

## CFSAC Comment from Lisa Petrison – December 2014

My name is Lisa Petrison. Thank you for allowing me to speak.

The term Myalgic Encephalomyelitis was first used in 1956, to refer to a series of illness outbreaks that had been reported around the world since the 1930's.

By the mid 1980's, there had been more than 100 papers published in the medical literature about M.E., with very detailed descriptions of illness presentation and typical illness course.

In 1985, several hundred individuals in the Lake Tahoe area came down with severe and classic M.E. Other U.S. clusters of M.E. also were reported.

The members of the Holmes Committee responding to those outbreaks were aware of the medical literature about the established disease of M.E.

Nonetheless, the committee decided not to acknowledge that the affected individuals were suffering from M.E.

Instead, in 1988, the committee created a totally new illness category, which it called "Chronic Fatigue Syndrome."

Considering that fatigue was the least of these patients' concerns, the Holmes Committee's decision to use that name was as problematic then as it is today.

An even bigger problem was that the definition written by the committee was so broad that it allowed many individuals who did not have M.E. to be diagnosed as having "CFS."

Over the subsequent 26 years, the government definition of CFS became even broader.

During the past year or so, the government has begun to refer to the condition that it recognizes as follows: "Chronic fatigue syndrome (ME/CFS)."

This makes me concerned that the government is now suggesting that M.E. is just another name for "CFS" - and therefore that everything that it says about CFS should apply to M.E. as well.

If this indeed is what the government is suggesting, it is highly inappropriate.

M.E. is a disease with a history going back more than 60 years. It has an established specific definition that is very different than the Fukuda and Reeves definitions that the government continues to use for "CFS."

Those in this community have asked numerous times that the definition of CFS be changed to an established definition of M.E., through the adoption of the International Consensus Criteria or the Canadian Consensus Criteria.

Even better would be for the government to officially recognize M.E. as its own illness category, using an existing M.E. definition.

On the other hand, it would be unscientific for the government to imply that just because their creation of CFS in 1988 was in response to an M.E. outbreak, their definition for CFS should hold sway over M.E.

M.E. already has a definition. It is an international definition that has been consistent since 1956. It is a definition wholly unlike any definition that the government ever has used for CFS.

It is not within the purview of the government of the United States to change the definition of M.E. to their definition of CFS.

Thank you.

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1) A 1956 article describing the established disease of M.E.

Lindan R. Benign Myalgic Encephalomyelitis. Can Med Assoc J. 1956 Oct 1;75(7):596-7. PMID: 20325349

“The onset resembles that of poliomyelitis with headaches, lassitude, neck stiffness and sore throat accompanied by pains in the limbs and back, and possibly paraesthesiae and palsies. In contrast to poliomyelitis, however, the fever is never very high; the temperature rarely exceeds 100 degrees F and may persist for long periods. The clinical picture is dominated by the severe muscular pains, accompanied at first by spasms and exaggerated tendon reflexes. These pains are not transient; they often persist long after any local signs have subsided and may be accompanied by an exquisite tenderness, but at no time does any muscular wasting develop. A further distinguishing feature of the disease is the onset of behavioural changes, such as emotional lability, irritability and depression....Disturbances of the cranial nerves such as diplopia and nystagmus, facial weakness, deafness or, in some cases hyperacusis, are common. A high proportion of cases show evidence of involvement of the reticuloendothelial system with enlargement of the cervical lymph nodes, particularly those in the posterior triangle, and, in some patients, hepatitis and splenomegaly.”

2) A list of some Myalgic Encephalomyelitis outbreaks.

1934	Los Angeles County Hospital - Atypical Poliomyelitis
1936	Fond Du Lac, Wisconsin - St. Agnes Convent - Encephalitis
1937	Erstfeld, Switzerland - Abortive Poliomyelitis
1937	St. Gallen, Switzerland - Frohburg Hospital – Abortive Poliomyelitis
1939	Middlesex, England - Harefield Sanatorium - persistent Myalgia following sore throat
1939	Degersheim, Switzerland - Abortive Poliomyelitis

- 1945 Hospital of the University of Pennsylvania - epidemic Pleurodynia with prominent neurological symptoms and no demonstrable cause
- 1946 Iceland – disease resembling Poliomyelitis with the character of Akureyri disease
- 1948 Iceland, North Coast towns - epidemic simulating Poliomyelitis
- 1949 Adelaide, South Australia - a disease resembling Poliomyelitis
- 1950 Louisville, Kentucky -- St. Joseph’s Infirmary - outbreak in nurses’ training school described as “epidemic Neuromyasthenia”
- 1950 Upper State New York -- outbreak resembling the Iceland disease, simulating acute Anterior Poliomyelitis
- 1952 London, England - Middlesex Hospital Nurses’ Home - Encephalomyelitis associated with Poliomyelitis virus
- 1952 Copenhagen, Denmark - epidemic Myositis
- 1952 Lakeland, Florida - epidemic Neuromyasthenia
- 1953 Coventry and District, England - an illness resembling Poliomyelitis observed in nurses
- 1953 Rockville, Maryland - Chestnut Lodge Hospital - Poliomyelitis-like epidemic Neuromyasthenia
- 1953 Jutland, Denmark - epidemic Encephalitis with vertigo
- 1954 Seward, Alaska - benign Myalgic Encephalomyelitis (Iceland Disease)
- 1954 Berlin, Germany - British army - further outbreak of a disease resembling Poliomyelitis
- 1954 Liverpool, England - outbreak among medical and nursing staff in a local hospital
- 1955 Dalston, Cumbria, England – epidemic and sporadic outbreak of an unusual disease
- 1955 London, England - Royal Free Hospital - outbreak in staff and patients of Benign Myalgic Encephalomyelitis
- 1955 Perth, Australia - virus epidemic in waves
- 1955 Gilfac Goch, Wales - outbreak of benign Myalgic Encephalomyelitis
- 1955 Durban City, South Africa - Addington Hospital - outbreak among nurses of “Durban Mystery Disease”
- 1955 Segbwema, Sierra Leone - outbreak of Encephalomyelitis
- 1955 Patreksfjorour and Porshofn, Iceland - unusual response to polio vaccine
- 1955 Northwest London, England - nurses’ residential home - acute Infective Encephalomyelitis simulating poliomyelitis
- 1956 Ridgefield, Connecticut - epidemic Neuromyasthenia
- 1956 Punta Gorda Florida - outbreak of epidemic Neuromyasthenia
- 1956 Newton-le-Willows, Lancashire, England - Lymphocytic Meningoencephalitis with myalgia
- 1956 Pittsfield and Williamstown, Massachusetts - benign Myalgic Encephalomyelitis
- 1956 Coventry, England - epidemic malaise, benign Myalgic Encephalomyelitis
- 1957 Brighton, South Australia - Cocksakie Echo virus Meningitis, epidemic Myalgic Encephalomyelitis
- 1958 Athens, Greece - nurses’ school - outbreak of benign Myalgic Encephalomyelitis with periostitis and arthropathy noted.
- 1958 Southwest London, England - reports of sporadic cases of Myalgic Encephalomyelitis
- 1959 Newcastle Upon Tyne, England - outbreak of benign Myalgic Encephalomyelitis
- 1961 Basel, Switzerland - sporadic cases of benign Myalgic Encephalomyelitis
- 1961 New York State - outbreak of epidemic Neuromyasthenia in a convent
- 1964 Northwest London, England - epidemic malaise, epidemic Neuromyasthenia
- 1964 Franklin, Kentucky - outbreak of Neuromyasthenia in a factory
- 1967 Edinburgh, Scotland - sporadic cases resembling benign Myalgic Encephalomyelitis
- 1968 Fraidek, Lebanon - benign Myalgic Encephalomyelitis

- 1969 Brooklyn, New York - State University of New York Downstate Medical Center - epidemic Neuromyasthenia, unidentified symptom complex
- 1970 Lackland Air Force Base, Texas - epidemic Neuromyasthenia
- 1970 London, England - Great Ormond Street Hospital for Children - outbreak of Neuromyasthenia among nurses
- 1975 Sacramento, California - Mercy San Juan Hospital - Infectious Venulitis, epidemic Phelobodynia
- 1976 Southwest Ireland - epidemic Neuromyasthenia, benign Myalgic Encephalomyelitis
- 1977 Dallas – Fort Worth, Texas - epidemic Neuromyasthenia
- 1979 Southampton, England - Myalgic Encephalomyelitis
- 1980 West Kilbridge, Ayrshire, Scotland - epidemic Myalgic Encephalomyelitis
- 1980 San Francisco, California – epidemic persistent flu-like illness
- 1981 Stirlingshire, Scotland - sporadic Myalgic Encephalomyelitis
- 1982 West Otago, Dunedin and Hamilton, New Zealand - Myalgic Encephalomyelitis
- 1983 Los Angeles, California - an unknown, chronic symptom complex involving profound “fatigue”
- 1984 Lake Tahoe Area of California/Nevada - Eventually characterized as Chronic Fatigue Syndrome

3) A paper about the Tahoe epidemic.

Buchwald D, Cheney PR, Peterson DL, Henry B, Wormsley SB, Geiger A, Ablashi DV, Salahuddin SZ, Saxinger C, Biddle R, et al. A chronic illness characterized by fatigue, neurologic and immunologic disorders, and active human herpesvirus type 6 infection. *Ann Intern Med.* 1992 Jan 15;116(2):103-13. PMID: 1309285

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6) Dr. Gary Holmes and Dr. Jonathan Kaplan of the Holmes Committee discussed Myalgic Encephalomyelitis in a paper focused on the Tahoe cohort in 1987:

Holmes GF, Kaplan JE, Stewart JA, Hunt B, Pinsky PF, Schonberger LB. A cluster of patients with a chronic mononucleosis-like syndrome: Is Epstein-Barr virus the cause? *JAMA.* 1987 May 1; 257 (17).

“Since the 1930’s, several reports have described syndromes of chronic debilitating fatigue associated with low-grade fever, myalgias, arthralgias, sore throat, headaches, neurological complaints, and a variety of other symptoms. Although these syndromes are remarkably similar, they have been described by several names, including Akureyri disease, Iceland disease, atypical poliomyelitis, benign myalgic encephalomyelitis, epidemic neuromyasthenia, encephalomyelitis and postviral syndrome. Despite intensive searches for the etiologic agents of these syndromes, all have remained idiopathic. Some reports, however, have described syndromes that were thought to represent recurrent acute infectious mononucleosis.

“In the past 15 years, Epstein-Barr virus (EBV) has been established as the cause of most cases of infectious mononucleosis, and EBV serological data has become commercially available. The suggestion that the fatigue syndrome might represent recurrent infectious mononucleosis has prompted recent attempts to link the syndrome with EBV. Several studies have described a syndrome of chronic fatigue that is similar to those described earlier and that is associated with persistently elevated serum titres of antibody against the early antigen (EA), viral capsid antigen (VC), and nuclear antigen (EBNA) of EBV). This syndrome has become known as chronic mononucleosis or, more specifically, chronic EBV disease (CEBV).

“In September 1985, we investigated a cluster of mononucleosis-like illnesses, thought to represent CEBV, in Nevada. The results suggest that EBV serology is inadequate for diagnosing these illnesses and that the illnesses may not be caused by EBV. However, they also suggest that some patients with these illnesses have an abnormality of infectious and/or immunologic origin.”

7) The paper published in 1988 by the Holmes Committee creating an illness called “Chronic Fatigue Syndrome.”

Holmes GP, Kaplan JE, Gantz NM, Komaroff AL, Schonberger LB, Straus SE, Jones JF, Dubois RE, Cunningham-Rundles C, Pahwa S, et al. Chronic fatigue syndrome: a working case definition. *Ann Intern Med.* 1988 Mar;108(3):387-9. PMID: 2829679

8) The Fukuda definition of CFS.

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9) The Reeves definition of CFS.

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10) The International Consensus Criteria:

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11) The Canadian Consensus Criteria:

Carruthers BM, Jain, AK, De Meirleir KL, Peterson DL, Klimas NG, Lerner AM, Bested AC, Henry PF, Joshi P, Powles ACP, Sherkey JA, van de Sande M. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. *Journal of Chronic Fatigue Syndrome*, Vol. 11(1), 2003.