

January 11, 2015

Office of Disease Prevention
National Institutes of Health
6100 Executive Boulevard, Suite 2B03
Bethesda, MD 20892.

ATTN: Paris A. Watson

PUBLIC COMMENT ON: NIH Pathways to Prevention: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Draft Report Dated December 18, 2014

Dear NIH Panelists:

I am now retired, but have a background in rehab and psychology. I taught at Columbia University and New York University and had a long-term private clinical practice. I am not an expert on ME or CFS, but I do know a little bit about psychology and the damage caused by inappropriate labels and fuzzy case definitions.

And, frankly, it boggles my mind that the CFS label and 1996-era Fukuda et al definition (“CDC CFS Definition”) continue to be used.

Putting aside the medicine for a moment, over the years, I saw many patients and patient families who were struggling to cope with both chronic and fatal illnesses. Even with diseases as clearly purely physical as cancer, there are ghastly dynamics of anger, resentment, blame, guilt, and (especially where children are involved) fear that can absolutely devastate the entire family. Really, the last thing that needs to be added to the mess is a belittling medical label and a psychotherapist who cannot easily ascertain the reality underlying the symptoms.

The designation ME and the various definitions for ME and ME/CFS, in stark contrast to the CDC CFS Definition, describe a distinct syndrome with rather apparent neuro-immune-endocrine presentation. (I’m actually quite befuddled as to why the endocrine components seem to have been marginalized.) Both definitions by Carruthers and colleagues, *i.e.*, the Canadian

2003 Working Case Definition and the 2011 International Consensus Criteria are thoughtful and detailed enough to give both MDs and PhDs something specific to work with.

The CDC CFS Definition and the CFS name are old and tired and need to go.

I am also old and tired and need to stop writing. I hope this somewhat rambling letter has been of some value.

Very Truly Yours,

Dr. Helen I. Green*

**The address of the writer has been redacted from the original letter.*