

Testimony

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I have been ill with CFS for more than 16 years, and I have never been more hopeful about CFS research than I am today. The NIH State of the Knowledge meeting showcased the current state of research, and identified key opportunities and challenges in the field. Out of necessity, I watched that meeting from my bed, but I saw researchers who were engaged, interested, and ready to solve CFS. Dr. Francis Collins and Secretary Kathleen Sebelius both appear to be paying more attention to CFS than any previous Director of NIH or Secretary for Health and Human Services. All of this gives me hope.

But hope is not a plan.

Committee members, we need a plan. As Dr. Baraniuk said at the NIH meeting, we need a Manhattan Project for CFS. Researchers must communicate and collaborate across the discipline silos that separate them. The CFS case definition is a barrier to success, and we need standardized data elements and outcome measures. Existing resources for data sharing and clinical networks must be leveraged. The current federal budget climate requires creative leadership on CFS so that progress may accelerate, not stagnate.

I submit to you that this Committee could choose to play a key role in developing such a plan. You have been appointed to serve because you already have expertise across many fields. You have access to ex officio representatives from almost every relevant federal agency. This Committee exists to advise the Secretary, and that Secretary may finally – finally - be willing to listen.

I have hope, but hope will not make me well. Research will. Research – high quality, rigorous, well-designed research – is the only way to find answers that will restore the health of children and adults with CFS. But the traditional research model, with individual scientists working in individual labs scraping for enough federal funding to run another study on 50 patients, is not working. We need new verbs in the CFS lexicon: coordinate, prioritize, innovate, share, strategize, act.

There is more political will to solve CFS than at any time in the history of this illness. Scientists are ready to collaborate on research into biomarkers, diagnostics, and treatment. What we need is a plan. Not just one agency's strategic plan, or one researcher's sense of priorities. We need a comprehensive plan that takes the whole CFS landscape into account.

I hope that you will undertake this crucial task.