

RUGGIERO – HB 5104

I would like to submit my story for the Lyme Disease meeting tomorrow at Wesleyan University.

My name is Kimberly Ruggiero and I have been a resident of Madison for the past 18 years. In June of 2001 I was bit by an insect that caused a large red raised rash on my face. The doctor prescribed a few days of antibiotics and steroids. A month later and monthly thereafter, I endured severe migraine headaches although I had never had them previously. I had been extremely active working, going to school and raising my family. The migraines lasted several days and involved my jaw, neck eyes and head with severe light and sound sensitivity.

After many months of these headaches I saw a neurologist who conducted an MRI which was normal and so I assumed they were a normal part of life. Over the course of four years these migraines increased in severity and length, until I would lie in bed for up to two weeks with excruciating head and neck pain. My primary care doctor ordered many tests including Lyme tests, all negative.

Then one day in fall of 2005, the pain moved into my body causing a cascade of strange and frightening symptoms including the following:

shooting searing/ electric shock type pain in legs, hands and feet,

crushing fatigue

pelvic pain

IBD

slurring speech

Difficulty swallowing

Memory loss

difficulty breathing

urinary pain,

Tinnitus

yeast infections

eye/face pain

After a battery of doctors and tests, the parade of professionals weighed in:

Two neurologists from Yale told me I was fine.

A rheumatologist told me I had fibromyalgia, maybe parvovirus.

A urologist said I had interstitial cystitis.

A Ear, Nose Throat doctor told me I was fine.

A gastroenterologist and gynecologist said I had irritable bowel disorder and endometriosis.

An endocrinologist said my adrenal glands were tired

Unable to work, go to school or care for my children, I believed this mystery disease would kill me and I spent many weeks in desperation.

After a visit to ER for chest pain which was found to be nothing, an older nurse whispered to me to retest Lyme disease, she said the tests were unreliable.

Dec 2005, I visited a infectious disease specialist who sent my blood to Stonybrook Lab, It was CDC Positive for active infection.

I can't believe that I live in a state where Lyme Disease was discovered and yet I had to suffer due to incompetency and ignorance. My primary care physician was angry if I mentioned Lyme disease and one neurologist from Yale after seeing my CDC positive test told me I didn't have lyme because he had just come from a conference at Yale and was taught that a patient can only be diagnosed with lyme if they have a bulls eye rash, bells palsy or a swollen knee.

Treatment was difficult as symptoms didn't resolve immediately and I endured severe herxheimer reactions with each new regimen which included 9 months IV antibiotics and 3 years oral antibiotics followed by intensive holistic rehabilitation. After 8 years, I am now functioning due to a strict adherence to a holistic health regimen and several lyme literate physicians and practitioners.

I have a science degree and my family runs a medical education business. I have worked in the medical field for many years. This has caused me to loose faith in the system that is there to protect us and I fear that politics and arrogance are causing thousands to suffer needlessly. I have learned much about the stealth pathogen borrelia burgdorferi and understand that it is challenging to study, culture and treat but that is no excuse for looking the other way.