

Testimony

Shane Carlson

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Dr. Jones and Members of the CFSAC Committee,

How many people have to die before you deem ME (CFS) important enough to address the critical issue of cohort definition and subsets of patients in CFS?

Is there ANY reason why you cannot begin ACTING on this issue before the end of THIS meeting?

How many lives have to be lost to this disease before you stop talking and start acting?

If the issue is not that enough people haven't died from this disease, then what is it that you are waiting for?

Is that you simply don't care enough to do this?

I'd ask each member of this committee to ask themselves this question and if the answer is yes, then please, do the one last thing that you can for the patient community and get out of the way. If the answer is yes, then the only honorable action would be to resign.

While this may be a matter of political will to you as a committee member, I ask you to never forget that it is literally a matter of life and death to me and millions of other patients.

Sincerely and respectfully,

Shane Carlson Salt Lake City, Utah