

PRESENTATION TO CDC
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My name is Jennifer Spotila, and it is my honor to serve as Chairman of the Board of Directors for the CFIDS Association of America.

In November 2006, I sat in a room at the National Press Club and participated in the launch of the CDC's public awareness campaign for CFS. Then-Director Dr. Julie Gerberding called CFS an "urgent reality," on par with avian flu. Swine flu might be a better choice today. And then-Assistant Secretary for Health Admiral John Agwunobi announced 7 new NIH grants, saying, "There's so much more research that needs to occur. We're pleased to announce this work, but we also commit to doing more as time goes on." The promises made that day in November 2006 have faded away.

Today, you have requested input only "on the CFS strategic research plan, not on CDC's overall CFS program." Strategic plans are forward-looking, but not to the exclusion of looking back. In order to draft a strategic plan, CDC must consider its overall CFS program, including the ways in which the program has fallen short or failed. Given the narrow invitation you have extended to stakeholders today, asking us to comment only on the plan and not the overall program, I wonder whether your internal planning process has been similarly myopic.

Your "Draft Strategic Research Plan General Outline" was made available for stakeholder review only five days ago. This outline is so devoid of specifics that the only input I can offer is to point out what is missing.

What is the priority order of the four goals? What funding needs have been identified? How will funding be allocated among the goals? What are the milestones and performance measures? Will you continue the use of third-party contractors for research studies? What are your plans and timeline for data sharing? How will you engage extramural researchers? Does the absence of any reference in the draft outline to patient registries or sample repositories mean that those initiatives will be abandoned? How, exactly, do you propose to develop international consensus on the management of CFS? Will you continue the use of the empiric criteria for CFS? What efforts will be made to expand use of those criteria by other researchers? I could go on.

Your general outline could have been written two years ago, or ten. "Refine understanding of the etiologic pathways," "improve clinical management," "move CFS into the mainstream." Yes, yes, of course. There is nothing new in this list of objectives. There is no specificity, no measurable commitments, and no accountability. There is no acknowledgement of the many problems in the CFS program, and no plan to fix them.

I offer my own list of immediate priorities:

1. Move quickly to utilize systems already in place to release the program's research data to other investigators.

2. Conduct a thorough audit of the program's use of funds and failures in oversight. This review should be conducted by personnel outside the program, and should include an examination of the program's practice of obligating funds to third-party contracts despite their lack of performance.
3. Focus on defining and diagnosing CFS through a multidisciplinary effort to identify objective biomarkers.

CDC may be an institution committed to excellence, but the CFS research program is losing its vigor and relevance, however excellent individual program personnel may be. If CDC fails to address the systemic problems within the CFS program, if corrective measures are not undertaken to address the wasteful spending and lack of accountability, then any five-year strategic plan will not be worth the paper it is printed on. Moreover, the opportunity costs of allowing these conditions to continue are incalculable.

My input is this: CDC is uniquely positioned to have enormous impact on the state of CFS research, but the CFS program is falling behind and failing its mission. Until you fix that problem, until the program is reinvigorated by accountability and purpose, you will be a barrier to success instead of being a part of it. Fix that problem, and you can truly create a new landscape for CFS.