

Testimony

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To the voting members of this committee: I believe that all of you serve with the best interests of CFS patients in mind. Therefore, I assume that the inaction of the Department of Health and Human Services frustrates you, as it does me.

Look at the track record for your own recommendations to the Secretary. Over the years, this committee has made recommendations on a variety of topics, including:

- Regional centers for research and clinical care
- Healthcare provider education and training
- Use of the name ME/CFS across all DHHS agencies
- Research funding commensurate with the burden of this illness
- National effort to arrive at a new consensus case definition
- Coordinated best practices for efficient and effective patient care

No meaningful action has been taken on these recommendations. Secretary Sibelius has given lip service to the importance of this committee, but does not seem to take your advice.

The most urgent need for action is more research funding. Five years ago, you recommended that NIH issue a new Request for Applications on CFS. It didn't happen. Many patients expected new funding to be made available after the April State of the Knowledge meeting at NIH. It hasn't happened. Today, we urge you to recommend that NIH issue an RFA for CFS research backed by at least \$10 million in funding, and that this RFA be issued in the next six months.

Despite all the woe-is-me budget talk we've been hearing from federal officials, we know that money is available. Dr. Anthony Fauci's appropriation of \$2 million for the Lipkin XMRV study proves that. Money is available, but Secretary Sibelius, Dr. Francis Collins, and Dr. Thomas Frieden are making conscious choices to spend the money elsewhere, on illnesses that are a "higher" priority. That is a value judgment not based on the facts. NIH's FY2012 budget request is for \$32 billion. Can anyone seriously believe that there is no money in that budget to increase research on CFS? Do you believe that this massive budget cannot be squeezed to find a few extra million for CFS research? The current level of NIH funding for CFS research is minuscule relative to the size of the problem and the total resources available to NIH. The money is there. It's just that DHHS does not think we are worthy of it.

At the State of the Knowledge meeting, Dr. Collins said that Secretary Sibelius had directed NIH and other agencies to give CFS "special attention." I say we test this alleged commitment to CFS. Send a recommendation to the Secretary that NIH issue a \$10 million RFA for CFS research in the next six months. At the next meeting of this committee, we can see if "special attention" actually translates into meaningful action.

While DHHS fiddles, our Rome – our lives – are burning. Physician education? We do that every time we go to the doctor. Consensus case definition? Researchers and clinicians – not NIH or CDC – have participated in devising case definitions based on true evidence. CFS research? We fund that ourselves. Non-profits are funding pilot research that can then secure government funding. And it is patient advocates who have provided accountability for government research funding, compiling data showing that many of the grants NIH counts as CFS-related are not.

We are doing all this work ourselves, in cooperation with researchers and clinicians. Voting members, help us by pushing harder, by demanding meaningful, measurable action. Pass a recommendation today that NIH issue a \$10million RFA for CFS research in the next six months, and at your next meeting, examine the action that I hope will be the result.