DATE: January 12, 2015

TO: Sylvia Burwell; Francis Collins; Tom Frieden; Susan Maier; David Murray; Wanda Jones; CFSAC; P2P committee.

FROM: Lisa Petrison, Ph.D.

RE: NIH P2P Report on "ME/CFS"

Following is a list of some of the most important problems that I see in the recent draft report from the NIH P2P committee charged with looking at "ME/CFS."

First, the opening sentence is misleading, inconsistent with the comments in the rest of the report, and factually inaccurate.

"Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a chronic, complex, multi-faceted condition characterized by extreme fatigue and other symptoms that are not improved by rest."

This makes it seem like the most important thing that people should know about ME is that it consists of "fatigue" (plus other symptoms that aren't important enough to mention specifically).

Especially considering the historical characterization of the disease as "chronic fatigue syndrome," this introductory statement will encourage physicians, researchers, government officials and others to continue to overlook the much more critical health problems that patients with ME face.

I request that the first sentence be rewritten to include specific mention of some of the more debilitating issues of ME, including cognitive dysfunction, orthostatic intolerance, pain, inability to tolerate a wide variety of environmental stimuli, and post-exertional relapse.

Second, the word "fatigue" used in the first sentence and then throughout the document is not an appropriate characterization of any of the health issues that people with ME endure.

Ever since the Lake Tahoe epidemic in the mid 1980's, severely ill patients have repeatedly tried to make medical professionals understand that describing their profound lack of ability to participate in normal activity as "fatigue" is as inappropriate as saying that the limitations that ALS patients experience are due to "fatigue."

The activity-limiting state experienced in this disease is nothing like what healthy people ever experience when they are tired or fatigued. It is much more like paralysis or like the feelings of inflammation that people experience when they are fighting the flu.

Research literature now demonstrates that ME patients indeed have abnormal physiological markers (including gene and heat shock protein expression, low cerebral oxygenation, inflammation, oxidative stress and C4a complement levels) subsequent to activity. (1)

Healthy people do not display these same markers no matter how much exercise they've done, how hard they've been working, or how little sleep they've been getting.

People with ME are ill, just as people with a bad case of the flu or with ALS are ill. This is not the same thing as being fatigued.

In addition to being an inaccurate description of ME patients' health problems, the word "fatigue" (by any definition) is not specific enough to be used as a primary descriptive symptom for this disease or for any other disease.

People with cancer, AIDS, Parkinson's, ALS, MS and many other conditions also experience an enormous decline in their ability to be active, for instance.

It would be wholly inappropriate for the government to point to "fatigue" as the defining symptom of any of those diseases. And it is wholly inappropriate for the government to continue to focus on "fatigue" as the defining symptom for ME.

I request that it be noted in the report that the problems that force ME patients to limit their activity appear to be nothing like the fatigue that healthy people experience.

I also request that the report suggest that the use of the term "fatigue" to characterize this disease may be inappropriate in general.

I further request that the focus on "fatigue" be decreased throughout the report. For instance, it could replace the mention of "fatigue" in the first paragraph with a comment about patients having "an abnormally limited ability to participate in physical or mental activity."

Third, positive governmental action toward this disease seems more likely if specific funding recommendations are provided in the report.

The primary stumbling block in terms of advancement for ME now is that there has been very limited governmental research funding in the past - and that virtually all of the available funds have been wasted on poor-quality projects.

I request that the report elaborate on the extent to which this disease has historically been underfunded.

Further, I request that the report suggest a specific NIH dollar figure that would provide a chance for scientific progress and that would be similar to the amount being spent on similarly devastating diseases (such as MS, autism, lupus, Parkinson's or Alzheimer's).

I also request that the report recommend that funding needs to go toward high-quality biomedical research projects, with primary emphasis on severely ill subjects.

Fourth, discussion in the report needs to be directed toward the relationship between ME and CFS, and should not be referring to the artificial construct of "ME/CFS" as if it actually exists.

"ME" has been an established disease since the 1950's, with many articles on illness outbreaks published in prestigious journals. It has had a quite consistent definition since that time.

Existing definitions of "ME" point to a specific group of patients who are very ill and who have a recognizable pattern of specific symptoms.

"CFS" was created by a CDC committee during the late 1980's. It has been characterized since that time by a variety of non-specific definitions, none of which look much like the descriptions of ME from the literature.

Existing definitions of "CFS" point to a very broad group of individuals, including many people who are only very mildly sick and experience only non-specific symptoms rather than the ones repeatedly reported to be characteristic of ME.

In 2012, the CDC website suggested that ME and CFS were different conditions, stating: "The name myalgic encephalomyelitis (ME) was coined in the 1950's to clarify well-documented outbreaks of the disease; however, ME is accompanied by neurologic and muscular signs and has a case definition distinct from that of CFS." (2)

"ME/CFS" is a term that first began being used by the government a little more than a year ago. It is of particular concern to many in the ME community because of the possibility that it may be interpreted as stating that ME is just another name for the government's badly named and badly defined "CFS" concept.

I wrote about this topic in a brief comment to the CFS Advisory Committee to the DHHS last month. (3)

I request that the report bring up the idea that establishing an official disease of "ME" using an appropriate definition for those who have ME (rather than forcing those people to be diagnosed as having the non-specific non-disease of "ME/CFS") might help to clear up some of the current confusion about the definition and move scientific progress forward.

Fifth, the continuing discussion of papers using only the Oxford definition as if the findings of those papers have any relevance whatsoever to ME patients needs to be put to a halt.

The report acknowledges that the Oxford definition is flawed. Every "ME/CFS" specialist and every ME patient I know wholeheartedly agrees with that.

I thus request that the report state that any published work done using only the Oxford definition should not be assumed to be applicable to people with ME, unless and until that research is replicated with a subject population selected using a less flawed definition.

Thank you for your attention to these issues.

Cordially,

Lisa Petrison, Ph.D.
Executive Director
Paradigm Change
www.paradigmchange.me
lisapetrison@gmail.com

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REFERENCES:

(1) Background information on medical abnormalities in ME or CFS.

http://paradigmchange.me/me-medical-abnormalities/

(2) CDC 2012 website page discusses the difference between "ME" and "CFS."

http://paradigmchange.me/wp-content/uploads/2015/01/CDC-ME-vs.-CFS.jpg

(3) Statement on "The Problem with "ME/CFS" (text follows).

http://paradigmchange.me/wp/mecfs/

The Problem with "ME/CFS"

By Lisa Petrison, Ph.D.

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 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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References

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
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 arthopathy 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 (still not included in the P2P literature review).

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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:

Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell T, Staines D, Powles AP, Speight N, Vallings R, Bateman L, Baumgarten-Austrheim B, Bell DS, Carlo-Stella N, Chia J, Darragh A, Jo D, Lewis D, Light AR, Marshall-Gradisbik S, Mena I, Mikovits JA, Miwa K, Murovska M, Pall ML, Stevens S. Myalgic Encephalomyelitis: International Consensus Criteria. J Intern Med. 2011 Jul 20. PMID: 21777306

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.