

Testimony

Andrew Bokelman

Thank you to the CFSAC for allowing me to speak. My name is Andrew Bokelman.

Before I became ill with chronic fatigue syndrome, I didn't take it seriously. But now I can tell you just how serious it is. In late 2005 I was hit with chronic fatigue syndrome. In January 2008, I was diagnosed with prostate cancer. Three months later I was diagnosed with a squamous cell carcinoma in my tongue. And now I also suffer collateral damage from cancer treatment. And after all of this, I can honestly say that having chronic fatigue syndrome has been much worse than dealing with two cancers. Because it is not cancer that keeps me from working and visiting friends. It is not cancer that makes me so sick I need help with basic personal care. It is actually chronic fatigue syndrome that has destroyed my life, as I used to know it.

Some people dismiss CFS because many of us don't look sick. But I also didn't look sick when I was diagnosed with cancer. And nobody used this to dismiss cancer. Other people dismiss CFS because some of us can articulate with the same strength and focus as healthy people. But I also articulated okay with a cancer tumor in my tongue, and I still can despite stiff scar tissue from radiation treatment. And nobody uses this to dismiss cancer. With most illnesses, people are seen as heroic for all they accomplish despite being sick. But with CFS, our accomplishments are used to dismiss us. They are used to discredit us.

So what is causing this dismissive attitude? I think one problem is the fatigue-centric model. The illness name is misleading. The description is

misleading. Most doctors who know the full description still think in terms of fatigue. They look only for energizing solutions. They ignore inflammation, immunity, and neurocognitive issues. In my opinion, part of this problem could be solved if the name and description were changed according to the International Consensus Criteria.

But I also think the available information about CFS is a problem. Imagine, if you would, that someone did a study on subjects who have chronic coughing and gave them sugar lozenges, and found moderate improvement in some subjects. And then I took this study and claimed sugar lozenges treat asthma, while ignoring that the subjects were not evaluated for asthma, only for chronic coughing.

Sounds crazy doesn't it. Yet, this is the type of thing that is being done with CFS. For example, on the Centers for Disease Control website there is treatment information that cites Oxford criteria studies. These criteria define a different syndrome that only requires physical and mental fatigue. No sore throat, no tender lymph nodes, no post exertion malaise. So it is not chronic fatigue syndrome – as defined in the United States. It only has the same name. And using different syndromes as if they are interchangeable is bad science, no matter what you name them. Yet, the CDC and others have been doing this for years.

Do you think the Department of Health and Human Services would be complacent if their divisions used generic coughing studies to evaluate treatments for asthma, pertussis, or lung cancer? Would you like this approach used with the medical care of your family? In my opinion, the DHHS should stop condoning this, and instead, they should explain to people how this corrupts the understanding of CFS.

Further, the clinical section of the CDC website is missing important information about medications. Now, I realize that pharmaceutical research is very limited. But it is more reliable than treatment models based on the wrong syndrome. So why not include the better medications, but also explain the limitations.

There is new leadership in key positions at the DHHS and CDC. So finally, the possibility exists for ending the practice of misrepresentation and selective omission of CFS information. I've seen some positive change already. I hope this is a sign of more to come, and not just a brief flurry of activity.

Thank you for letting me speak.