

From: Alyson Butcher [mailto:alysontom@yahoo.com]
Sent: Thursday, May 28, 2009 12:36 PM
To: OS OPHS CFSAC (HHS/OPHS)
Subject: Comments from Public Commentary on May 27

Thank you for having me.

My name is Alyson Butcher, and I flew in from Houston, Texas to be here. I am also happy to have my parents from Washington, DC and my cousin from Modesto, CA here to support me.

I am a CFS advocate and patient, and I do what I can to give a face and voice to the many CFS patients who are too ill to leave their homes. I'm 30 years old and have had CFS for my entire adult life; though I've only been officially diagnosed since 2005 because it took more than four years and four doctors to finally get diagnosed.

My original plan for today was to come and sit in on the entire advisory committee meeting, but my plans were foiled by my disease. This morning I woke up, ate breakfast, then took a five hour nap. My disease is a great frustration. This weekend my husband and I celebrated our fourth anniversary at Disneyland. The ONLY reason I survived the weekend is because my husband pushed me around in a wheelchair. I'm not going to explain how this disease has affected my marriage or quality of life right now because it will take more than five minutes.

I am here today to give you a sense of urgency. Not enough progress has been made in the education of physicians and other health care workers. My own mother-in-law who is a Registered Nurse does not really understand CFS. The doctors I went to before finding my current one were skeptical at best and completely dismissive at worst when I proposed the possibility of my having CFS.

More needs to be done more quickly on all fronts --educating health care professionals and the public, research on the disease including diagnosis and treatment. I've already lost my 20's; I don't want to lose my 30's. Please use your power and influence to help us move forward.

Thank you.