

## Testimony

Laurel Bertrand

Dear CFS Advisory Committee,

September 17, 2010

I would first like to thank the CFSAC committee members for your time, perseverance and dedication. Your service on this committee is invaluable to all those who suffer from this devastating illness.

I gave a [video testimony](#) a year ago and was grateful for that opportunity. I regret to inform you that my health has declined even further since that time. It is for this reason that I am unable to give a video testimony again today, and must therefore instead send it in writing.

I got sick when I was 24 years old quite suddenly from a virus. I am now 38. I cannot stand, walk, talk, care for or even fully bathe myself. I have lost 14 years of my young adult life. Fourteen years that were supposed to be filled with career-building successes, travel, volunteer work, adventure, marriage and children. Instead, I have had over a decade of my life completely wiped away by this illness, and without a single genuine moment of reprieve.

I had graduated magna cum laude from a top university and was at the start of a great career at a well-known publishing company when I initially fell ill. I had just completed my first course in graduate school, hoping (at the time) to get a master's in human resources management. I had big plans for my life. I wanted to make a difference in the world.

But I won't carry on about my personal story again today, because I know government agencies are probably more interested in objective findings and numbers. So let's talk findings and numbers then.

There are 1 to 4 million people with ME/CFS in the U.S. alone, and at least 17 million world wide. Every one of those people has a story. Every one of them means the world to their individual family and friends. Every one of them, were they not ill, could have made great contributions to society. And every one of them deserves to have their illness, which the CDC has admitted can be as or even more debilitating than MS, lupus, cancer and AIDS, be taken every bit as seriously as those illnesses are taken. They deserve the same amount of funding, advocacy, and biophysical research into the cause and treatment of their disease.

It has been estimated that ME/CFS costs the U.S. economy at least 9 billion dollars in lost productivity alone, with the full economic impact estimated to be as high as 24 billion.<sup>1 2</sup> Yet, despite its seriousness, prevalence and cost to the economy, ME/CFS remains one of the least funded of all illnesses in the United States, with a mere 5 million dollars allocated towards it by both the NIH and CDC each year. More money is spent studying hay fever and attention deficit disorder than ME/CFS. In fact, ADD gets an astonishing \$55 to \$111 million more in funds every year than ME/CFS.<sup>3</sup>

It is simply inexcusable that an illness which afflicts up to 4 million Americans and can leave some of its patients unable to walk, stand or care for themselves would get less funding than virtually any other illness in existence. This absolutely and unquestionably must change. More funding needs to be

allocated to biophysical research, and without hesitation or delay. There are thousands of published, peer-reviewed studies showing a clear, biophysical pathogenesis in CFS. It's past time to greatly expand this biomedical research, and to do it quickly and effectively.

As everyone on this committee is already well aware, last October, *Science Magazine* published a study showing that 67% of ME/CFS patients tested positive for the newly discovered human retrovirus XMRV (part of the murine leukemia virus (MLV) family of gammaretroviruses).<sup>4</sup> In August of this year, the FDA/NIH found MLV-related viruses in up to 87% of ME/CFS patients.<sup>5</sup> Each study also found this family of retroviruses in up to 3-7% of healthy controls. As such, the FDA/NIH estimated MLV related viruses to be in the blood donation supply at between 3-7%.

I don't think I need to point out how incredibly significant and important this is, on multiple levels, nor how urgently more needs to be done. We must immediately examine the role of XMRV and MLV related viruses in ME/CFS, and what that means in terms of pathology, treatment options (through clinical trials) and prognosis. Funding should be given to those agencies, such as the Whittemore Peterson Institute, the Cleveland Clinic or the National Cancer Institute, who have demonstrated the ability to actually find this family of retroviruses, rather than to those who have shown that they can't.

In fact, it is important to note that the Centers for Disease Control (CDC) did not find XMRV or MLV's in ME/CFS.<sup>6</sup> They also couldn't find it in healthy controls. They couldn't find it period.

This lack of ability to find MLV's in the CDC samples points to many problems in methodology and patient sampling. As Dr. Suzanne Vernon of *The CFIDS Association of America* pointed out, the CDC's test tube collection methodology was not suitable for viral isolation.<sup>7</sup> Further, the CDC used their highly inadequate "empiric definition" of CFS, and thus included patients who merely had fatigue and did not have CFS. They themselves state the following about their study participants:

These CFS cases are different from CFS patients seen in general practice and referral clinics; of the participants from the population based study in Georgia, only half had consulted a physician because of their fatigue, about 16% had been diagnosed with CFS, and 75% described an insidious onset to their illness that had no obvious relation to an acute infectious disease. (*Retrovirology*, 2010; 7:57)

This is indeed contrary to most cases of CFS, which often have a sudden, viral (i.e., infectious) onset. Also, I found it rather peculiar that a study of a specific disease would only have 16% of one of its study cohorts actually diagnosed with that disease. This can only mean that **approximately 84% of the subjects in this study population had not been diagnosed** with the very disease the CDC claimed to be studying.

What this clearly shows is how little the CDC understands CFS, and how imperative it is that all use of their highly inaccurate, empiric definition immediately cease in order for any kind of research to actually move forward. A recent study by Dr. Leonard Jason has already shown that the empiric definition erroneously includes people with psychiatric illnesses who do not have CFS.<sup>8</sup> The CDC is the only one to use this definition, and it serves no purpose but to confuse patient populations and create conflicts in research findings.

It is also important to note that the 1994 Fukuda CFS definition is equally inadequate and out of date.

According to this definition, patients need only have four out of eight symptoms and to have experienced “fatigue” for six months or longer. You don’t need to be a scientist to see that patients studied under this broad of a definition could end up including people of various and entirely different illness etiologies.

Furthermore, the Fukuda criteria does not list post-exertional malaise, one of the true hallmarks of this disease, as a requirement for diagnosis, but rather only as one of several potential symptoms. How can something that many CFS patients describe as the most debilitating aspect of their illness not be required as part of the criteria for diagnosis?

The 2003 Canadian Consensus definition is the most accurate one to date, and as mentioned above, the Whittemore Peterson Institute and its collaborators have already shown what research using this well defined case definition can look like.

All research on CFS should now require the Canadian Consensus Criteria, or at the very least, the Fukuda criteria (with post-exertional malaise as an absolute essential for inclusion), for their patient sampling so that research can actually be effective. Seven years have gone by with the CDC dilly-dallying over random telephone interviews and questionnaires while a clear, concise and accurate definition of CFS already existed. It's time to adopt it and move on.

In addition to a proper definition, the name chronic fatigue syndrome must be changed back to its original name, myalgic encephalomyelitis, or a new name that accurately reflects the true nature and physiology of this illness. This illness is not about being fatigued, but about being terribly sick.

Harvard University's Dr. Anthony Komaroff, a long respected ME/CFS specialist, was recently quoted as saying:

“... there is now abundant evidence of measurable abnormalities in the central nervous system and the autonomic nervous system in people with this illness. So that makes it neurological. That's why I think it makes sense ... to call it myalgic encephalomyelitis or encephalopathy, because I think those two words adequately classify or describe an underlying biology that tests have shown to be the case.”<sup>9</sup>

As such, CFS also needs to be removed from the Office of Women's Health. It doesn't belong there, and never did. ME/CFS is not a woman's disease. It afflicts both men and women, as well as young children. It does not discriminate.

I would also like to point out that, in May of this year, Dr. Martin Lerner published a study in *Virus Adaptation and Treatment* showing some benefit in treating ME/CFS patients with high dose antivirals over several years.<sup>10</sup> While this was encouraging, I am struck by the fact that, in the nearly 30 year history of this illness in the U.S., despite most cases of ME/CFS having a sudden viral onset and clear evidence of immune dysfunction, the CDC has, to my knowledge, never done one single long-term study on antiviral treatment in ME/CFS.

What concerns me most about Lerner's study is this: the longer the patient had been sick, the less likely they were to respond to treatment. Let me repeat that. The longer the patient had been sick, the less likely they were to respond to treatment.

It is also worth noting that Dr. Leonard Jason published a study in 2006 showing that people with ME/CFS die of cancer and heart failure at rates significantly higher and at ages significantly lower than the normal population.<sup>11</sup>

Do you see the urgency here? We cannot afford to wait any longer. Not just because our lives are slipping away. Not just because we are enduring a living hell day-in and day-out year after year. But because every day that government health agencies dismiss us, wait to take action, or fail to respond, is one more day we lose in our chances of ever recovering at all.

Please listen carefully to the testimonies being presented today. We are not asking for much. We are simply asking for the basics of what should be expected with any illness: a clear and accurate definition, an appropriate name that doesn't belittle the disease, adequate funding, clinical trials, awareness and serious biophysical research. That's all. It's what is done for every other illness of equal severity. It's even what is done for illnesses of lesser severity. Why is it so hard for it to be done for ME/CFS?

I urge the CDC and NIH to take action immediately. We don't have time to wait around and accept any excuses anymore. Every year these meetings come and go, the same recommendations are made over and over again, and nothing ever comes of it. We don't hear back. This year, I want to hear back, and I really don't want to hear any no's. I've already lost 14 years of my life to this devastating disease. My fiancé (who, it is worth noting, was a former athlete and earned a PhD from Carnegie Mellon) has lost over 26 years. Twenty-six years. That is nearly half a lifetime.

The CDC has wasted three decades on poor definitions and poor science. We don't have any more time to waste. We want our lives back, and we want them back now.

Thank you.

Sincerely,

Laurel Bertrand

#### References

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<sup>3</sup> [NIH Research Portfolio Online Reporting Tools](#)

<sup>4</sup> Lombardi V et al.: **Detection of an Infectious Retrovirus, XMRV, in Blood Cells of Patients with Chronic Fatigue Syndrome.** *Science* 2009, 326: 585-589

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- <sup>5</sup> Lo SC, Pripuzova N, Li B, Komaroff A, Hung GC, Wang, R, Alter H: **Detection of MLV-related virus gene sequences in blood of patients with chronic fatigue syndrome and healthy blood donors.** *Proceedings of the National Academy of Sciences* 2010, 107 (36) 15874-9
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- <sup>9</sup> Komaroff, A: Lecture through *The Massachusetts CFIDS/ME & FM Association* entitled “**The Latest Research on CFS,**” April 2010
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