

Testimony

Robert Miller

Good Day, Mr. Chairman, members and ME/CFS patients, especially the young patients here today and for those at home watching.

I'm Robert Miller, an ME/CFS patient of 25 + years from Reno, NV. CFSAC members, We patients thank you for listening today and for your continued efforts to help this patient population. I also wish to thank Wanda Jones and her staff for all their assistance.

I wish to start today with a thank you to President Obama for promising my wife Courtney at a Reno Town Hall meeting that he would talk with NIH, see what they could do to increase scientific research on CFS. In her short question, she was able to contrast the multi-billion dollar costs to US taxpayers for disability, Medicare and lost tax revenue with the paltry \$6 million NIH spends annually for research that affects 1-4 million Americans, and ask for his help for our family and for others suffering.

President Obama invoked his faith, stating that God gave us brains to figure things out and to make our lives and our environment better. Mr. President, your response gave me faith again. I've always had faith that science would improve my health, like it has for HIV and cancer patients and based on my own family's history of involvement in clinical trials for cancer treatments. But I know that science won't improve the health of CFS patients if there is no funding for scientists to study us. There is no funding now. I have faith that you can change that, Mr. President, and I am in your debt.

Today I call on this committee to make a bold and specific recommendation on funding.

Here we are after the SoK(State of the Knowledge) just weeks ago where researchers, clinicians and scientists were discussing many important findings, but with a chorus of statements that they have no money for studies and research, or the grants are so small they cannot study subgroups. How is it that illnesses comparable in disability and overall costs to the U.S. -- such as Multiple Sclerosis and Autism -- have NIH funding of between \$150-\$200 Million annually, yet CFS has only \$6 million? How is there no Center of Excellence for CFS, while there are 11 Centers of Excellence for just one of those illnesses? There are Five Centers of

Excellence for alternative medicine funded by NIH, which I believe is probably of general benefit, but no Centers for CFS. Please understand I support that level of funding for MS and Autism and other illnesses which were dismissed for decades as psychological or behavioral -- just like CFS. I cite them to show that the NIH knows how to attack an illness and they know how to produce the science that changes the lives of ill Americans. They just aren't doing it for CFS.

CFSAC has made a recommendation for CFS Centers of Excellence 6 times in the last 7 years. I am perplexed that even though the Senate Appropriations Committee directed the NIH to implement your recommendation to establish Five Centers of Excellence in its 2008 budget, yet none have been set up. NIH has ignored your recommendations for years and ignored directives from the Appropriations Committee in 2006, 2008, 2009, 2010, and 2011 to aggressively tackle CFS research. That needs to end now.

NIH must use their "God Given Brains" to attack this illness. That will only happen with NIH Funding, Funding, Funding... So that burden falls on you CFSAC members. It is time for CFSAC to make a specific recommendation on funding. I call on you to request and recommend that NIH reach a funding level for ME/CFS of a minimum of \$100 Million annually by fiscal 2014. NIH was able to do this with Autism, MS, HIV and many other chronic illnesses. And their progress in treatment is a beacon to us.

Before I get up from this table, NIH reps. and other agencies around the room will start talking you down. I've never heard a staff representative on this committee acknowledge what everyone in government knows – that \$6 million is pennies. It is the same level of funding NIH gave to CFS in 1992, when CDC estimated only 13,000 people had the illness. Now CDC estimates 4 million patients. Taxpayers spend pennies on CFS science and pounds – billions of pounds – on disability, Medicare and lost tax revenue. Please do not let staff tell you, you can't make a funding recommendation, this is your obligation to all us ME/CFS patients. It is the responsible thing to do for patients and taxpayers, and now is the right time.

Thank you,
Robert Miller

Clip of President Obama "promise".

<http://www.youtube.com/watch?v=U2IFtkXofss#t=47m01s>