Public Comment
Lori Chapo-Kroger

YouTube video testimony: https://www.youtube.com/watch?v=za1dMlESRuI

Hi, I'm Lori Kroger, President of PANDORA Org. Thank you for the opportunity to give public comment.

I know many of you have sincere interest in understanding this disease to help make a difference in the lives of patients. Some of you have a personal connection to the disease. And I can see when you become discouraged because you work hard for patients, but your motives are constantly questioned. You are frustrated when your agency is targeted by public criticism when you believe you are doing things that will serve the patients best.

I also know you're aware of the government's neglect, misappropriation of funds, and misguided research that is based on psychological bias. This soured the relationship and destroyed patient trust and we are very suspicious of any government plans with this disease.

It's like a marriage where one partner committed adultery and the Betrayal and Infidelity killed the trust. The burden is now on the adulterer to do all he can to gain back the trust of his partner. That means more communication of where he is, what he's doing and how long it will take. He must go beyond normal interaction and communication to show full commitment to never betray again.

Suspicion is always there so, one mistake of being a little late from work, and his wife will feel all those fears again.

A few agencies have improved communications. The FDA is having phone meetings where we can ask questions live. They want patient input and this creates a better relationship.

The CDC is working with ME/CFS experts and communicating with patient groups.

This is progress but it's very small.

Last year, you were asked if there could be more patient engagement by having patients be part of the ad hoc meetings. The answer was no. If the answer had been yes, it would have helped built trust.

There was a huge opportunity for HHS to build trust by engaging patients and our experts in solving the definition controversies. Instead, there was a break down of communication. You don't have a good track record so fear and loss of hope took hold.

We went to Wanda Jones, and to people at the IoM, and many others and asked a lot of questions.

The public needs to be informed of the answers so we asked you to put out an FAQ. You addressed some of the issues, but you left out the most important things.

One question that still isn’t clearly answered is why can't the HHHS adopt the CCC on the recommendation of ME/CFS experts and the IACFS/ME?

Dr. Wanda Jones mentioned to us some restrictions on the HHS's role on developing or approving clinical guidelines since a 1990s scandal on back pain that involved the AHCPR, now AHRQ. If there is some regulation or other congressional limitation that has prevented the HHS from endorsing the CCC without an IOM study, then why wasn't this communicated?

It wasn't mentioned when CFSAC members first discussed HHS adopting CCC in October of last year, wasn't mentioned in the spring CFSAC meeting when CFSAC members again asked why the CCC can't be adopted now, and it wasn't in the FAQ answers last month?

Instead it looked like you just don't like the CCC or don't respect ME/CFS experts.

Another question still not clear is why the HHHS didn't host a workshop primarily of ME/CFS experts. Dr. Jones said this has something to do with severe meeting restrictions put on government agencies due to a Department Of Defense scandal on meetings last year.
http://www.defensenews.com/article/20120916/DEFREG02/309160002/

If some congressional limitation prevents the HHS from holding a workshop of medical experts, as the CFSAC recommended in October a year ago, then why wasn't this communicated? It wasn't mentioned in the spring CFAC meeting and it wasn't in the FAQ.

If there is no regulation preventing you from adopting the CCC on the recommendation of experts, then why don't you do it? If there is no regulation from congress preventing you from hosting a workshop primarily of ME/CFS experts, then why don't you do it! Communicate"

If you want to improve the situation and build trust you must communicate, communicate, communicate, and be as transparent as possible.

Have more patient advocates as voting members of the CFSAC.

Have patients be part of the planning and strategy discussions between CFSAC meetings.

Don’t make any plans or announcements in response to a CFSAC recommendation without first communicating it to the CFSAC members.

When a public announcement is made, give an explanation of why this action is being done.

Offer to have a phone call with patients soon after an announcement where you can answer all their questions live. If the FDA can do it, so can you.

It’s a lot more work, but it takes effort to build trust in a relationship that is damaged by betrayal.