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.

References

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


“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
1955  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
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  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.


Acheson ED. Benign myalgic encephalomyelitis. Lancet. 1957 Apr 20;272(6973):834-5. PMID: 13417614


---. Myalgic encephalomyelitis, or what? Lancet. 1988 Jul 9;2(8602):100-1. PMID: 2898668


5) Peer-reviewed articles mentioning predecessor conditions to M.E. published by 1988.


Sigurdsson B. Clinical findings six years after outbreak of Akureyri disease. Lancet. 1956 May 26;270(6926):766-7. PMID: 13320872


Salit IE. Sporadic postinfectious neuromyasthenia. CMAJ. 1985 Oct 1;133(7):659-63. PMID: 4042036

McHugh SM. Sporadic postinfectious neuromyasthenia. CMAJ. 1986 Jan 15;134(2):106. PMID: 3942909


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:

“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.”


8) The Fukuda definition of CFS.


9) The Reeves definition of CFS.

10) The International Consensus Criteria:


11) The Canadian Consensus Criteria: