Public Comment
LaVonne Woodruff

TO: The CFSAC, a 'CFS' (Fukuda, et al) advisory (only) committee

This committee, and the CFS--and now other mixed in—patients, do not have the authority to make-up, or change, formal illness classifications, nor the codes assigned to them.
Nor to change terms and names and wordage, at will, of any papers or reports or formal scientific studies, which is an attempt to skew things to your advantage (i.e., arrive at an end product that 'sounds more serious' than CFS).

The vast majority also do not have the formal training required, nor the medical education and licenses to do so. And NONE of you have the gov'n assigned authority &/or autonomy to act as you continue to try to.

Your approach is certainly quicker, cheaper and faster than adhering to a strict scientific approach, and allows you to continually RIG THE GAME. However, it also damages your reputations and takes away significantly from any semblance of honesty and integrity. And it PROVES nothing.

It also does grave harm to ME-defined patients (Ramsey, Hyde), who are most adversely affected by these continued childish games and manipulations. Overall, this too many years long behavior is reprehensible, outlandish, and morally and ethically WRONG in every way. It must STOP.

The CFS (Fukuda, et al) remains a tiny little 'syndrome' written based on 'fatigue', and a 'diagnosis of exclusion' only able to be made after 6 months, and when everything else has been crossed off the list. Classified under R53.82 by the USA CDC under Rickettsial, Vector-Borne, Zoonotic. (NOT Brain, Neuro, CNS, as ME is) It is comprised of just 2 major, and at least 4 of 8 minor symptoms:
http://www.cdc.gov/cfs

USA NCHS Dir Pickett's Nov 2011 public comments regarding the CFSers request to reclassify CFS the same as ME, and her explanations about why this is NOT allowable:
Code ME and CFS Together? 9 Arguments Against
http://healthmattershow.com/

Submitted by: LKWoodruff, a 14 yr ME-defined patient (Ramsey, Hyde) and serious advocate for 10 yrs

Here is a **'CFS' versus M.E. Comparison Chart (2012)**

This chart illustrates many—tho not all-- of the many differences between Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (M.E.), It clearly lays out how CFS, and M.E., are **not** the same..

Notice that NONE of the above ‘CFS’ (Fukuda, et al) symptoms appear in the ME column on the R.

‘CFS’ versus M.E. Comparison Chart (2012)	
Chronic Fatigue Syndrome (CFS)	**Myalgic Encephalomyelitis (M.E.)**
The ‘syndrome’ CFS was created b/n 1988-1994 and did not exist prior to this time.	The disease M.E. has existed for centuries. The first well-documented outbreak was in 1934 and the disease was formally given the name M.E. in 1956.
CFS is characterised by ‘chronic fatigue’ and ‘malaise’.	M.E. is characterised by damage to the brain and the brain stem (which is observable on SPECT scans, and is similar to the CNS damage seen in M.S.). **It results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. M.E. is primarily neurological, and secondarily a vascular disease.**
The symptoms associated with CFS have been thought to be caused by many different viruses, bacterial infections, trauma, physical or emotional stress, toxic exposures, nutritional issues and many other causes. **However, to-date, none of the explored options has been PROVEN.**	M.E. is caused by a virus. Significant evidence exists to show that it is caused by an enterovirus. **The four most experienced and knowledgeable M.E. experts (Drs Hyde, Dowsett, Ramsey and Richardson)** all consider M.E. to be an enteroviral disease.
CFS does not occur in outbreaks.	M.E. occurs in epidemics, as well as sporadically. Over 60 M.E. outbreaks have been recorded worldwide since 1934.
Patients do not have to have neurological damage of any kind to qualify for a diagnosis of CFS. Patients that qualify for a CFS diagnosis do not have central nervous system damage (CNS).	The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. The neurological damage suggested by these terms is an essential M.E. feature and has been confirmed in M.E. patient autopsy.
CFS does not have any distinct incubation period. Note that many viruses previously considered causes of CFS, such as EBV and HHV6, have much longer incubation periods of over 40 days.	M.E. has as a short incubation period of 4 - 7 days. It starts acutely (i.e., suddenly).
CFS is not contagious. It is listed as ‘infectious’ by its authors.	M.E. can be passed on to others in the early stages.
CFS describes a gradual onset ‘fatigue syndrome’. Symptoms appear gradually over many weeks or months.	M.E. is a sudden (i.e. acute) onset disease. Most M.E. patients can tell you not only the exact day, but even the actual hour they became ill. The onset of M.E. is dramatic and sudden and the

	severe symptoms begin on day one of the disease.
CFS does not have a defined ‘prodromal phase’.	The well-defined (Hyde) prodromal phase of M.E. involves: a respiratory illness, gastrointestinal upset, vertigo and/or a moderate to severe meningitic type headache.
CFS has a set of criteria (symptoms) that patients MUST FIT to be given the diagnosis. This checklist is not a description of an actual disease; patients must merely meet certain criteria to qualify for the diagnosis.	M.E. has a distinct and testable definition, which describes the main features of this disease and it’s many symptoms, and how it presents in patients.
CFS is not a distinct disease with a distinct cause and pathology. CFS is a mere diagnosis of exclusion (i.e., a wastebasket diagnosis).	M.E. is not a diagnosis of exclusion. It is a distinct disease with a distinct definition, symptomatology and pathology.
CFS cannot be diagnosed until after 6 months have passed.	M.E. can be diagnosed within a few weeks. M.E. is an easily recognisable, testable, distinct and organic neurological disease that is not difficult to diagnose when the physician is familiar with the disease.
There are no tests available which can be used to confirm a suspected CFS diagnosis. **If testable causes of symptoms are found then a person no longer qualifies for the CFS diagnosis**.	Abnormalities are seen on many different objective tests in M.E. within weeks of disease onset. A series of tests (including SPECT scans) can confirm a M.E. diagnosis with a high degree of accuracy. **If all tests are normal, then a diagnosis of M.E. cannot be correct**.
Abnormalities on physical exam are not associated with CFS.	A number of abnormalities are always seen on physical exam in M.E.
If a patient with a CFS diagnosis is then found to have medical reasons for their fatigue, such as cancer or vitamin B12 deficiency, they would no longer qualify for a CFS diagnosis, as it is a ‘diagnosis of exclusion’.	If a patient with M.E. is also diagnosed with other diseases such as cancer or vitamin B12 deficiency, this makes no difference to their status as an M.E. patient as a patient can have other conditions alongside M.E. M.E. is not a diagnosis of exclusion.
The fatigue of CFS is ‘medically unexplained’.	The many dysfunctions caused by M.E. are not medically unexplained or mysterious. Much is known about the viral cause of the disease and of its symptoms and other characteristics.
CFS does not have unique features or symptoms. Patients must merely have a small number of vaguely defined symptoms to qualify for a CFS diagnosis.	**M.E. has several unique features and symptoms and is virtually identical in presentation from one patient to the next.**
CFS is not associated with neurological damage (to the central and autonomic	Consequences of neurological damage in M.E. such as loss of homeostasis in many of the

nervous systems) or a loss of homeostasis.	body's systems are an essential feature of the disease, as is damage to the ANS.
Fatigue is the defining and essential symptom of CFS. **Patients must have fatigue lasting more than 6 months to qualify for a CFS diagnosis.**	**Fatigue is not a defining feature of M.E. and is not essential for the diagnosis.** Some M.E. patients may have this minor symptom while many others will not. **Every M.E. patient however has acquired damage to the CNS.**
CFS is associated with patients being constantly fatigued (or tired all the time) for longer than 6 consecutive months, for no discernible reasons.	Part of what defines M.E. is the striking variability of many different neurological and other symptoms over the course of an hour, day or week. M.E. is not a stable disease.
While exercise may be tiring, CFS is not associated with a delayed relapse following overexertion.	M.E. causes a delayed relapse following physical, mental or sensory overexertion of 24 to 72 hours or more (in some instances, weeks to months).
CFS patients do not have seizures, paralysis, cardiac abnormalities, vasculitis, CNS damage and the many other ME symptoms.	**The core feature of M.E. is CNS damage.** Also: a. Different types of seizures (absence seizures, other minor/conscious seizures and occasionally, grand mal seizures) b. Paralysis (affecting all muscles including the heart). c. Vascular/cardiac abnormalities. Cardiac issues have been reported in M.E. since the earliest M.E. outbreaks; the virus that causes M.E. has an affinity for the heart. Reduced circulating blood volume (and reduced cardiac output) and associated problems such as Orthostatic Intolerance (OI)—**the inability to sit or stand upright for any length of time**--are core features of M.E. and a major cause of the inability to complete basic daily tasks that M.E. causes. d. Significant neurocognitive dysfunction is always seen in M.E. and this can be severely disabling. e. M.E. includes a serious and <u>testable</u> sleep disorder. M.E. also causes other symptoms, such as alcohol intolerance, sensitivity to warm and cold temperatures, vestibular problems, sensitivity to drugs and other medications, and many different types of pain (including chest and heart pain and extreme pain at the back of the head).

Studies have demonstrated that CFS patients improve over time (approx. 4 years) with rest and then gradually increased exercise, plus treatments for their generalised symptoms. They do not suffer long-term adverse effects, or setbacks, or death, from exertion.	Patients that improve with exercise therapies do not qualify for a diagnosis of M.E. Exercise therapies can and do leave M.E. patients far more severely ill and bedbound than they were before and in need of emergency care. **These therapies may even prove fatal**. M.E. patients that are able to rest adequately in the early stages of the illness have the best prognosis. **M.E. patients must strictly avoid overexertion to achieve and maintain any quality of life, albeit small.**
Overexertion may cause short-term post-exertional malaise or fatigue in patients who qualify for a CFS diagnosis, but they do not worsen seriously with overexertion or suffer long-term effects from overexertion.	**Overexertion quickly causes a worsening of symptoms, serious relapse or disease progression, cardiac events, and possibly even death, in the M.E. patient.**
Patients do not have to be severely or even moderately affected to qualify for a CFS diagnosis. Mild symptoms are adequate. A significant percentage of CFS diagnosed patients no longer qualify for this diagnosis after several years as the symptoms naturally resolve. **CFS is not associated with fatalities.**	M.E. is a severely debilitating, life-altering, long-term disability (generally lifelong). ME patients do not live to old age.
The CFS (Fukuda, et al), is classified by the USA CDC under R53.82. Rickettsial, Vector-Borne, Zoonotic. Similarly to Lyme, and Rocky Mt Spotted fever. Its symptoms are also often confused with the symptoms of Candida, burnout, overwork, EBV, Ross River infections, glandular fever, mononucleosis, herpes infections, various nutritional deficiencies, influenza, clinical depression, and many other common and resolvable 'fatiguing' conditions.	M.E. is classified by the WHO, under G93.3, Brain, Neuro, CNS, similarly to diseases like M.S. and Polio.
According to the latest CDC estimates, 2.54% of the population qualify for a CFS diagnosis.	Fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis. It is a RARE complication of an enteroviral event.