

STATEMENT FOR THE APRIL 27, 2009 CDC MEETING
REGARDING THE CHRONIC FATIGUE SYNDROME RESEARCH PLAN

I appreciate the opportunity to address the CDC regarding my views on its proposed research program.

I serve on the Board of Directors of The CFIDS Association of America. I am a Clinical Psychologist specializing in the treatment of people with CFS and their families and author of the book *Chronic Fatigue Syndrome, Fibromyalgia and Other Invisible Illnesses*. I have served on panels to develop educational curricula for physicians and for behavioral health professionals.

In addition I am a CFS patient who became ill in late 1984 – now in my 25th year of illness, having declined over the years and ultimately having become disabled in 2001. In fact I have been ill for approximately the same length of time as the CDC's involvement in CFS. This represents a sad silver anniversary; as I reflect on my years with the illness and the CDC's inadequate efforts over that time, it would be accurate to say neither of us has made any significant progress.

The history of the CDC in regard to CFS is dismal, beginning with assigning a name both trivializing and inaccurate, an inadequate and inaccurate case definition, misappropriation of funds and poor-quality research, in terms of both the focus of its studies and its methodology. The CDC has not had a meaningful or significant impact on our understanding of the illness or how to treat it.

Along with quite a few people from the CDC, I served on a committee whose purpose was to develop an educational curriculum for professionals. To my disappointment, those from the CDC were ill-prepared to make a meaningful contribution and did not seem to have an accurate understanding of the illness.

The CDC has acknowledged that CFS is a complex, chronic illness that affects millions of Americans, one that costs our nation a considerable amount of money in lost productivity and wages, medical costs and disability benefits and that it therefore merits immediate action and rigorous study. However the CDC, although in a unique position to make progress in the understanding and treatment of CFS, has continually failed to do so.

The CDC has invited comments regarding its five-year research program for discussion at its May 27, 2009 meeting but on short notice and without prior release of the details regarding this program. Unfortunately this seems to be consistent with CDC's slipshod approach to the study of CFS over the years – lip service without evidence of any real planning or commitment behind it.

The CDC and others have conducted an abundance of studies of psychological and psychosocial aspects of CFS and epidemiological studies with continual revision of the estimated number of persons with CFS. Given the large number of people with the disorder, I am dismayed with the relative paucity of attention to the pathophysiology, cause(s), biomarker(s) and treatment of CFS, obviously not a priority to the CDC.

The lack of shared data from previous CDC studies another roadblock to progress. Researchers operating in a vacuum rather than cooperatively will not solve the puzzle that is CFS. I urge the CDC to share their data – not just their findings but

their raw data - and to work collaboratively with non-CDC researchers to get the answers we need.

Sadly, the CDC has not appeared to be very interested in delving into CFS with the necessary rigor to make significant progress and I fear that the program currently under discussion will be more lip service that results in little participation by the CDC in meaningful CFS research.

It is my understanding that no one in the CDC attended the March, 2009 symposium presented by the International Association for ME/CFS in Reno, Nevada. This is a strong indicator of the CDC's lack of desire to keep abreast of recent research developments, hardly a good sign of interest in moving forward by building on existing knowledge.

To summarize, my suggestions for the CDC's 5-year plan for future research is as follows:

- Adoption of an accurate case definition, e.g., the Canadian case definition.
- Shared Data: The CDC should allow open access to all research-related data. Cooperation and collaboration with researchers in the public and private sectors are vital to assembling the puzzle pieces of CFS without unnecessarily duplicating research efforts.
- Rigorous Science: The CFS Research Program should be directed toward the meaningful study of CFS – its pathophysiology, cause(s), marker(s), treatment and ultimately its cure. A purposeful effort and timely, well-focused research, rather than a scattered, half-hearted approach, is necessary to achieve this goal.
- Spending and accountability: Curtail excess spending to delegate funds to a focused and relevant research program.

The CDC's consistent lack of meaningful involvement, wanton spending practices and lack of progress have been a continuing, dismal disappointment to those of us who have CFS and/or assist and advocate for those who have CFS. We need to see a definitive plan and steps to implement that plan to know that the CDC is dedicated to progress in CFS research.

Efforts to date have merely compounded the loud and clear message that the CDC does not take CFS seriously and has no organized approach to investigating this complex and devastating disorder. I would like to believe that the CDC takes CFS seriously and is willing to dedicate the necessary funding, concerted effort and rigorous, high-quality research necessary to achieving real progress, although I have serious doubts that this is the case. I have little to be optimistic about when I examine past lack of performance. By the CDC's own count, millions of lives rest upon its decisions and follow-through. I would like to believe that this time will be different.

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