

Submitted by Mary Dimmock on Oct. 27, 2012

On June 5, 2012, an alliance of ME/CFS patient organizations and advocates sent a joint request to Secretary Sebelius of DHHS requesting that key deputies meet with us and begin to work with us to formulate a strategic, coordinated and fully-funded response to ME/CFS. We reiterated that request in a letter to Secretary Sebelius on August 8.

[Editorial Comment: To read these letters, click on [DHHS Response to Joint Request for Action prompts second letter](#) .]

To date, we have been unable to secure the meeting with key deputies that we requested. Four members of the alliance (Joan Grobstein, Jennie Spotila, Mary Dimmock and Charlotte von Salis) did meet with Dr. Nancy Lee, Deputy Assistant Secretary for Health - Women's Health and Dr. Cairra Woods, Advisor for Health and Science Policy, Office on Women's Health.

The key points discussed in that meeting were:

- * The Ad-Hoc Workgroup (described in DHHS letters to the community and at the CFSAC) is formulating a plan focused on budget sharing and coordination across agencies. It is charged to do what it can with no additional funding. It is not charged with developing a formal strategic plan or action plan. Dr. Lee also stressed that the agencies have a great degree of autonomy, although they do collaborate with each other.
- * Given that DHHS has not agreed to the requested cross-DHHS meeting and has not committed to a cross-agency strategic, coordinated, fully-funded response, other avenues should be pursued. Dr. Lee suggested approaches that include non-profit or private sector solutions and following up with CDC and NIH separately.
- * There are tactical opportunities that could be pursued in parallel and in partnership with CFSAC that include engaging as stakeholders in the case definition process that CFSAC committed to and finding ways to improve engagement and two way dialog within the CFSAC itself.
- * We also discussed the CDC CFS Toolkit. The link to the CDC CFS Toolkit has been removed from the CFSAC website which is very good.

Note that the Toolkit is still on the CDC CFS website itself. We will have to pursue that separately.

The need for a cross-DHHS strategic, coordinated, fully-funded response, developed with

meaningful stakeholder input is as critical now as it ever was. However, it was clear from this meeting that we will need to use alternative approaches to make incremental progress while working toward the full objective. Besides the approaches suggested above, there are also legislative and other non-governmental options. Given our community's limited resources, we will prioritize those activities that are most critical to both our short and long-term success.

If you have ideas on the areas that you would prioritize that you'd like to share, please share them with your organization or send them to MECFSACTION@Yahoo.com. We'll summarize any ideas we get in and share them back with the community.