

The CFIDS Association of America

Working to make CFS widely understood, diagnosable, curable and preventable

STATEMENT TO THE
DEPARTMENT OF HEALTH & HUMAN SERVICES
CHRONIC FATIGUE SYNDROME ADVISORY COMMITTEE
OCTOBER 29, 2009

My name is Kim McCleary and I'm president & CEO of the CFIDS Association of America. I am grateful for this timely opportunity to address members of the CFS Advisory Committee, the ex-officio agency representatives and the public – here and viewing the videocast. I believe I hold the unique distinction of having attended every single meeting of this committee and its predecessors since they were first opened to the public in 1993. This morning's session was the best session of this committee, in my memory. I extend gratitude to Dr. Wanda Jones for inviting Dr. Peterson and Dr. Coffin to address the committee and the public on the important XMRV research.

A lot has happened since that first open meeting 1993, and at the same time, too little has happened. In fact, a lot has happened since the most recent CFSAC meeting in May, and (again) too little has happened.

Since 1993 a few facts have been documented beyond dispute. CFS is a very real condition and it seriously affects the lives of millions of people worldwide who have it, and people who love those who have it. CFS is complicated. Whether it's caused by a retrovirus called XMRV or it is the result of multiple genetic and environmental factors, including one or more agents acting together, it has defied explanation for a quarter of a century.

What we knew in 1993 and what we know today is that we need more research. We need better medical care. We need more people – especially doctors – to understand and to care about CFS.

But what has stumped this panel of CFS experts and all of us who have taken part as advocates over the years is how to mobilize our federal resources to accomplish those things. There is now the scientific momentum to fuel mobilization.

Notably, the National Institutes of Health has participated in the XMRV research through the National Cancer Institute's intramural program and the National Institute of Allergy and Infectious Diseases recent grant to the Whittemore Peterson Institute to support expanded research on XMRV. NCI director Dr. John Niederhuber has reiterated his institute's support of continued research on this topic to understand the relationship of XMRV to human disease, including CFS and prostate cancer. He also provided very helpful interim guidelines, at the Association's request, to help patients, family members and the public while this research expands.

In addition, the NIH's Office of Research on Women's Health collaborated with the CFIDS Association to host a meeting of funded investigators last month at Cold Spring Harbor Laboratory's Banbury Center, with the outcome of unparalleled consensus that a formal research network linking CFS investigators would propel the field through enhanced communication, establishment of best practices and implementation of standardized operating procedures for CFS studies. The XMRV research, and many of the issues discussed after the lunch break, could be immediately enhanced if this network

existed. We are moving forward to implement recommendations arising from the Banbury conference to create this network. In the meantime, the CFIDS Association, like the WPI, is helping to coordinate with researchers in the U.S. and abroad who have genuine interest in replicating XMRV research.

In spite of this very recent progress, NIH funding for CFS is at the same level it was in 1993. There are many avenues of scientific investigation worthy of NIH support, and it is important not to lose sight of the many body systems affected by CFS that warrant continued study. We urge the CFSAC to recommend that NIH immediately issue an RFA to capitalize on increased interest in CFS research arising from the XMRV publication and the promise of a formal research network.

Six months ago when this committee met, the CDC presented a draft five-year strategic plan. The agency reports having received almost 1,200 “items of correspondence” about its draft by July 30. The final version distributed today incorporates some welcome additions, including recognition that the empiric criteria should be re-evaluated as the foundation for CDC’s research. However, the repetitive emphasis on psychosocial features, risk-conferring behaviors and chronic unwellness reflects a disregard for and/or dismissal of the major criticisms of the draft plan loudly and plainly echoed by organizations and individuals at public meetings held in April, May and in written correspondence. I am reminded of the first public ICC meeting in 1993, held in Atlanta, at which federal agencies threatened to define CFS out of existence by eliminating the 11 symptom criteria and focusing solely on chronic fatigue. Now, this CDC plan imposes a similar death sentence. We implore the CFSAC to aggressively challenge this plan to protect hard-earned progress of the past 16 years and not waste \$25 million that should fuel important research.

In conclusion, the federal resources being applied to CFS must catch up with the magnitude of this condition, and must – at least – match the proportion of private investments. The momentum is building, and the time is now to solve CFS.

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President & CEO