

Public Comment

for December 2014 CFSAC meeting

Welcome to the new DFO, new AHRQ (Agency for Healthcare Research and Quality <http://www.ahrq.gov/>) ex-officio and to new CFSAC (Chronic Fatigue Syndrome Advisory Committee <http://www.hhs.gov/advcomcfs/>) participants.

I'd like to start by reminding you how far from normal our lives are.

My sons and I took a remarkable excursion last month. We went and saw a movie! I joyfully told friends and in return they responded exuberantly, saying things such as:

“That is fantastic. Any outing, is celebratory and wonderful.”

“I think that's really awesome. You must have really enjoyed the experience!”

“Thanks for letting me know. These milestones are important!”

And yet I imagine there are those among you who are wondering why going to a movie is deserving of such exuberant responses. You are thinking “What's the big deal?”

The big deal and the exuberance is because this was a **big** event for us.

Among other things, it meant my sons were well enough to go out somewhere and then endure the repercussions of having done so.

We had not been able to see a movie in a movie theatre for eight years.

During the past eight years there had been several movies we would have liked to have seen, but at the time of their release, my sons were never well enough to go, which meant we had to wait until they came out on DVD.

So last month, eight years since we'd last gone to a movie theatre, we saw a new release IN a movie theatre!

That is why I was rejoicing and why friends responded exuberantly.

To be clear. To minimize my sons' energy expenditure, I drove us to the movie and *straight* home again. We did not for instance, grab a meal beforehand. That would have involved too much sensory overload to be able to go to the movie afterward.

As it was, a “simple” outing to a movie, resulted in post-exertional malaise/collapse (PEM/PEC) for both of my sons. We have no idea how long it will last.

Our lives are far from normal if something like going to a movie exacts such a toll.

For those who do not know, my sons were **12** and **14** years old when they came down with this horrid

illness. My younger son is currently 21 years old, meaning he has been sick for nearly ten years. My older son is 23, which means he has been sick for nearly 9 years.

YES. - KIDS. ALSO. GET. THIS. HORRID. ILLNESS! This horrid illness that has PEM/PEC, and cognitive and autonomic dysfunction as some of its most debilitating symptoms.

As a reminder of what PEM/PEC is – it is often unpredictable, is triggered by minimal physical and or cognitive exertion, bringing on an exacerbation of symptoms as well as additional ones. The onset can be immediate or delayed. It can last for weeks or longer and worsens with activity. At best, recovery from PEC/PEM means returning to baseline – that place where symptoms are somewhat tolerable.

For my sons, cognitive dysfunction means impaired reaction time; difficulty processing, storing and retrieving information; inability to multitask; and more. Their intelligence is not impaired – but their ability to access it is **severely** impaired.

As for autonomic symptoms – among others, my sons endure postural orthostatic tachycardia, lightheadedness, shortness of breath, nausea, migraines, syncopal and pre-syncopal episodes.

And many patients, like my sons, and others are housebound or bedbound because of this illness, unable to study or work, and too disabled to care for themselves!

Since so many patients are so severely disabled and unable to effect change because they struggle greatly with day-to-day survival, we need to be able to count on you (CFSAC members, non-voting liaisons, ex-officios, etc.) to be aware of things going on that affect the patient population and to take proactive stands.

But we haven't be able to count on you.

Here's one example:

The AHRQ (Agency for Healthcare Research and Quality) evidence review protocol (<http://effectivehealthcare.ahrq.gov/ehc/products/586/1906/chronic-fatigue-protocol-140501.pdf>) was released in May (2014), and from the questions it was looking at, and the inclusion/exclusion criteria it used, the outcome of the evidence review was pretty.darn.predictable.

However, during the June 2014 CFSAC meeting, the CFSAC did not question or discuss the AHRQ evidence review protocol at all and that is reprehensible!

In fact the only mention of the protocol was surprisingly by Carol Head of SMCI regarding the letter (http://solvecfs.org/wpcontent/uploads/2014/06/Letter_ParisWatson_NIH_reP2P_final.pdf) SMCI sent to Paris Watson ODP (<https://prevention.nih.gov/about/odp-staff/paris-watson>) at the Office of Disease Prevention (<https://prevention.nih.gov/>).

And in not questioning or discussing the protocol, it meant that (among other things) the CFSAC did not discuss the protocol's exclusion of studies involving pediatric patients. This in turn meant there was also NO discussion of the consequences of excluding these studies.

One of the consequences of this exclusion involves orthostatic intolerance (OI). Remember - orthostatic intolerance is a significant problem for many patients, including my sons. And most studies on orthostatic intolerance in conjunction with this illness, include pediatric patients in the study population, which means that in addition to pediatric patients being ignored in the evidence review, virtually all work on OI was excluded from the evidence review thus creating one of the review's many significant flaws.

What should the CFSAC do?

CFSAC needs to be proactive regarding things such as these that affect the lives of all patients – adult and pediatric! The report by the P2P panel will have far reaching implications for this community including, but not limited to, research, health insurance and disability benefits.

In your examination of the P2P agenda (<https://prevention.nih.gov/programs-events/pathways-to-prevention/upcoming-workshops/me-cfs/agenda>), you have no doubt noticed gaps and problems in it.

Did you also notice that there is nothing to suggest that pediatric patients will be discussed during the meeting? This exclusion is unconscionable!

The P2P meeting will be held next week (December 9th and 10th, 2014)!

I urge the CFSAC to immediately go on record as questioning the glaring omission of pediatric patients from the P2P agenda. Start being proactive NOW!