

## **ME/CFS**

To Those Concerned:

We have been watching our 33 year old son suffer with this illness for over a year. We were hopeful that the recent P2P conference would bring about some change of direction. We were gravely mistaken. Not only was the process flawed and inadequate, but without suggesting conspiracy theories, it seems to have mostly continued the vague and directionless ideas of the past 20 years.

We feel that this is an issue to be evaluated and decided by the qualified medical professionals who have knowledge in this area. It is not the role of a government agency to define it. Indeed, the illness has been very well defined already (see the Canadian protocol). The idea that a group comprised of non-expert members and called the P2P is a travesty, not to mention a waste of a lot of funds that could have been better used. We read with interest, the comments of the CFSAC which expanded on the best of the conclusions of the P2P, and added better ones of their own. I strongly urge that they be adopted.

In addition to the suggestions set forth by the CFSAC, there needs to be a mechanism that defines the criteria to not only diagnose this illness, but one that also defines the parameters that will facilitate meritorious research toward alleviating it; research that will stand an excellent chance of funding.

Also, it is important to take the additional step of creating dialogue and ideas that will end up in facilitating actual, and significant funding to direct and target the research needed to end this suffering. I need not show you your own graph <http://i.imgur.com/92ttER5.png> to point out the current sick and very sad state of funding that ME/CFS now receives in comparison to other illnesses with fewer or similar victims.

The time has come to stop backpedaling and get to work on definition and research. All the damage to many sufferers has been well documented in terms of time lost in their lives, the financial loss, the humiliation and isolation. It is time to educate primary caregivers by defining this illness, in order to stop wasting time in curing this illness. One would hope that those of you who are charged with the responsibility and trust in these matters by the American people, will uphold that responsibility and trust and do the right thing.

Sincerely,  
David and Janis Olson