

Dear Wanda Jones

My name is Keith Baker and I have suffered from CFS since the age of 17. That was 23 years ago and now I just turned 40. I was hopeful in all these years that a cause, treatment or cure would be found by now. I believe that a cause or treatment would have already have been found if the federal government would have followed the CFSAC's recommendations over the years, especially the five centers for excellence they always recommend at every meeting.

Not only do I have CFS and am very limited by it but my whole family came down with it at once after an apparent infection. My brother has never been able to finish college or work and my mom could only drag herself to a job and then go to bed in pain. I have been able to work a low paying, low stress job but come home and crash to mono like fatigue and pain. My muscles ache, I cannot do any aerobic activity without crashing into crushing fatigue and pain. Before CFS I was a high school track star and Junior Olympic runner. I had won many state and Junior Olympic Medals. After CFS I could never run again.

For 23 years we have been waiting and praying for help and relief. I have for 23 years watched the federal governments response to our illness and have been deeply saddened and disappointed. We need more funding and centers for excellence. We need our illness to be taken as seriously as other disabling illnesses are by the federal government.

I was very hopeful after watching the last CFSAC meeting that maybe things were finally changing for the better. The Wpi was invited and there research into XMRV was very hopeful. Dr. Bell and Peterson were great speakers and Anette Whitmore was inspiring.

Unfortunately since then the momentum seems to be slowing down again. I was disappointed to find out no one from the WPI was invited to the next meeting for an update on XMRV. No one at all is giving an update on CFS research or XMRV. I find that concerning.

Also we don't know still who the new members of the committee are and the next meeting is almost upon us. Why has this not been announced.

This should be done in a timely manner.

I have a few other requests I would like to make as a 23 year sufferer of this illness.

- 1) That the Committees charter be renewed.
- 2) That the committee meet 4 times a year like I believe it used to.
- 3) that the agenda for the meeting be filed in a timely fashion.
- 4) request the video stream be written into the charter.
- 5) Request that the status of the CFSAC's recommendations be posted

You see my family and I would like to be well again someday and have our lives back. We need a strong response from the federal government and if all of the CFSAC's recommendations were followed over the past decade we would already be where we need to be in my opinion. My family and I are running out of time and patience to get our lives back from CFS. Please help by strengthening the CFSAC and following it's recommendations. I would like my written testimony posted if that is possible.

Thank You
Keith Baker

PS. Thank you Mrs Jones for getting the meetings online. The CFS community is appreciative of your efforts and support.