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CFS Advisory Committee written testimony

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I do not know if anyone from the Department of Health and Human Services (DHHS) will actually read this testimony; over the years there has been little evidence of DHHS acting upon or even listening to the input from the ME/CFS, advocacy or medical sectors.

In each recent meeting of the CFS Advisory Committee (CFSAC) there have been portraits of patients who could not attend on the empty chairs. Each portrait represents not only that individual, but many tens of thousands of others who have been relying on the help of DHHS, reliance that has for the most part gone unanswered.

I ask that you look at those portraits and when you go home please look at yourself in the mirror. As you do so please ask yourself, "Has DHHS done all it could on behalf of ME/CFS patients? Have you done all I could?" I suspect the answers will be the same conclusions that most often the ME/CFS patients and the medical sectors have come to about DHHS's actions and inactions. The only objective conclusion is that DHHS has inadequately met its obligations set forth by the very principles with which DHHS was founded to help ME/CFS patients.

That is why there are so many empty chairs at the CFSAC meetings in recent years; patients have objectively lost faith that DHHS will act in their best scientific interest, or act at all in ways that will lead to patients eventually getting their healthy lives back. Years ago patients had hope and faith in the DHHS. CFS Coordinating Committee meetings were packed, sometimes with standing room only. The DHHS and most notably the CDC and NIH have proven to all the invisible hostages of ME/CFS that neither the input of patients, advocates nor medical experts has any significant influence upon what the agencies do pertaining to ME/CFS.

So too is this why so few doctors have been sending in grant requests; for DHHS has been no more forthcoming in funding for important biologic research of the illness than it has been in conducting such research.

The CDC CFS department's goal has been two fold. It has aimed to create a new CFS definition that narrowly focuses on dysfunctional stress response, ignoring most of the physiology involved in the illness. Such a diagnostic definition is not representative of true ME/CFS, but it does possibly define a larger population of individuals. As evidence of this, the department's epidemiology studies using the new criteria have captured a four fold greater number than studies using prior CFS definitions.

If anyone in the administration of the CDC or DHHS is in fact reading this, I beg you on behalf of all ME/CFS patients to please get back to studying the actual illness. Please give us a truthful commitment to use your resources towards that goal. Please make whatever administrative changes are necessary to reach that goal. And please give us evidence that the CDC, NIH and all of DHHS is truly doing all it can to give all ME/CFS patients their healthy lives back.