

**Testimony to the
DHHS Chronic Fatigue Syndrome Advisory Committee
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Good afternoon. My name is Amy Squires and for over 15 years I have worked with federal and state government agencies to help them achieve their missions more effectively. I bring a “good government” perspective to thinking about combating CFS.

With a relatively new and still poorly understood illness such as CFS, the government *should* play a critical role to seed research to define the illness, understand the causes, understand the most effective treatment regimes, and align the broader health system to support those who suffer from it.

So then I ask myself: What *is* my government doing? What kind of performance *should* I expect? How *would* I expect them to use my hard-earned tax dollars?

Well, I sure wouldn't expect what I just heard.

I have just heard testimony that tells me that the CDC since 2005 has spent upwards of \$11 million to study 30 CFS patients and publish 3 papers.

Let me repeat that: the CDC has spent \$11 million and all they have to show for it is the beginnings of a study of 30 CFS patients and 3 measly papers. So, basically, the CDC has spent \$11 million for some paperwork. And please, don't try to rationalize to yourself, or to any of us, that it's more complicated than that. At the end of the day, it really isn't.

This is not good government. This is a farce. It's insulting to taxpayers. It's insulting to patients and their families. And it is an absolute failure in leadership and a violation of the public trust.

I have worked on government contracts for much of my career. I am mystified by the information reported about CDC's contract activity and the apparent lack of meaningful results from it. When I've worked on a government contract, I've always had to perform and show results. When I've worked on a government contract, I've had to demonstrate superior results for the money the government had *already* obligated, *before* earning the Government's trust and confidence to obtain *further* funding. When I've worked on a government contract, I've had to compete with other firms so that the

government got the best service available, at the best value—or, I've had to have such specialized expertise *and* such a strong, demonstrated track record of exemplary performance and results that the government could feel comfortable in awarding a sole source contract.

So I think about how CDC has allocated \$11 million in funding and it just seems to me that there are probably a lot of companies that can produce paperwork—it really doesn't require specialized expertise, and many can probably do it a lot less expensively.

Of \$11 million allocated to CFS since 2005, several million are still sitting in an account somewhere, apparently waiting for the contractor to bill against the funds. There are enormous opportunity costs associated with the CDC's mismanagement of these funds. On the one hand, they *are spending money to get nothing*, and on the other hand, they are *tying up money* so that they get...*more...nothing*. It is as though CDC's mission is to spend as much money as possible to do as little as possible. What is this money sitting there for? The models that come to mind are: slush fund...entitlement.... Frankly, I don't know what to call it, other than Bad Government.

I look around and wonder, is anyone leading on CFS? And I see the example of the CFIDS Association. This year the Association successfully raised \$1 million for CFS research. It hired a science director to head up a comprehensive research strategy. It solicited proposals for research and received over 20. Imagine that, in one year: \$1 million, a science director, and 20-some proposals. Meanwhile, CDC has tied up \$11 million over the last 4 years and gotten 3 papers for it.

I think that comparison speaks for itself.

Yes, I do expect more from my government. I reasonably expect more for my tax dollars. And for bestowing upon my government my trust.

As I understand it, the CFS Advisory Committee's role is, among other things, "to advise and make recommendations to the Secretary of Health and Human Services about CFS, including the current state of knowledge and research..."

Well, from where I sit, the current state of knowledge and research within HHS is, quite frankly, appalling.

I believe you, the Advisory Committee, have your work cut out for you. And I believe you take your charge seriously, and I would ask you to do so more *assertively*. I would

encourage you to fully inform and fully advise the Secretary (particularly the incoming one) about the *utter failings* of the CDC's own research programs, about the *gross* mismanagement of millions of taxpayer dollars, and about the *complete abdication of responsibility* to the taxpayer and to the CFS patient who rightfully expects leadership from his/her government—leadership that we all have paid for. We as taxpayers and as individuals who suffer from CFS deserve no less.

There is a lot of work to do to conquer CFS. We can do it **if** we step up to the challenge. I hope my government will step up, because as of today, the track record is pretty poor. And millions of people suffer the consequences of this agency's mismanagement of the precious few dollars it has seen fit to bestow thus far on this significant public health crisis.

Thank you for giving me the opportunity to speak to you today.