

Testimony

Gabrielle Lewis

Dear CFSAC

I shall open my testimony with a quote: "Who's responsible? You are."

My name is Gabrielle Lewis and I am 29 years old. I have been ill for four years. I do not suffer with Chronic Fatigue Syndrome. I suffer with a disease called Myalgic Encephalomyelitis under G93 of the ICD-10 classification. And I testify today that the CFSAC has a responsibility, not just to the citizens of its own country, but to the rest of the world, who will follow by example if a bid for change is made. The CDC's current treatment and classification model for the disease Myalgic Encephalomyelitis is not fit for purpose and poses a real danger to patients such as myself.

How long has the CDC embraced the psychosocial model of Chronic Fatigue Syndrome? Why is the classification issue SO important to patients like myself? Because the way ME is treated by the medical profession nearly left me for dead.

I was officially diagnosed with ME in March 2009 after two years of being ill, in that time I managed marketing campaigns for shows such as Chicago, Lion King and Phantom of the Opera. I loved my job but became too ill to work. I was told by one specialist in the early days that I had feared promotion and working, leading to deconditioning and agoraphobia. I can honestly say that I would have preferred to have been well and used my invitation to various movie premieres and events instead of passing out with a fever every night. Buying an apartment in Primrose Hill, driving a sports car and affording designer clothes was my dream, not this, not a life where I cannot interact with people, cannot function and cannot walk.

My dreams lie in tatters but you have the ability to turn that around.

To this day doctors do not believe me when I tell them that I have had 17 outbreaks of Shingles since December 2007. Tests have shown that I have immune deficiency and am HHV6+ yet I was informed by my doctors that ME is a psychological disease and I would be helped by cognitive behaviour therapy. I became so weak and frail my parents were desperate for answers and flew me to a private specialist overseas. I was told that I likely had a rare adrenal tumour and a liver condition. On return to my doctor I was told either condition were not possible as I was perfectly healthy but suffered from an illness which was caused by abnormal illness beliefs. I was refused screening for cancer and told my liver

was fine. One year later and it emerges I have hepatitis and borderline Addison's disease. Had I not previously been diagnosed with ME I would have been treated like a human being instead of being made to suffer, thinking I had cancer. Some form of viral infection is killing my liver, has eaten away at my immune system and attacked my muscles. I have the right to know why and get research for this disease. Should myself, like many others, test positive for XMRV then that's where the funds need to be allocated. Why people's immune systems end up like mine is also being researched by the likes of Nancy Klimas but where are the funds?

Now patients like me were not studied on the PACE trial? These were not even the types of patients who were used for Switzer's XMRV study funded by the CDC? Using the Reeves questionnaires is no way to determine real ME patients. As Leonard Jason pointed out at the State of Knowledge Workshop, *"It's important for researchers to include patients with the disease and exclude patients without the disease, if researchers are looking at samples from the wrong patients then the whole scientific enterprise is jeopardised. Using a broad or narrow definition of CFS will have important influences on CFS epidemiological findings, on rates of psychiatric co morbidity and ultimately, on the likelihood of finding a biological biomarkers for this illness."*

We all know the UK embraces the works of Professors Simon Wessely, Peter White and Michael Sharpe. The US is now no longer under the spell of Dr Reeves and these dangerous individuals and can look to the work being done by Nancy Klimas, Judy Mikovitz, Paul Cheney and others. Where the US leads, others will follow. If the CDC reclassify Chronic Fatigue Syndrome back to its real and deserved name and stop promoting CBT and GET as treatment options then the UK may follow suit and end the abuse of many thousands of patients across Europe.

But until that breakthrough is made I urge the CFSAC to make a bid for the reclassification of ME as a distinct entity and end the wastebasket diagnosis of CFS for good.

Sincerely,

Gabi Lewis