

Testimony – Marc Tillinghast

Ladies and Gentlemen of the Committee:

You will definitely receive more eloquent messages with more precise recommendations, but please hear my requests.

We need a strong CFSAC that has the means and the willingness to stand up to the organizations who do us harm if my no other means than ignoring or trivializing our condition and therefor our humanity. This is an "invisible" illness but we should not be made to feel invisible.

It is time to demand funding commensurate with the prevalence and severity of our illness. The amount spent on this disease is appalling. There are one million (or more) of us waiting to be well in order to contribute more to our families, our schools, our neighborhoods and to speak the language of our government - to pay taxes. The mindset needs to change to 'let's make an investment today to see the rewards tomorrow'. Are these organizations blind to a cost/benefit analysis?

It is sad to realize that the only CFSAC meeting that has drawn any true outside interest is as the result of the discovery of XMRV, a shiny retrovirus that caused tremendous scientific interest, which may or may not BE the cause of our illness. There should be interest and urgency EVERY DAY not 2-4 times per year. If there were in the preceding decades we would not be where we are today. Please be an active part of the solution - we have so few avenues for hope for an improvement in our daily lives let alone effective treatments.

I respectfully request the following:

- Please renew the CFSAC charter
- Please fill vacant positions immediately
- Please continue Dr. Wanda Jones in her current role
- Return meeting times to four times a year
- Provide video presentations of the committee meetings and archive them for availability for those who wish to see them later.
- The CFSAC Charter should require that CFSAC members yearly produce a strategic plan for the CFS federal research effort that incorporates budgetary elements and tell them what we really need
- Please help be a platform for the patient community to have a public voice. We don't have multi-million dollar lobbying money
- Please FIGHT HARD and LONG FOR US. We need your help. If you back down you have failed us like so many others

Thank you,

And the how is up you.