

To Whom It May Concern,

In light of the upcoming CFSAC meeting next month, I would like to make the following requests:

- * that the committee meet four times a year rather than just two
- * that replacements for outgoing committee members be filled in a timely fashion
- * that the agendas be posted in a timely fashion
- * that video live-streaming of the meetings be available
- * that the status of the CFSAC's recommendations be posted online
- * that serious consideration is given to creating centers of excellence for neuro immune disorders across the US, such as the Whittemore Peterson Institute or the proposed NJ NEI Center.
- * More funding be allocated towards biophysical ME/CFS research

I am dismayed that this year's meeting has been announced so late with no current agenda, that the WPI and NCI have not been asked to participate or give updates, that the new committee members have not yet been announced (with the meeting just weeks away), that patient testimonies have been limited to 3 minutes, and that the meeting has been downsized to one day vs. two.

I am pleased that, since the last CFSAC meeting in October, Dr. Bill Reeves has been removed as head of the CFS division of the CDC. This is a step in the right direction. However, I would like to know more about his replacement -- her credentials, her goals, her plans, etc. I would like to know what progress the CDC and NIH have made in moving forward in their investigation of the link between XMRV and CFS. I would like to know what, if any, progress has been made in decisions about the US blood supply in light of XMRV, and whether CFS patients will be asked not to donate blood. Other countries (e.g., Canada and New Zealand) have already taken the lead in taking precautionary measures.

I gave a video testimony last October, and greatly appreciated that opportunity. It's been 6 months since that date, and my health has only worsened. Yet there are still no viable treatments for CFS available to me or to others with this disease. People's lives are slipping away and there are still no answers. More needs to be done.

Thank you.

Sincerely,

Laurel Bertrand