

Testimony

Jill Justiss

The year 2001 was the year my health took a dramatic downturn. I was only 31 years old but found myself crawling up my stairs. Several years later, and after many humiliating doctor visits, I was referred to an ME/CFS literate doctor. I am one of the lucky few who happened to live in a city with the only ME/CFS literate doctor in Texas, and was fortunate to have the ability to pay for my healthcare. This doctor diagnosed me with ME/CFS along with several co-infections.

My doctor started me on antibiotics, antivirals and glutathione/ATP injections which, no doubt, saved me from living my life from a bed or my chair. I was still ill, but could now function and take care of my children.

By this time, I was already several years into our struggle to find help for my son, who had been diagnosed with ADHD, asperger's syndrome, obsessive compulsive disorder and tourettes syndrome. We had already spent thousands of dollars on psychiatrists, CBT therapy and social skills with no visible improvement.

In addition to scouring the internet to find help for my son, I began researching my symptoms and the treatments that worked for me. I began to try to understand my diagnosis. In this process I realized that there is a connection between my symptoms and my son's condition. In fact, I realized my son was ill and that there was much more we could do to help him than psychiatric drugs which had only made him worse. I realized that we could treat my son's illness in much the same way as my doctor was treating my illness and that he could get better, just as I had. Indeed, this is exactly what happened.

Of course, as it is with ME/CFS, finding that doctor is the challenge all parents must face once they come to the realization that everything they have been told about their child's condition is incorrect. The message we parents are given is that there is nothing to do but accept this "syndrome" and that this is who they are. No treatment, No cause, No cure. I do not accept this and do not believe we are our illness.

There is now an understanding that there is a link between ME/CFS, autism and other neuroimmune disease. This understanding grows in the minds of parents like me who are ill and have children who are also ill with neuroimmune disease. We are gathering on the internet and talking about this connection. Our voices are multiplying and we are not going away.

We have come to the realization that these neuroimmune diseases are only part of a much larger picture. There are many thoughts as to why we are ill. Is it our toxic environment including vaccines, mercury, chemicals or mold? Or could it be a retrovirus that is being triggered by these toxins? I don't have the answers to these questions, but I do know we must set politics and our own agenda aside to do everything we can to find this answer.

This is not just about ME/CFS, it is about neuroimmune disease, which is simply a symptom of a much larger problem.

Autism is not about vaccines, but just part of a larger picture which we must face before we destroy another generation.

The Whittemore Peterson Institute is the only organization that is willing to discuss autism in relation to our disease, and this is to the possible detriment to their own future funding. This has not gone unnoticed among us parents and patients. I applaud their courage and determination to find the truth.

Meanwhile, we have seen apparent hostility toward one of the few groups that "GETS" this larger picture and much of it comes from our only U.S. ME/CFS advocacy group. We have watched Dr. Judy Mikovits receive a public scolding from the scientific director of this advocacy group because Dr. Mikovits dared to suggest that we could not wait for the conclusion of the Lipkin study to treat patients.

We see a government institution that states XMRV is a contaminant while, simultaneously, testing their own lab workers for XMRV, and finding it.

We see researchers who state XMRV should be left behind before it has even been properly researched.

We see the Centers for Disease Control website spreading inaccurate information to physicians.

And we see a steady stream of researchers, doctors, and government officials who seem ambivalent to looking at treatment options until further research is concluded.

How long will this be? Another Five, Ten, Fifteen years?

We will not wait that long. Many cannot wait that long.

There are many treatments that have been found to improve the lives of people with ME/CFS, Autism and related diseases. My son and I are prime examples of this. Now we simply need doctors to use them.

FUNDING, RESEARCH, PHYSICIAN EDUCATION, TREATMENT...this is what we need Now, Not Tomorrow.

Sincerely,

Jill Justiss