

**CFSAC OCT 13, 2010 Testimony
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Number one.

I first looked at NIH CFS funding in 2003. In 2004 I presented an informal report to the CFSAC showing one or two new CFS grants funded per year.

In 2007, I was asked to present at the IACFS Ft Lauderdale conference. The funding session was introduced on a positive note. Look forward....look forward. Amid the spit and polish and subsequent glad-handing, I was the only one looking backward and asking WHY we had so few CFS grant awards over a 7 year time frame.

In my hands I had a comprehensive and admittedly complicated NIH funding report that showed through NIH data... a dismal past and a predictably negative future in grant awards for CFS.

Perhaps, because of the vast amount of knowledge one has to acquire about grant making, the ever changing policies at NIH and my own tendency to embellish, I took my eye off the ball.

Not so this time. Submitted to you today is my final report, a 3 page summary of a 10-year history of inadequate and inappropriate CFS funding.

This "follow the money" paper is based on Freedom of Info Act requests. We went from a funding rate of 24% (GAO report 2000) for grants where "CFS is the primary focus" to the current 5 - 6% funding rate for grants where "CFS is the primary focus."

I do not expect that these issues be explored today. This is a beginning. I stand by my information. I do not live in the world of science or academia or government institutions. I cannot present a scientific report or strive to deliver what those of you in institutions might expect. It is the best I have to offer. AND.... IT IS NOT ABOUT ME.

A decade ago, the NIH reported to the Government Accounting Office that yes, there was vigorous ongoing research. This is about accountability.

However, in the last 10 years, we have no evidence of NIH commitment to biological research where CFS is the primary focus.

NIH RESEARCH MATTERS: I recommend that the CFSAC begin an investigation of CFS NIH funding. The question is: Why has the CFS funding rate declined from about 24% in 2000 to the current rate of about 6 % . I am ready to support the CFSAC in this endeavor.

To the CFSAC members who are cycling off the committee...thank you.

Number two.

The 2007 CDC CFS External Blue Ribbon Panel report says...

Under placement of the CDC CFS program

Other considerations:

Need to develop primary prevention interventions: Bullet 2: Aging is accelerated in CFS patients which has implications for premature onset of obesity and osteoporosis.

AGING IS ACCELERATED. Is that a fact? Where is the research data? If it is a fact, then what is premature onset? For what diseases does this apply? What is the economic burden of a premature aging CFS population?

I had early onset of severe osteoporosis at age 44. I have taken supplements, hormones and medications none of which my body can tolerate. I have gone to endocrinologists. As you know, I am not mousy.

Now I am pushing 61. My bone density is a negative 5. 6... My spinal bones are disintegrating. The prognosis is horrid.

More importantly, as I skim CFS message boards, I see patients reporting ...I am 26, I am not making estrogen. I am 32. My bone density is a -4. This is not about ME.

Are we just CFS anecdotes, thus invisible and unimportant?

It is silly to study CFS prevention when we do not know what this CRUD is about.

After listening to patients for 25 years, I think aging is accelerated. Prove it.

It is imperative that scientists have money to do prevalence studies on premature aging in CFS.

Common sense tells me that the CDC and the NIH can develop a cautionary checklist for CFS patients, one that community doctors can use to look at indicators of premature aging.

I mean...they do not have to believe in CFS. I don't care. You confirm that CFS is poorly understood, but indicate that simple primary care for these patients include checking for markers of early onset diseases of the elderly.

What will you do for ME/CFS patients tomorrow. ACT NOW.