

Testimony

Helen Holt

My name is Helen Holt. I was born and raised in New York. I was officially diagnosed with Fibromyalgia in 2001. However, my illness has been active for many years prior. As a child, I was what they called “sickly”. I had chronic respiratory infections and had to be hospitalized. Many times I had to be submitted to the ICU unit and was administered high doses of steroids and antibiotics. Back then, it was not common knowledge that these substances are harmful to the body’s homeostasis and though they work in the short term the long-term side effects are devastating. I always seemed to have some kind of infection-tonsillitis, bronchitis, pneumonia, and sinusitis. None of my doctors ever made the connection between the state of my immune system and my chronic illnesses. Nutrition was not discussed with me. I was never tested for nutritional deficiencies or hormone imbalances. My medical treatment was solely crisis management. I was diagnosed with epilepsy at age 11 and was prescribed anti-seizure medication to control the seizures. I would get routine blood work but again was never tested for deficiencies and moreover I was not treated for them. My freshman year of college was when I developed Mononucleosis. I never fully recovered after that incident. The acute immediate symptoms weaned after a month but I immediately contracted bronchitis back to back in the subsequent two months. These medical traumas were negatively impacting my academic pursuits. I had extreme difficulty maintaining a high-enough grade point average in my classes. In May 2007 I was academically dismissed from the university I was attending.

I had to pay rent so I did temp work after my academic career was over. I was in chronic pain and eventually had to quit my job. Ever since then, I have been on public assistance, both local and federal. It has adversely affected my social life, my career goals, my dreams, my ability to have children-just to name a few.

The biggest issue I face with this illness is the ambiguity of it. The only doctors who treat CFS and diseases like fibromyalgia are in the private sector. They are very expensive and cater to the wealthy. So does the “healthy” industry. Organic food is too expensive for someone on public assistance and who cannot work. Adequate vitamins and supplements are also out of most people’s price range-at

least too expensive to fit into a monthly budget. Because of my nutritional deficiencies, I have to take Vitamin D, a multivitamin, detox powder, iron supplements (I'm anemic) thyroid medications, and omega-3 caplets. This adds up to be very expensive and I am forced to make choices about what I need more during the present time.

My other grievance is the fact that CFS, fibro and other illnesses get no respect. You are considered lazy if you have this disease. Doctors many times don't believe you, your family doesn't either, and overall the social attitude is apathetic. This is the only disease that takes everything from you. It is inconsistent, so one day you feel good and the next you are bedridden. Invisible illnesses like Cancer or MS get more respect. No one is doing a walk for CFS because people with CFS cannot walk. And if they do, they will be out of commission for a while if they push themselves.

I find all this very unjust and downright frustrating, because I want to get well, but I can't afford it. And society won't acknowledge my condition is legitimate.

What I want is for neuro-immune diseases such as Chronic Fatigue syndrome, fibromyalgia and Lyme disease to be given public acknowledgement in the mainstream media and academic communities. Awareness is the first step. I suspect that as with diabetes, where there are "pre-existing diabetes" there are many people with "pre-existing neuro-immune syndromes". Everyone is run down and tired. Everyone is nutritionally deficient in some way, and it will only progress into something worse over time.

I believe the hesitancy of our nation's leaders and those with power and influence stems from the fear of these diseases. It has been said that the diagnosis for fibromyalgia and similar disorders are a "diagnosis of exclusion". In my understanding this means that it is a result of a compilation of things. The XXMR virus has been identified as one of the culprits in many patients but the fact still remains that the cause is not a cut-and-dry one. There is no quick fix in terms of a cure. I believe this is because it is a combination of environment, genetics, and lifestyle, which is a unique blend for every individual. Also acknowledging these conditions means that the medical community will have to reinvent itself to begin treating people in a more holistic fashion. Nutrition, hormone panel testing,

therapeutic massage, chelation, and dietary supplementation will need to be more mainstream.

Thank you for your time and for reading my story.

Sincerely,

Helen C. Holt