

Testimony

Christine Williams

Good morning. Thank you for the opportunity to provide public testimony today. My name is Christine Williams and I was privileged to have served as an Ex-Officio to the CFSAC for the Agency for Healthcare Research and Quality until my retirement from the federal government in June of this year, after 30 years of service.

I spent my career in health policy and health services research - about half of the time on Capitol Hill as the senior health policy staff to the Senate Majority Leader, George J. Mitchell (D-ME), and the balance at the Agency for Healthcare Research and Quality (AHRQ).

In August of 2008 I had a sudden onset of flu-like symptoms that never went away. I spent 7 frustrating months having doctors telling me there was nothing wrong with me - or that I wasn't "tired enough" to have CFS/ME. Through my own persistent on-line searching I found a practicing physician, with expertise in CFS/ME, who determined that I had 7 of the 8 symptoms established by the CDC.

My illness significantly affected my personal and professional lives. I was no longer able to travel for business, needed to work at home on a regular basis, and too often did not have the energy to attend meetings to develop partnerships for the Agency, which was my primary job.

Because I was determined to complete the remaining 2 1/2 years of federal service so I could retire, I spent most of my limited energy working. I had to decline most after work activities with my husband or friends. I spent evenings and weekends on the couch trying to rest so I would have the energy to go back to work.

And so, I was very relieved when I was able to retire in June.

I spent my career in government because I believe it can be a force for good and can make an important difference in people's lives. I have witnessed that positive impact both on Capitol Hill and in the Executive Branch.

The Department of Health and Human Services (HHS) has the opportunity and the ability to make an enormous difference in the lives of people with CFS/ME, but that opportunity has not been fully realized. I would like to make a few suggestions about how the Department might move toward maximizing that opportunity.

1) Leadership: The Department must provide public and active leadership to move the debate forward. The Secretary, Assistant Secretary for Health, Drs. Collins, Jones and Lee have all exhibited their commitment to this issue, but the commitment needs to extend to all levels in the Department and Agencies. And the leadership **must** be backed up with action.

2) Research: The Department, through NIH, AHRQ and other research agencies and divisions needs to be a leader in CFS/ME research, making it a priority, building on new studies and partnering with academic institutions and others in the field. "Reverse translational research" from clinical experience must be part of this effort.

3) International Consensus Criteria: HHS needs to be part of the dialog around the recently developed International Consensus Criteria, which demonstrates progress toward sharpening the case definition for CFS/ME. A more refined case definition could be the basis of improvements in focused research, patient registries, etc. The existing "babble" and broadness of case definitions is a barrier to meaningful research, and other critical efforts to find answers to this complex illness.

4) Convener: HHS can convene key stakeholders. The 2011 State of the Knowledge Conference at NIH was an important start - some of the researchers at the table had never connected before. HHS can create and

facilitate an ongoing “Learning Network” with these researchers and clinicians to help them “connect the dots” across disciplines.

5) Coordination across HHS: The Department must beef up its efforts to coordinate activities and initiatives across the agencies, through this committee or another group. Agencies should not duplicate efforts, need to know what others are doing, partner to maximize resources and initiatives, and **must** be a source of current scientific information on its websites.

Finally, don’t let difficult fiscal times and bureaucratic red tape be a barrier to progress. There are actions this Department can take now. Move forward on the CFS/ME name change and other existing recommendations from the CFSAC, which have been pending for some time.

When the AIDS epidemic hit in the 80s HHS rose to the challenge to find treatments for people who were dying.

Patients with CFS/ME have lives that have died. They are in beds and on couches watching the world pass them by. This Department needs to be a real leader in the search for effective treatments so that people can recover.

I know this great “Department of the People” can rise to the challenge.

Thank you