

To: Chronic Fatigue Syndrome Advisory Committee
From: Jennifer Spotila, J.D.
Date: September 16, 2010

I congratulate the Committee on the renewal of its Charter through September 2012. I also commend the Committee for convening scientific review sessions on October 12, 2010. Given the pace of developments in CFS research and related issues, the Committee's work is of critical importance.

Assistant Secretary Howard Koh told this Committee that, "[W]e're hoping that this new administration can work more closely with you on CFS as we move forward...We are committed to continuing the momentum here." Dr. Koh also admitted that he "wants the Department to do better" in responding to the Committee's recommendations. (*Minutes of May 10, 2010 CFSAC meeting*).

CFS patients have heard this before. At this Committee's meeting on July 17, 2006, then Assistant Secretary John Agwunobi acknowledged, "I'm not so sure that we've done everything we can in the past to support this Advisory Committee's work." (*Minutes of July 17, 2006 CFSAC meeting*). Dr. Agwunobi promised that DHHS would do more to help CFS patients.

More than four years have passed, and CFS patients are still waiting.

We are waiting for federal research funding in proportion to the economic and human toll of CFS. We are waiting for objective, validated diagnostic biomarkers. We are waiting for consensus clinical care guidelines. We are waiting for widespread healthcare provider education. We are waiting for treatments. We are waiting for a coordinated federal response to CFS that is more than lip service, more than promises, and more than just more of the same.

Interest in CFS-related research is at an all-time high. You have an extraordinary opportunity – right now – to propel CFS into the mainstream and on to the agenda of Secretary Kathleen Sibelius. This Committee must secure the support of DHHS leadership for FY2011 investment in NIH extramural CFS research at double the FY2010 level. FY2012 investment in CFS research must double again. Surely you see the urgent need for CFS research, as well as the urgent need for coordinated efforts among federal agencies.

I challenge this Committee to hold Dr. Koh to his commitment to continue momentum. Send Dr. Koh immediately actionable recommendations aimed at tangible improvements in the federal response to CFS. Do not settle for anything less than true and meaningful change.