

Dear Dr. Jones,

First of all I would like to thank you for the way you have handled CFSAC meetings and for your hard work in making the October meeting the best I have attended. It was a time of encouragement and gave everyone hope that progress would finally be made. A lot has happened since then, including the two-day meeting being whittled down to one, and public testimony being limited to 3 minutes when it was already very, very difficult to speak in 5 minutes. We are all eagerly awaiting news on who will replace those who have left in October as well.

In regards to this upcoming meeting, I was very disappointed to hear that WPI has not been invited back to speak. Neither Dr. Peterson, Dr. Mikovits or Annette Wittemore have been contacted. Can I please ask why? Someone pointed out part of the charter to me:

"The Committee shall advise and make recommendations to the Secretary, through the Assistant Secretary for Health, on a broad range of topics including: (1) the current state of knowledge and research about the epidemiology and risk factors relating to chronic fatigue syndrome, and identifying potential opportunities in these areas".

I believe that inviting those who discovered XMRV in many CFS patients should be part of the meeting. It seems incredible to me that after the amazing vitality this discovery brought to the CFS community, it is dropped like dead weight, and from what I understand, unlikely to be discussed at all during the meeting. As a patient advocate, a WPI Facebook administrator, and a member a two CFS forums, I can tell you the CFS community is very upset about the handling of this upcoming meeting. Not only that, but the hope that was being built with the importance of the last meeting is dwindling away. Belief that the government will help us in any way is failing. Many are placing all their hopes on WPI, and while I support them 100%, I do not believe they should hold the responsibility solely on their shoulders for what the government should have been doing in the first place. While the WPI's discovery upholds the best of American ingenuity, it also speaks of the failures of our government. Their pleas for further funding have been denied over and over. I have to wonder what more biological proof the government wants in the way of contagions and disease than what WPI, NCI and the Cleveland clinic found. Dr. Peterson said in the last meeting that things need to be picked up on the government's end at this point and they need to run with it. Instead, we find opposition almost every where we turn.

As our last hope that anything might be done by the government to answer our prayers for validation, physician education, and a worthwhile treatment or cure, please do not let the CFSAC fall by the wayside and let it continue to stand as a way for our voices to be

heard and for intellectual discussion to take place to advise those in charge of decision making. Help us create a life for ourselves that is more than merely breathing.

Thank you.

Sincerely,

Heidi Bauer