

Dear Committee:

I have been ill with ME/CFS for 27 years. Initially, I got Encephalitis and have never been well since that time. I was a single mother trying to work and raise my kids and offer them as normal of a life as I could. Unfortunately, the years following getting ill have been very difficult. One of the most difficult things to handle was the fact that little was known about ME/ CFS at that time. It took several years for the doctors to diagnose me and then it became even more frustrating because there was no treatment. There was no place I could go to learn more, and of course there weren't many doctors I could see that even believed that I was sick. Luckily, I had periods of time when I would have a short remission of my illness but for the last 20 years, I have had no remission, and although I have better days, I am mostly home bound. However, in the 20 or so years since I have been diagnosed, very little progress has been made.

I am horribly ill and I need help. I need the definition of this illness stated clearly so that others will not have to go through what I have gone through. **The Canadian Consensus Definition 2003 is the best description of what ME/CFS is.** I think that any doctor of merit treating this disease would recognize that fact. Why has this committee not recognized it. The Fukuda definition is worthless to those of us with ME/CFS and I would hope the committee would take definitive action to recommend this better definition...or at least a similar one as research indicates.

Obviously, this disease is not taken seriously. When I look at the amount of research money allotted by the NIH in 2009 for CFS (5 million dollars), I am totally dismayed because I know so much more is diverted to other diseases, some of which cause little or no disability. The incidence of CFS is similar if not greater than MS, and yet MS has over 300 million dollars that is spent on research. CFS is reported to cause more disability than some types of MS. We need research money in line with MS and other such illnesses.

As far as I know, these issues have not been addressed.

We are dying. And had this committee acted more vigorous, perhaps many would be living and contributing to society. We would be able to be active parents and grandparents.

The last meeting was wonderful! It brought hope to so many people and it seemed like a new beginning for the committee. I do not understand why we can't have 4 meetings per year and status updates with recommendations in line with what was discussed. I don't know what action the committee has taken since that time. We need adequate follow up on what we learned from the fall meeting with WPI, and research and replications studies regarding XMRV (in conjunction with WPI).

We need you to set up a better way to keep people informed. We are able to go online and find up to date information by many organizations, but so far you haven't set up an avenue for us to do so.

In addition to research, we need the future medical profession in America trained to deal with the complexity of this illness. Unfortunately, I believe, it is at the university level that ME/CFS is denigrated and from there no one takes it seriously. Until of course, a doctor or nurse becomes ill or has a family member or friend who becomes ill. As we know, most of the caring physicians who take care of PWC's are those that have personal experiences with it. That has got to change. Any PWC's who has gone to the emergency room for related health issues are ridiculed and

dismissed. We should not have to experience this. With the proper training, this would not happen.

We need innovative researchers involved in our meetings and we need to see the Committee take action on what is presented. As far as I know the Committee has taken no action regarding the patient testimonies either.

We need the Committee to set up plans for research into ME/CFS, including developing a biomarker, research into the pathology of the illness over the course of time, and research into the relationship between the pathology of the illness and XMRV. There should be a plan to implement these goals.

We need ME/CFS centers set up by the Secretary of Health and Human Services, which encompass both research and clinical care.

We need the Committee to help change the name of this disease to something that better describes the seriousness of the illness. Not just a symptom.

There are also many people disabled with this disease that have no disability income or insurance. This needs to be addressed.

And we need to catch up with other countries that don't allow PWC's to donate blood!

I appreciate your effort to listen to those of us who are ill. I only hope that the letters you receive will have some impact on the future of CFSAC.

Thank you for your time.

Sincerely,

D. Bradshaw