

To the CDC Board RE: CFS/ME Definition and Funding
Submitted 10/14/09

CFS/ME/FM are difficult diseases to understand on their best days. Please notice the use of the word Disease. These illness are NOT break-offs or causes of depression in any form. They are diseases in their own right caused by something outside of its host.

From the testing I have read about done with the Wichita group etc. A two-day question and answer by doctors who have already decided by the tone of their questions that this is a depression issue will obviously get the answer they seek.

Two days in the life of someone with CFS/ME/FM is like studying someone normal to see if they are going to catch a cold this year.

Try lining all test subjects up, have them scrub a bathroom, run the vacuum, grocery shop and then watch them for the next week and see how many of them walk out of there and how many are bed bound for the next week or more. Or more to the point, can't do it at all.

All your questions, all your observing, suggest to us that you have no other ideas as to what CFS/ME/FM is other than to point to depression and leave it at that.

RE-THINK, RE-ASSESS. What are you looking at?

We are in massive pain. Our thought process' are befuddled. We are gung ho to go somewhere but when we get home we are wiped out in bed for days. We want to join in, we want a life. We just lack the physical stamina to make it so.

This is NOT Physiological, its Physical.

We WANT a life we just cant make our bodies work to have one.

Depression doesn't want a life but have the physical to do it.

There are major differences.

Leave the Mental Illness where it belongs, it has it's own following and funding.

We are CFS /ME/ FM : chronic deep fatigue, pain in muscles and joints, brain fog, Post-energy-malaise (24 hr or more) inability to stand for more than an hour, extreme sensitivity to light, noise, general sensory stimuli overload., limited energy to run minor errands on own. More and More homebound even bed bound everyday. NOT A DEPRESSION ISSUE.

Here is a good test for you. Take 30 CFS/ME/FM veterans (10yr or longer) along with 30 Non-ill people and study them for minimum of one week. How they get up in the morning, how they handle tasks for the day, what do they do in their free time, how do they do on at outing of minimum three hours. What happens when they return. Do a real study. Questions, and watching people sit around all day will NOT get your results.

Address the right illness here. Melancholy depression is NOT CFS /ME / FM.

Know who there were before they became sick, it's very enlightening. High Energy, Responsible, Go-To people. Not watchers, not sideliners.

Please consider what your description means to a population who is fighting to have a life beyond the boundary of their own bed.

The frustration we feel when we encounter someone who uses Dr.Reeves Def. of CFS.

Oh their just depresses.

Dr.Reeves has done us a great injustice so no we must fight harder than ever before with the very little energy we have left.

An email like this take at least two days to compose because we can't do it in one sitting.

Not enough energy or brain cognition.

Consider these things very carefully when you plan our health care rights and definitions. The Canadian Definition might be a place to start.

The Fate of Many Lay in your Hands,

Sincerely,

Stacey Gray