Testimony

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May 2011 Testimony to the Chronic Fatigue Syndrome Advisory Committee Joseph D. Landson

Note to government editors: This testimony involves the use of Enhanced Interrogation Methods on a *rubber ducky.* I am a *former intelligence professional and therefore vaguely qualified to implement these techniques. The ducky has been briefed on safety and time-out procedures. The assessed level of risk to the ducky* is *low. The risk to viewers, to include either being offended and/or falling out of their chairs laughing,* is *moderate.*

CFSAC members, ex-officios, fellow patients & advocates here and on the web, good afternoon. My name is Joe Landson. I've been ill for six years.

My purpose today is very simple: I'm here to give my highest possible endorsement to the use of Cognitive Behavioral Therapy, also known as CBT. It's my firm belief that if clinicians, medical researchers and health administrators undergo a carefully supervised program of CBT, they can fully recover from their incorrect illness beliefs about MEjCFS.

Now, I read the blogs, I keep up with word on the MEjCFS street: I know there are those who just don't accept CBT. Some say we patients are at war, that we should treat doctors, officials and scientists with incorrect illness beliefs as enemy combatants, and treat them accordingly. Let's explore that thought for a moment:

(Present Biggus Duckus, the rubber ducky.) So here is our doctor with incorrect illness beliefs, represented by Biggus Duckus here. Let's see how he responds to the familiar range of Enhanced Interrogation Methods.

(To the camera.) Now kids, don't try this at home; I am an intelligence professional.

We have stress positions. (Place duck in stress position.)

We have intimidation. (Large toy dog barks at duck.)

We have gender identity humiliation. (Place ladies' underwear on duck.)

And last but not least, everyone's favorite, waterboarding.

(Duck speaks.) What's that? (Duck speaks again.)

The duck has made a valid point. He dunks in water all day; he enjoys it. So enhanced interrogation may be the wrong approach. (Hey, let's face it, most surgeons are sadomasochists anyway, so torturing them is probably counterproductive.)

But here's the real question: Having used these classic techniques on the duck, have I finally convinced him that I DON'T have a psychogenic illness???

(Long pause.)

Well, no: I've likely convinced him that I *do* have a psychogenic illness ... even ifhe didn't think so before ... and kind of like some of you are thinking right now!

(Push duck and interrogation gear aside.) So, tell you what, let's push CBT and other interrogation methods aside, and ask ourselves seriously, what would it take to change how medical people think about our illness? Put another way: How do we get from here ... to care? *(As* opposed to the carelessness most of us now face in the real world.)

To answer those questions, I'd like to tell you a story. It's about the physician assistant the Veteran's Administration assigned to my care. (The VA is the only health insurance I have left.) I tried really hard to explain MEjCFS to him over the course of a year, and finally gave up. I should have known he wouldn't get it from one of the first things he did. He looked at my blood test results, turned his 400-pound, neck-less body toward me and said, "Your cholesterol levels are a bit high. You should consider reducing your fat intake." This was his most memorable contribution to my medical care.

The point of my anecdote is that, unlike the exceptional clinicians we have here in this room, the average clinician doesn't actually think, in the way that thinkers understand thinking. In all fairness we've created a world in which most clinicians lack the luxury of time to think. So, the clinician merely reacts to the printed test results placed before him. Appalling as this is, the good news is that if we can produce a diagnostic test he can use, he can react to it accordingly. Imagine, if you will, a GEl CO-sponsored MEjCFS diagnostic test: It's so easy a cave-doctor can do it! (No offense intended to clinicians present, of course.)

What's more, I don't think it's realistic to think we can produce this dream test in a timely fashion with our own current resources. So regardless of how unique

MEjCFS is, let's find commonality with related communities. Other people have gut issues or dysautonomias, not to mention credibility issues with mainstream medicine. How could, for example, the autism and Lyme communities reinforce us, and we them?

(Presents monkey.) Finally I'd like to remember those primates who've given their lives in the service of MEjCFS research. As you know, researchers have been sacrificing and autopsying rhesus macaques infected with the retrovirus XMRV. The found the retrovirus lodged in the lungs (we seem to have trouble breathing or processing oxygen); the lymph nodes (ours typically swell up); the reproductive organs (many of us have reproductive organ pain or dysfunction); and the gastrointestinal tract (many of have digestive trouble).

But clearly -- clearly -- this apparent retrovirus-symptom overlap is just a random coincidence caused by a likely lab contaminant. (He's lying.) No, the real tragedy of this study is that no one involved, to my knowledge, asked these macaques about their illness beliefs. Where are the SF-36s they filled out? What graded exercise did they perform? When was the screening for childhood monkey sex abuse? What a missed opportunity for science! I really hope future studies are better designed -for the rhesus macaques' sake, as well as our own.

Thank you for your kind attention.