

Testimony

Mary Dimmock

Thank you for this opportunity to talk to you today and for all that you do for this community as individuals and as a committee. Your efforts are essential.

I am the mother of a 24-year-old man who came down with ME/CFS in 2010. Since then, I have had to come face-to-face with the hard reality that he is sick with a disease that patients have suffered tremendously from for thirty years, many barely eeking out an existence and others dying prematurely. Thirty years during which our government has neglected this devastating illness by seriously underfunding research and diddling around with studies focused on psychiatric issues. Thirty years during which the devastating neurological disease from which patients are suffering has become hopelessly confounded with generalized fatigue and depression. Thirty years with doctors ignoring them or worse, giving them harmful advice.

I wake up every morning, thinking that this can't really be happening. What parallel universe have I entered?

Others will speak to you of the desperate need for adequate funding to support biomedical research specifically into ME/CFS. I am here to ask you for two things that I think are also critical to getting us out of this mess - reclassification of CFS as a neurological disease in the ICD-10-CM and replacement of Fukuda with a case definition that truly reflects the *specific and unique* nature of ME/CFS as a disease with significant neurological pathologies.

Regarding the reclassification of CFS in ICD-10-CM:

First let me acknowledge that everyone wants the name CFS to be wiped out. But obviously, this will not happen overnight. Until that happens, it is critical that CFS, the name actually used in the U.S., be properly classified.

The reclassification proposal that I authored and that was submitted to NCHS by the coalition requested exactly what you recommended – reclassify CFS from its current position under ‘Chronic Fatigue’ in Signs and Symptoms to G93.3 in Diseases of the Nervous System. As you know, this is exactly how it is listed in ICD-10.

However, NCHS is concerned that doing this will result in the loss of historical data that has been collected specifically for CFS and PVFS, which currently use separate codes. In the September 14, 2011 meeting materials, the NCHS stated that these separate codes allows ‘the differentiation of cases of fatigue syndrome where the physician has determined the cause as being due to a past viral infection from cases where the physician has not established a post viral link’. To address this concern, the NCHS has put forth their own proposal, called Option 2, which creates one sub-code for ME/CFS cases that are virally triggered and another sub-code for cases that are not virally triggered.

Option 2 is not acceptable because it does not comply with the Canadian, the ME International or even the Fukuda case definitions, which do not discriminate into two separate diseases based on the trigger. It also doesn't agree with published studies or diagnostic practices which result in a CFS diagnosis for those with a viral trigger. Implementing this option will further confound an already tortured disease definition. If the NCHS mandate to track their historical data requires that PVFS and CFS have separate codes, then the NCHS must consider available alternative options before the ICD-10-CM is implemented in 2013.

Given your role to advise HHS on the science and definition of ME/CFS, I ask that you actively work with NCHS to ensure that the final decision on reclassifying CFS reflects the best option for the ME/CFS community. I also ask that you work with NCHS to ensure that this change is made before ICD-10-CM is implemented in 2013. Further details are in the written version of this testimony.

Reclassifying CFS in ICD-10-CM is an important step, a declaration that we are not talking about generalized chronic fatigue or a psychiatric illness. But alone, it is not sufficient, which brings me to my second request.

Some patients have voiced a legitimate concern with reclassifying CFS as a neurological disease in ICD-10-CM as long as Fukuda is the case definition used by the CDC. The concern is that Fukuda does not describe a neurological illness, does not adequately describe other facets of the disease or even require the hallmark post-exertional malaise as a necessary condition. What do we get instead with Fukuda? A "conceptual framework to study fatiguing illnesses" and a Chinese menu of optional symptoms. No wonder ME/CFS has become so confounded with depression and chronic fatigue. No wonder we have such paltry and potentially harmful information on diagnostics and treatment on the CDC website. Will the latest CDC's educational efforts discussed by Dr. Unger at the New Jersey CFS meeting in Oct 2011 use this same foundation? God help the patients if that is the case.

Given its age and its focus on fatigue, Fukuda is incapable of reflecting what is known about this disease today. It has outlived its utility, especially in the arena of clinical care. But there are other established case definitions that do reflect what is known - the well respected and tested Canadian Consensus Criteria or the recently released ME International Consensus Criteria. Case definitions shaped by ME/CFS experts through the last 30 years of working with real ME/CFS patients.

Like others before me, I ask that you take your recommendation to reclassify CFS as a neurological disease to its logical conclusion. I ask you to work assertively with the CDC to get rid of Fukuda and replace it with a proper case definition that reflects the unique and specific range of neurological and other pathologies that mark ME/CFS.

Until this happens, patients will continue to suffer and die in their parallel universe.

Thank you.

Additional details on the ICD-10-CM proposal.

1. The proposal submitted by the Coalition to the NCHS was to move CFS to G93.3 where PVFS and ME are. This recommendation is aligned with how CFS is represented in the ICD-10 used across many countries and also with other IDC-10 clinical modifications. The proposal also requested that this change be expedited before 2013 when ICD-10-CM rolls out. This is needed to correct the current situation, which lists CFS under Chronic Fatigue.

The NCHS has accepted this proposal for review and called it Option 1, listed below.

2. NCHS is concerned with this proposal because they have historical data on CFS and PVFS that would be lost if the two terms were to be merged under one code. Currently, PVFS and CFS have different codes. This is not an issue for ME since ME is rarely used. As a result of this concern, NCHS countered with a proposal called Option 2, which creates two sub-codes - G93.31 for PVFS and ME and G93.32 for CFS.

In the materials for the Sept 14, 2011 meeting, the NCHS has stated that the current version of ICD-10-CM, where CFS is at R53.82 and PVFS is at G93.3 allows ‘the differentiation of cases of fatigue syndrome where the physician has determined the cause as being due to a past viral infection from cases where the physician has not established a post viral link’’. Splitting ME/CFS into two separate diseases in this way is not supported by case definition since the ME/CFS Canadian criteria, the ME International Consensus Criteria and even the Fukuda definition do not discriminate cases into two separate diseases based on the trigger. Further, as reported by patients, cases with viral triggers still get a diagnosis of CFS. Finally, the literature itself includes both viral and non-viral triggers in the various studies into CFS or ME/CFS.

Selecting Option 2 will only further exacerbate a poorly understood disease.

3. In response to Option 2, which was made public a few days before the meeting, Option 3 was presented at the Sept 14 meeting. This option avoids the concerns stated above. Unfortunately, Option 3 is not being considered at this time and would have had to be submitted with the original proposal before July 15, 2011 to be considered for review.

As a result, of the two options that the NCHS has agreed to consider, Option 1 is the only acceptable option for the reasons stated above. However, If the NCHS needs to be able to maintain their historical data, it is imperative that they consider Option 3 or other similar options. Doing so will likely require the submission of another proposal under expedited review to ensure that the selected option best meets both the needs of the ME/CFS community and NCHS’ data tracking needs and is implemented before ICD-10-CM is rolled out in 2013.

In addition to making a recommendation for the appropriate option, other specific issues that need to be addressed across options before NCHS makes a final decision include:

1. The heading of the G93.3 category for Option 2:

When the NCHS created Option 2 and moved PVFS to a sub-code, they needed to have a new heading for G93.3. The term that was selected was "Postviral and Other Chronic Fatigue Syndromes". This is a terrible heading that extends the disastrous legacy of the name CFS. An alternative name of 'Post-infectious Fatigue Syndrome' was presented as part of Option 3. It is recommended that this or a similar name that is compliant with WHO standards be used instead of 'Postviral and Other Chronic Fatigue Syndromes' for any option that creates sub-codes under G93.3.

2. Exclusions

ICD-10 and ICD-10-CM contain exclusions to control how two diagnoses are given to the same patient. The NCHS has recommended an Excludes2 between Chronic Fatigue and Chronic Fatigue Syndrome meaning that a patient can be diagnosed with both conditions at once. As recommended by an attendee at the September 14, 2011 meeting, this should be an Excludes1, which effectively prevents a patient from being diagnosed with both Chronic Fatigue (CF - the general sign and symptom) and Chronic Fatigue Syndrome. This should be done regardless of the option selected and should probably be done for G93.3 as a category.

The ICD-10 contains an exclusion between Neurasthenia and the G93.3 category, which appears to be missing in ICD-10-CM. An Excludes1 should also be added back in here as well.

3. Use of the term Chronic Fatigue Syndrome NOS

The draft ICD-10-CM uses the term CFS NOS under Chronic Fatigue. In the materials for the September 14, 2011 meeting, the NCHS stated that CFS NOS means "not specified as being due to a past viral infection". This usage has been carried over into Option 2. For the reasons stated above, it is inappropriate to use the term CFS NOS and would likely be problematic in implementation since patients don't always know what the trigger is. The word NOS should be dropped.

Details on the three options

Option 1 (Proposed by the Coalition and included in the NCHS material for the Sept 14 meeting)

G93 Other Disorders of the Brain
G93.3 Postviral fatigue syndrome
Chronic Fatigue Syndrome
(Benign ME is already listed against G93.3)

Option 2 (Proposed by NCHS and included in the NCHS material for the Sept 14 meeting)

G93 Other disorders of the Brain
G93.3 Postviral and other chronic fatigue syndromes

G93.31 Postviral fatigue syndrome

Benign myalgic encephalomyelitis

G93.32 Chronic Fatigue Syndrome

Chronic Fatigue Syndrome NOS

Excludes2: chronic fatigue, unspecified

Option 3 (Coalition counter-proposal)

G93 Other disorders of the Brain

G93.3 Post-infectious Fatigue Syndrome

G93.31 Postviral fatigue syndrome

G93.32 Myalgic encephalomyelitis (benign)

Chronic Fatigue Syndrome

Excludes1: chronic fatigue, unspecified

Excludes1: neurasthenia