

April 26, 2010

Greetings from a person disabled with CFIDS for 21 years, sick from it for 28 years,

Obviously, I am in favor of extending the CFSAC charter. Last October's online video of the meeting was the first time in my life that I have had any encouragement for the idea that maybe someone in my government gives a damn about me and the illness that has taken my life without quite killing me.

I am very disappointed that this year's conference is to be shortened to one day and that testimony is to be shortened to 3 minutes. Please don't "balance the budget" on the backs of CFS sufferers. We've been shortchanged for too long, as it is.,

I paid taxes for 20 years before becoming disabled and would have been paying substantial taxes for the last 25 years if this illness had been taken seriously by my government.

I find that the autism community has a much better charter than ours:

*"The Committee shall (1) develop and annually update a summary of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or ruling out a diagnosis; intervention, and access to services and supports for individuals with autism spectrum disorder; (2) monitor Federal activities with respect to autism spectrum disorder; (3) make recommendations to the Secretary of Health and Human Services (Secretary) regarding any appropriate changes to such activities, including recommendations to the Director of NIH with respect to the strategic plan; (4) make recommendations to the Secretary regarding public participation in decisions relating to autism spectrum disorder; (5) develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorder research, including proposed budgetary requirements; and (6) submit to the Congress such strategic plan and any updates to such plan."*

Since we who have CFS generally do not have parents with money and energy to advocate for us, we are at a distinct disadvantage in getting the attention of those who control the purse strings. I am asking that the above mentioned features of the autism committee's charter being used in forming the CFSAC charter. They have 5 members from NIH!

This committee comes up with a strategic plan for research, submits it to Congress and NIH, including budgetary recommendations. You know,.....what the CFSAC has been saying for years that it cannot do. Only 18% of recommendations from prior CFSAC meetings have been put into practice. This is not acceptable.

The per patient amount of research money allocated to CFIDS is just about the lowest of any illness! This is not acceptable!

According to the NIH website, chronic fatigue syndrome got NO MONEY for research in 2009, an estimated \$5 million in 2010 and is slated to get \$5 million in 2011. This paltry sum

despite the recent discovery of XMRV, implicated in CFS, and lots of other private research showing possible biomarkers.

The Whittemore Peterson Institute in Reno NV was started with \$5 in private donation because the Whittemores could find nothing to help their daughter who suffers from CFS. They found XMRV in less than two years. The Federal research on this illness is disgraceful!

The only illnesses that are slated to receive LESS than CFS are hay fever, Pick's Disease, and vulvodynia !!!

Diseases getting more \$\$ than CFS:

AGING (Is that a disease? We who have CFS die about 15 yrs. earlier than normal): \$3172 million

ARTHRITIS: \$259 million

AUTOIMMUNE DISEASE: \$923 million  
(since CFS is thought by many to be all or partly involved in the immune system, why isn't some of this money going to CFS research?)

BATTEN DISEASE: \$6 million (why is this getting 20% more than CFS?)

COOLEY'S ANEMIA: \$22 million

CYSTIC FIBROSIS: \$90 million

DYSTONIA: \$ 17 million

**FIBROMYALGIA: \$12 million**

FRAGILE X SYNDROME: \$ 29 million

HEALTH DISPARITIES: \$ 2970 million

HIV/AIDS: \$ 3184 million

HOMELESSNESS: \$17 million  
(Many CFS sufferers have become homeless)

INFERTILITY: \$ 82 million  
(Many CFS sufferers have had to avoid having children)

LUPUS: \$ 121 million

LYME: \$ 26 million

MALARIA: \$116 million (1,300 cases in the US, per CDC !!!) (At least a million CFS sufferers, up to 10 million by the Reeves definition, in the US alone!!! Millions more worldwide...)

And the list goes on...

I have NOT earned at least \$792,000 in the last 21 years, NOT adjusted for inflation since 1988. That means that I have NOT paid approximately \$118,000 in taxes. Instead, I have received approximately \$137,000 in disability payments and thousands of dollars worth of Medicare and Medicaid.

Even if no one in the Federal government cares about our suffering and the loss of our lives and livelihoods, surely someone can see that not researching this illness costs the country more in the long run than does malaria, dystonia, infertility or fragile X syndrome.

Stop the disparity in research allocations!

Ignore us no more! Do right by us!

Thanks for allowing us to get rid of Bill Reeves at CDC; now please try to correct all the damage he did to us while he was there. All his psuedo-research is still polluting the CDC website and the "education" of the public and the medical establishment. The money he wasted cannot be recovered but the insulting idea that we are simply suffering from "stress" and "childhood abuse" can be removed from the website.

Thanks to Wanda Jones, who at least seems to respect us and understand our quandry.

Sincerely,  
Lilly Cooper