

Cort Johnson - Oct 13 Presentation to CFSAC

Whenever the CFS community asks for funding we always hear are that ‘money is tight’ - too tight to help out with CFS - as if doing so would somehow break the budget.

The truth is there's always money for the NIH to do what it wants to do. Every year even in the tightest budgets many diseases get substantial increases in funding. You can go down the list...over the past three years funding for Alzheimer's has shot up \$68 million, arthritis \$37 million, asthma \$64 million, atherosclerosis -\$62 million, COPD \$26 million....and - I've just gotten to the C's.... the list goes on and on. I could give you dozens of examples of diseases that got substantial funding increases during these ‘tough economic times’. But for a disease like CFS the money is always too tight. In fact, get this, earlier in this decade the budget for ME/CFS declined as the NIH's budget almost doubled.

The point is that there's plenty of money for the NIH to do what it wants to and there's never enough for it to do what it doesn't want to do and the one thing it has made very clear over the past decade in particular is that it does not want to do is spend even small amounts money on CFS. .

The Committee this session will talk with the people that hold the purse strings for CFS at the NIH: the Trans NIH Working Group - They have the opportunity to ask them what it is about the NIH that makes it so difficult for them to throw even pennies, in medical terms, at CFS.

The Trans NIH Working group should know - because under their charge of ‘stimulating CFS research - they have overseen the greatest decline in CFS funding ever. Since they've been in charge the 3 CFS research centers were closed. The Groups unwillingness to provide even nominal funding for what Vivian Pinn called the smallest RFA possible meant it took the ORWH three years to come up with the money to produce the Neuroimmune RFA.. After that all the Group could dredge up was a Workshop created to tell CFS researchers how to bypass the Working Group in their search for funds - an amazingly bald admission of how ineffectual they were at their core mission. Meanwhile funding for CFS fell to levels not seen in decades.

How could this happen? How could the NIH say year after year after year that even minimal resources are too much for a disease that strikes 1,000,000? The fact is that the NIH has been treating and funding a serious disorder that causes substantial disability like it's hay fever and CFS is not hay fever!

Now it's time to ask the Trans NIH Working Group why?

Dr. Koh last session said treatment/research centers for CFS seem so, so reasonable yet the Working Group has seemed to regard them as some unreachable fantasy. The Committee should ask why they have been advised again and again not to ask for that something for that seems to be ‘so, so reasonable’

Remember we are not asking for a lot of money. What we are asking for is basically chump change for an Institution that has a 25 billion dollar a year plus budget We at least deserve to know why they won't provide even that.

During his presentation Dr. Koh called CFS a 'vital area'; he said that 'there are far too many people suffering' and that 'we want to make progress in as many areas as possible'; all nice words but we've heard them before and the words are meaningless until money goes alongside with them - and the CFS Community should be very area that none was forthcoming.