

**Public Comment**  
**Susan Kreutzer**

My name is Susan Kreutzer, I have requested the opportunity to speak today to express my continuing concerns with how the United States government is coordinating investigations, research and public dissemination of information related to the illness identified as ME/CFS.

I am a patient with this illness and I have personally experienced the systems in place to assist people with this illness in both receiving an adequate diagnosis, treatment, public services and public information. My experiences have been shocking to me and I believe wholly inadequate and shameful as it relates to how resources and information are provided by the U.S. government to individuals who have been afflicted by this complex and devastating illness.

I can provide specific examples of my personal experiences with medical professionals and institutions, disability insurers, social security administration and other third parties charged with assisting in research, investigation and dissemination of information about this illness.

I am fairly new to the CFS world, but in the very short time I have come to understand the history of this illness and the lack of progress that has been made for over 25 years to investigate, understand and provide adequate support to individuals affected, by this illness. I am saddened, angered and disheartened that this is the best the U.S. government can do to help a large group of disabled U.S. citizens. Please note that my criticism is directed toward the highest levels of our government, not at those individuals employed by the U.S. government who have worked diligently to try to effect change to the public understanding of this illness and the resources that can be effectively marshaled to provide adequate help for this illness.

I realize the time that can be allocated to any one individual giving public testimony before this committee is limited, therefore I am requesting that the highest ranking government officials in every agency, which this illness touches be charged to give this illness highest priority to coordinate a plan of action. In my opinion, the plans put together over the last 25 years by this government have not been sufficient to bring about the needed changes and dissemination of information that is needed across multiple levels of our government.

President Obama made a promise to a patient last year in a press interview that he would look into this illness and try to get the help that people with this illness needed. Mr. President and Secretary Sebelius of the National Institutes Health, I am urging and begging you to follow through on this promise. President Obama, you are the ultimate person in charge of all the agencies who have some impact with this illness and without your active help and oversight of what has gone on in the past with this illness, present and future I fear no substantial plan to help us will ever be implemented. I also fear that a significant portion of US citizens and patients around the world will not receive the care, attention and resources that this illness so badly deserved.

I apologize for any errors I have made in my written or oral testimony.

I am trying to communicate in a very short time frame with cognitive neurological deficits resulting from this illness. I am available at anytime if you or any person who is charged with the responsibility with overseeing this illness on behalf of the United States government would like to speak to me or my family to obtain additional information regarding my concerns, experiences and suggestions for how a plan could be implemented to afford positive changes in the government's response to this illness.

Thank you for time given me to speak publicly about my concerns.