

# The CFIDS Association of America

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

## **CFS Advisory Committee Meeting**

October 14, 2010

Public Testimony of Kim McCleary

My name is Kim McCleary and I am president and CEO of the CFIDS Association of America. Thank you for the opportunity to speak again before the committee. Yesterday morning, Dr. Jones began with a brief apology for technical difficulties that placed one of the video engineers in the middle of these tables as things were getting started. She explained that while this wasn't "Dancing With the Stars," webcasting the meetings sometimes means production delays. The reference to the glitzy tv show sent a little chuckle through the room. But for many people in the CFS community, this meeting is like Dancing With the Stars. There is anticipation about the agenda, sometimes forceful reaction to the lineup, and always color commentary and judging of the performances.

Dr. Jones, you have brought the lights and the cameras to these meetings, and I'll add my urgent request to others' for the action. In the first two days, we've seen some stars of CFS research, who give hope for better diagnostics, evaluation tools and therapies. And I was proud that many of the presentations we heard were started, sustained or in some way supported by the CFIDS Association of America. Yet, listening to moving testimony given by individuals with CFS and their caregivers, people who make real-life personal sacrifices to participate in these meetings, a common theme I hear is that they want the respect for CFS that exists in this room – among these experts – to extend beyond those doors. They want – we want – CFS to be a mainstream medical concern met with the level of research funding, clinical attention and societal concern that its magnitude truly warrants. In fact, that desire for respect and recognition is also common among the researchers who pursue CFS (even though it is not a well-funded area or a sure path to tenure), as well as the health care professionals who care for CFS patients, help them document disability and validate their suffering, even though reimbursement is generally uneven and disproportionate.

The CFIDS Association is pleased the CFSAC charter was renewed and that several of our recommendations were implemented, particularly the addition to the committee of representatives from AHRQ and CMS. Thank you, Drs. Jones and Snell for your leadership through that process. At the meeting this past May that requested testimony to shape the charter renewal, I urged that the committee's charter be revised to reflect the authority to develop a cohesive, comprehensive research agenda for the Department of Health and Human Services to serve as a blueprint for the health agencies, academia, industry and nonprofits to meet the challenges of CFS head-on. Even though that change did not make it into the new charter it is entirely consistent with its purpose. I renew my strong recommendation for the committee to develop such an agenda that identifies the most important ways in which each agency could perform its mission in the context of CFS – many institutes at NIH, several centers at CDC, different functions at FDA, guidelines, training and quality assurance at SSA and the health care reform initiatives under way at HRSA, ARHQ, and CMS. A cohesive research agenda would propel scientific momentum that has accelerated over the past year with the increased attention and focus spurred by XMRV; establish accountability and benchmarks for each of the federal health agencies; provide pharma and

other industry concerns with incentives to address a vastly underserved market; and help synchronize efforts by not-for-profit organizations that have been the engine of innovation and empowerment for the past 25 years. It would also be a potent tool for advocates to cultivate engagement by Congressional authorizers and appropriators. Aging, autism and rheumatoid arthritis are just three of the many fields that have benefited from coordinated federal research agendas.

I attended the first public meeting of the predecessor of this committee 17 years ago, and I've been to every meeting since. That 1993 meeting was transformative for me in my work for the Association and on a personal level. It was there that I learned how much we as citizens have a right to expect from our government. This committee has the opportunity to be transformative today by making the kind of bold recommendations that form a progressive, aspirational agenda for immediate action with long-term impact for every person living with CFS and for every person who has given something of themselves to solve CFS.

Lights, camera, action.

(For more information about the October 2010 meeting of the CFS Advisory Committee, please see <http://www.cfids.org/cfidslink/2010/110403.asp>)

(You can watch this testimony at [http://hhs.granicus.com/MediaPlayer.php?view\\_id=5&clip\\_id=105](http://hhs.granicus.com/MediaPlayer.php?view_id=5&clip_id=105) by selecting "Public Comment – Speaker 5" from the index.)