

Testimony

Mike Dessin

I first would like to start off by saying last month's SOK conference seemed promising and I hope we use that conference as a stepping stone in making a big leap forward in research, treatment and awareness for ME/CFS. As for the current state of ME/CFS...well it's a mess as we all know. The mainstream lack of research, physician knowledge and public awareness remains the same as two decades ago!

I truly believe the name Chronic Fatigue Syndrome is the single biggest reason for lack of progress in all these areas, as well as the utter neglect and abuse patients' experience. I know there has been much discussion and campaigns regarding the name in the past but there needs to be more discussion as the name Chronic Fatigue Syndrome has made a total mockery of a very serious and life threatening disease, Myalgic Encephalomyelitis...The new trend is stating CFS as ME/CFS, but they shouldn't be mentioned in the same sentence.

In saying that, I would encourage the committee to recommend research into the phases of progression within one illness, Myalgic Encephalomyelitis, rather than trying to declare subsets or making CFS interchangeable with ME...Furthermore, it seems as though, the various definitions of CFS, which include Empirical, Fukuda, Canadian and the WHO definition do not describe CFS, rather distinct phases of ME.

CHART

I would like to refer to Lucinda Batemans graph presented at the SOK meeting, excuse the art Work but I tried my best. The chart shows her patients in order of severity level and difficulty treating, the more severe the more difficult to treat. The mildest cases being under the empirical definition to the severest being full blown ME in the middle. From my experience as a patient with ME and talking to many other patients and clinicians, these are not subsets, rather ME seems to be one distinct and clearly defined illness with 3/4 phases.

CHART 2

So maybe in the future Lucindas chart may look like this, with targeted treatments and specific bio-markers for each phase.

In conclusion, I hope the committee can recommend abolishing the name CFS completely, as it has Caused a dilemma for ME patients lasting decades. Also encourage more research into ME as one distinct illness with Phases that may already be defined by Empirical, Fukuda, Canadian and WHO definitions.

Thanks