

Public Comment
Denise Lopez-Majano

Briefly - In February, the CDC quietly posted info on pediatric ME(cfs).
(<http://www.cdc.gov/cfs/pediatric/index.html>)

A group of advocates are reviewing the pages. We expect to submit our feedback to the CDC soon.

Before I talk about the P2P Workshop I want to share an encounter with you.

My younger son has been sick for over 9 years.

Some of his daily symptoms are:

post-exertional malaise/collapse

profound cognitive dysfunction

unrefreshing sleep

pain

orthostatic intolerance

syncope

migraines

high resting heart rate

symptomatic cervical spine abnormalities.

We recently had to see a neurologist. In reviewing his symptoms the neurologist focused only on sleep.

His recommendations? Good sleep hygiene, because my son spends too much time in bed. He said once my son is sleep deprived, his sleep efficiency and symptoms will improve.

I held my tongue. But this is the PG version of what was BLARING through my head -

"Do you think we have spent over nine years twiddling our thumbs while my son wakes up each day feeling as tired as when he went to bed?"

Do you really think we are so ignorant that we haven't tried all these things?

And do you, doctor neurologist, really have no idea what unrefreshing sleep is?"

Obviously, the neurologist is NOT an ME expert. Obviously he DOES NOT KNOW this illness. Because despite the evidence in front of him – demonstrable hyperreflexia, very high resting heart rate, joint hypermobility syndrome etc, this doctor's biased view of my son's symptoms focused on sleep.

This bias, inappropriate focus and lack of ME expertise brings me to the subject of P2P.

I am very concerned about the entire process. I am particularly concerned about the concept of a NON-expert panel writing the P2P report. This fills me with DREAD.

Dread because - the protocol questions will produce a report dealing with garden variety fatigue rather than post-exertional malaise (collapse) as it manifests in ME. This report will form the basis for the workshop agenda and the material the NON—ME experts will use to write the P2P report. Just as the aforementioned non-ME-expert (the neurologist) ignored the evidence and looked only at sleep, I am concerned that the P2P panel of NON-ME-experts will bias their focus, read the report on garden variety fatigue through the lens of their own specialties and write their report without regard for the reality of this horrid illness.

I urge NIH to stop the P2P workshop and ask that NIH re-consider the best way of collaborating

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with the research and clinical community about ME.