to come up with a case definition of the illness. This committee was headed by Dr. G.P. Holmes of the CDC and included many others, including Dr. Anthony Komaroff of Brigham and Women's Hospital Boston, a good friend of Massachusetts CFIDS/ME & FM Association.

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### **Oxford and 1994 Definitions**

In 1991 the British invented the Oxford definition of CFS, which essentially just says the patient is tired. In 1994, the CDC revisited the 1988 definition. Development of both CDC definitions occurred in response to a number of epidemic outbreaks in the U.S. Moreover, a number of clinicians had experienced groups of endemic cases within their practices. Despite the careful clinical reporting which demonstrated a very similar organic pathophysiology of the both epidemic and endemic cases, the CDC chose to place a partially psychiatric emphasis on the illness. This bias led to the 1994 definition which was less evidence-based and more of a *compromise* between those who wished to characterize the illness largely as fatigue and somatization, and those who understood the illness to be primarily physical in nature. As a compromise definition, it gave something to both views—thereby allowing for the proper diagnosis of many patients, but also for egregious misdiagnosis. Patients with psychiatric illness could be misdiagnosed as having the physical syndrome, or patients having the physical syndrome could be falsely diagnosed with psychiatric illness. The consequences for either group of patients in obtaining either ineffectual or harmful treatment are immediately obvious.

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### 2003 Canadian Definition

The lack of clarity and accuracy of the dominant, but somewhat amorphous 1994 CDC definition led a number of the leading researchers and clinicians from the U.S. and other nations to develop and publish in 2003 a new and much more accurate case definition for the illness: *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Definition, Diagnostic and Treatment Protocols*.

As this definition was published partially under the auspices of the Canadian Ministry of Health, it is informally called the Canadian Definition. The Canadian government assisted in organizing a committee following "input from invited world leaders in the research and clinical management of ME/CFS patients." (The combined experience of the committee was with over 20,000 patients.)

It draws together the most rigorous findings both from the CFS CDC-sponsored research and the ME European research. Authors include CFS/ME experts Dr. Kenny De Meirleir of Belgium and Drs. Martin Lerner, Daniel Peterson, and Nancy Klimas of the U.S., among others.

*In our opinion, to date the 2003 Canadian Definition is the most medically accurate and detailed case definition available to physicians and patients. A patient and his/her physician will best determine presence of the illness using the Canadian Diagnostic Criteria.*

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**More Resources**

[\*Detailed Explanation of the 1994 CFS Definition Criteria\*](#)

[\*Orthostatic Problems in CFIDS/FM and Post Polio Syndrome\*](#)