

The Lyme Log

Part 4: 2007

January 26, 2007:

I returned to Dr. Minerva. He had spoken with Dr. Walker and taken many notes on my medical history and situation. He said he did not know what was wrong with me. He said since the only symptom I had was pain, I do not fit any diagnosis.

He said many things were fibromyalgia-ist, but, I am missing key symptoms to even make that diagnosis legitimate. He suggested the possibility of ankylosing spondylitis or something in the spondylitis family, again, all my tests were clear. He told me to come back in a month.

February 17, 2007:

I talked to a neighbor who is a doctor about symptoms and asked for possible advice. He suggested something in my neck and then advised I see a neurologist. He said he didn't believe it was an infection since "something" would have happened by now (either better or worse).

March 20, 2007:

Per my neighbor's advice, I met with Dr. Chris Reid (Bryn Mawr), a neurologist. After an exam, he said he could not find anything neurologically wrong with me. He suggested physical therapy and I told him I had tried that, believed the practitioners were good, but found it useless. He suggested maybe everything was related to a lack of sleep and prescribed a sleep study.

March 23, 2007:

I went back to see Dr. Minerva. He wrote a prescription for physical therapy and suggested someone who deals with chronic pain issues. I couldn't actually read the name or phone number, or anything on the paper he gave me. I began find the dizziness that occurred when I would go to sleep appeared in the shower - when washing my hair, I would close my eyes and I would fall.

Dr. Reid's sleep study test came in and showed nothing abnormal.

April, 2007:

The pain in my chest was getting worse and I was having more difficulty breathing. One very bad night, I couldn't sleep because I felt as if no matter how much air I took into my lungs, I couldn't get enough. I took aspirin, cough syrup and Maalox. By morning it had diminished, but I still felt like I could not breath. Besides being a little stressed at the situation, my heart felt like it was racing without beating fast.

I did finally come to terms with the fact that I was dying even though no one knew what was wrong with me.

I stopped walking up (or down) stairs, mostly because to get up the 13 steps in my house, I had to take

two breaks. I ate as little as possible as it exhausted me.

I forgot how to use the turn signals in my car. My vocabulary was significantly reduced - I found I could not find the words in my brain. I was also unable to touch type when I could do it since high school.

I often thought my contacts were in the wrong eyes because I felt my perception of the world was somehow distorted. My body felt very weak and I almost felt like I was asleep at my desk. I began having a chronic cough.

May 13, 2007:

Saw Dr. Burke of West Chester. My Mom found him and took me there. He is a Lyme Disease Specialist and happens to have Lyme. Ironic. He ordered some blood tests (Western Blot) and explained the ELISA blood test, which I have, weigh anti-bodies. The Western Blot test actually looks at the anti-bodies. That's how Lyme "hides".

Dr. Burke ordered a brain scan (SPECT) and heart ultrasound, as well, to check for other tick-borne infections and potential damage being that I have had the thing for 10 years. I got the blood test and brain scan that weekend, he would do the ultrasound in his office.

May 24, 2007:

I was having trouble breathing and my heart was racing throughout the morning. In the middle of a department meeting, I passed out. Actually, I made it out of the room into the hall. My Mom came to get me.

Unable to make it up stairs without taking two breaks. Horribly weak, joints unsteady but unable to sleep. Difficulty breathing become severe enough to impact activity.

I called Dr. Burke's office and demanded my test results. The blood test showed severe, active Lyme - and the SPECT showed so much infection in my brain, there was no room for my brain to go which had been causing the headaches and other issues.

April 1, 2007:

While driving home, I almost passed out. I got home ok but I spent the day on the couch I found when I looked at objects it seemed as if they were shaking.

Dr. Burke reported my heart was working at about 40%, with a very damaged valve. A stroke or heart attack was possible at anytime. He scheduled me to go on intravenous therapy (IV) through a Peripherally Inserted Central Catheter (PICC) line

June 14, 2007:

I went to Dr. Burke and had the PICC installed in my right arm. I have a bag of IV antibiotics to give myself a day. First infusion, at the office, made me feel better. A little drunk, occasionally, as well.

Later: Felt horrible. Worse than before. The doctor explained this is Herxing (Jarisch-Herxheimer

Reaction) which means the bacteria is dying faster than my body can flush it from my system which creates a toxic system and more pains.

June-July, 2007:

Began a two IV bag a day treatment. Began puking. End of July, able to attend family reunion. First time out in years. I have weekly blood tests plus a monthly blood test order.

August 2007:

Blood test shows the Lyme is in retreat. The toxin level has dropped, the antibodies are up, my dosage has increased to "puke-tacular" levels. . . 600mg.

Dr. Burke told me since the Lyme is under better control, I need to start treatment on the parasites. I have Bartonella (Cat Scratch Fever) and Babesiosis (American Malaria). Apparently, if the parasites aren't killed, they can actually protect the Lyme bacteria making it resistant to antibiotics.

I was still having breathing problems so another heart ultrasound was ordered.

September 2007:

Had a bad fever, temp of 104. Recovered.

October 2007:

PICC pulled!

I tested negative for Lyme and negative for the co-infections although I have some clinical symptoms.

My antibody level has dropped significantly from a month ago – that indicates an "exhaustion" in my adrenal system so I need to have some hormone tests done as well as a stress test to see if I need additional therapy. I will also need pain therapy (in the form of a couple one-time non-cosmetic botox injections) in my back.

November 2007:

Exhaustion continues and pain returned to my legs. Dr. Burke said this is probably due to the bits-n-pieces of dead parasites floating around in my body.

Stress test showed heart beating slower than normal. Blood pressure low. Infection in brain was almost gone.

December 2007:

I was weened off drugs due to good progress in my blood work. I noticed, due to brain infection, I have lost many many memories from about 1996. Other than what I have been told and what I wrote down at the time, I don't remember when I started treatment. Mentally, I have difficulty with transmitting information from short-term to long-term memory.

Parasites are still lingering. While the blood came back negative, I still have pain and rashes. But, I can work out. My weight up to 160 (fro 140) and I have a constant headache.