Glass Half Full - CFSAC, January 2017

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Chronic Fatigue Syndrome Advisory Committee meeting
Washington D.C., January 12-13, 2017
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Several of our members attended the meeting of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) or gave public comment Libby Potter, Leah Williams, Robie Robitaille, and myself. It was frustrating for those who tried to watch or listen from home, as the technology was much inferior to that used for previous meetings, due to the location of the meeting. We didn't know about that in advance, and there should have been better instructions for those attending remotely. For those able to attend in person, it was another reminder of the importance of face to face interaction and being able to get to know one another at least a bit. Informal conversations can lead to better understanding and make it much easier to work together going forward.

Near the beginning of the meeting Carol Head presented an impassioned plea for the CFSAC to recognize the urgency of the ME/CFS public health crisis and to take immediate steps to become a more effective body. Several committee members made suggestions, as did the advocates in attendance, some of these suggestions relating to how members of the public attending in person could participate in the meeting. This set the tone for the rest of the meeting.

Over the course of this meeting it began to feel more like we were all one team, committed to the same goals and working to solve problems together. The group discussed the process and how it could be improved – in the past, the Committee has written recommendations to present to the Assistant Secretary without much input about whether they were actually realistic, given constraints the various agencies have. This has resulted in frustration when responses were negative or inadequate, and no concrete action or progress resulted, or the agencies' actions were not what was recommended. The agency representatives offered to work with the committee members to write the recommendations in a way that they could be implemented, and on second thought, if we all agree on what needs to be done and can be done, why wait to start doing it?? So at least the working groups for stakeholder engagement and pediatric ME/CFS are using this model and working directly with their agency partners. Thanks to patient representative and member Donna Pearson for pioneering this approach by inviting Dr. Unger to participate in the P2P/IOM working group along with advocates and committee members. In addition, Beth Collins-Sharp, who serves as Director, Division of Program Innovation, in the Office on Women's Health, will be working with CFSAC's new DFO Gustavo Seinos to develop meeting procedures which are more inclusive of patients and the public, as well as put together a document outlining the Committee's Operating Procedures to provide a knowledge base and starting point which can be improved over time.

Some other highlights:

- SSA medical education efforts –Social Security Administration ex-officio Cheryl Williams described the SSA initiative to educate adjudicators and contract doctors about ME/CFS. SSA has stayed up to date regarding ME/CFS, publishing a new ruling, 14-1p (https://www.ssa.gov/OP_Home/rulings/di/01/SSR2014-01-di-01.html), in April 2014, which incorporated features of the CCC and ME-ICC diagnostic criteria and specifically recognized ME. A policy interpretation ruling, DI 24515.075 (https://secure.ssa.gov/poms.nsf/lnx/0424515075) Evaluating Claims Involving Chronic Fatigue Syndrome (CFS), was published in November, 2016.
- Working groups – CFSAC now has at least 3 active Working Groups: Stakeholder Engagement, Medical Education, and Pediatric ME/CFS (school nurses and education issues). Working Groups are critical because they can include members of the public (e.g. patients and advocates). The groups work between meetings, sometimes quite intensively, to research a topic and

develop recommendations, which can be responses (e.g. to the P2P/IOM reports) or plans of action. Their work is presented to the full committee for discussion and approval. While formal recommendations are the official output, implementation may not have to wait for direction from the Assistant Secretary, but may begin immediately by the members of the group. The Pediatric working group is at the implementation stage, the Stakeholder Engagement group is working actively with its ex-officios to coordinate planning for stakeholder involvement in each agency's program, and the Medical Education group is just getting started with 3 committee members, 3 ex-officios, and 3 advocates.

- NIH announcements – Much has been written already about the NIH announcement on funding for the RFA for Collaborative and Data Management Centers. The total amount is a bit over $29 million over a 5-year period (about $6 million/year), which NIH thinks will fund 2 or possibly 3 Collaborative Centers in addition to the Data Management Center. Many advocates were sorely disappointed since this is far short of the $250 million/year which is considered to be commensurate with the burden of the disease and relative to other diseases of similar burden. Advocates are also disappointed that the RFA was for a specific purpose and not a pot of money reserved for ME/CFS research which would encourage investigators to submit grants. NIH sees these Centers as the first step in building a solid infrastructure that will ground and coordinate sharing of results among researchers, as well as attract new researchers to the field. In addition NIH personnel will be actively involved in partnership with the Centers, which will facilitate two-way communication and education. We would all like to see more funding, and know that there are many qualified researchers whose grants were rejected. The re-invigorated Trans-NIH Working Group and the Special Emphasis Panel (SEP) for ME/CFS will help ensure that grant applications for ME/CFS get fair treatment, and NIH is committed to actively working with investigators to help ensure their applications are as strong as possible. Meanwhile private funding is supporting important research, and providing seed money which will enable new lines of research to be undertaken, and hopefully this will lead to more substantial funding from NIH in the future.

Thank you to our Board for enabling our attendance in person, which is so important. Because I was there, I was able to volunteer for the Medical Education working group, and others who will be in the group know who I am. I will participate in this group representing an "independent ME/CFS organization" with "strong connections to patients" as suggested in Chapter 8 of the IOM report, "Dissemination Strategy" (our Association was specifically named within this category). Without more education of health care providers, patients will never get the care and treatment they deserve, and a centrally planned, cross-agency strategy with federal backing will be more effective than whatever we can do alone in Massachusetts.