

The Lyme Log

Part 5: 2008

January, 2008:

After feeling as if my head weighs a ton, Dr. Burke finds with the reduced medication, I am in relapse for Babesiosis which has caused a resurfacing of symptoms. I returned to some old medication and he prescribed some new ones.

I had been dry-heaving a lot and Dr. Burke said this was due to a lowy stress hormone level (Cortisol). I began some light hormone therapy in hopes everything recovers.

Feb, 2008:

My period was 10 days early due to hormones. Dry heaving. Feeling frustration, longing and all around unease.

March, 2008:

My hormones levels are happy and being produced well enough to be used for their primary jobs as well as their secondary jobs. I have slight hypothyroidism which should clear up on its own hopefully without additional treatment. My immune system as a whole is back, looking very non-exhausted and communicating well with that whole system.

Both my parasites are back and they have infected my brain again leading me to have worser-than-normal memory issues/black-outs. In laymen terms, they have hit my input processing centers (memory, basically) but not my output processing centers (communicating, basically). Both are resistant to the 15 pill-a-day treatment I am on so, we're stopping treatment.

Tomorrow, I start up with a series of "rescue drugs" which are not widely known/used drugs since they are only in severe cases to prevent any drug-resistances in the population in general.

April 2008

The doc has decided the parasites have gone cystic. This means, they have encased themselves in thick walls of protein that are very hard to break down and are floating around. Good news is this is a remission but the parasites can live like this well after I am actually dead and reemerge at anytime. They can cause problems. .as any foreign body bouncing around the system can. However, this does means I can be pulled off medications used to kill the live/active parasites.

I still have several "troubling" neurological systems (like randomly falling over) so the doctor wants to do some more brain scans to see exactly where the damage from the infection is. If it's anywhere near the central brain, that's another round of treatments/therapy that will be needed. My heart is beating fine, I had an EKG, it's just beating slower than normal which is. . .what it is.

I still have fatigue and pain so I am being pulled off all but three medications to see what issues are

being caused as side-effects of the medication and what is related to damage/sickness. The doc would like to do a nerve test to test my pain receptors.

My blood work is looking good, other than my body storing anything I eat as fat. I still have to take it easy because too much "stress" will throw everything off.

June, 2008:

I had more testing on my brain to determine (or rule out) inner-ear issues. The lacerations in brain are then determined to be in the central brain and memory retrieval areas. Memory might heal with "use", central brain much harder to heal and might not recover.

I had trouble swallowing so Dr. Burke ultrasounded my throat and found masses on my thyroid. Dr. Burke determined them to be benign (goiters) and medications added to try to shrink them rather than go into surgery.

July, 2008:

I suffered from extreme fatigue and mood swings apparent. Additionally, I was feeling very, very sick. Dr. Burke removed me from the thyroid medication and sent over additional request for blood tests. Dry heaving beginning again, mostly in the morning.

Big toe on both feet have strange painful bruises although they have be subjected to no trauma.

July 18, 2008:

Blood work finally looking better. If it continues, I can be weaned off medications. I have a 10% chance of having a Lyme relapse but higher risk for the Bartonella and Babesiosis.

I still have a low-grade air-hunger making it feel like you are slowly suffocating.

The bruising on my toe was determined to be the result of infection in the veins. It frequently leads to random bruising, often in the eyes.

I need to get another SPECT scan and heart ultrasound since the Bartonella can cause heart damage after the infection is under control. It's the "favorite" organ of the parasite.

August 7, 2008:

Feeling really sick, dizzy and exhausted. Called the doctor to leave a message for him or a nurse. I got a call back about 10 minutes later saying the doc wanted to see me at 4pm.

August 8, 2008:

Finally get to see the doctor. The herxing of the Bartonella is out of control causing the feeling of wanting to puke, vertigo and RAGE. He took me off everything but Rifampin and Larim and added a detox supplement, glutathione.

My brain scan is not in yet, he will call with the results as soon as he can find/get it.

Talked with two people with Lyme at the doc. Convinced one to stay. He is ready to sue his insurance company since the Lyme infection is destroying his vision. It's a double whammy since he is self-employed so he pays for his own coverage and now his own treatment.

Also, my Uncle was diagnosed with Lyme. Maybe he has had it for a few months, he spent one of those days in the hospital with bad heart palpitations when he thought he was having a heart attack. They don't want to go to my doctor, the drive is too far. So, without a LLD, we'll watch him get sicker and die. He has 30 days antibiotics, per the normal.

September 19, 2008:

I'd like to welcome special guest Cindy to the doctor's lab.

Finally got my brain scan results! There is still infection which is making some cognitive issues and dizzy issues. The doc told me to take a supplement, Acetyl L-Carnitine, to help with rebuilding my brain.

After going over the blood work and everything, he has decided to give me a new medication in place of the Mefloquine called Alinia (nitazoxanide) which has less side effects (PHEW!) but has proven very effective in all 22 patients he has prescribed it to.

In my reflex test, my toes FINALLY pointed down. Can't be that. I have no swelling of the lymphoids (though some tightness a couple days last week). I'll get my new meds on Monday. I am also back on the Dapsone.

September 28, 2008:

After a week long headache, I ended up having heart palpitations and a lot of "rubbery" fatigue. I called the doctor and he was convinced it was herxing, but, told me to stay off medications for two days.

October 15, 2008:

SURPRISE! Forgot I had this appointment. Opps. I forgot to get my bloodwork done, too. Ooops. Either way, the concern was for my heart because of the palpitations and occasional chest pain. I have two appointments set up for a heart scan and follow-up. I am showing some light signs of Bells palsy but it is very faint. I am having spontaneous deafness/ringing in my left ear and my one eye is "lazy." It's a good time.

November 5, 2008:

I can't tell you how sick I have been feeling - and when I say "sick" I mean dry-heaving, waking-up-due-to-pain, not eating, exhausted, worse flu when you are car sick sick. I have some inflammation in my eyes, mostly in the left, which throws off my perception and makes me nauseous. It also gives me headaches. The rest is just die off. . just? Yes, you aren't dying, it just feels like it. However, due to the amount of toxic stuff, I am take a two-day a week break from medication. That should help.

My heart is in good condition. I have the same valve problem as before. But, it's not worth treatment. The damage might be permanent, but, it's not life-threatening. There is no excess fluid around the heart

sac, either. *phew*.

November 18, 2008:

I have been feeling pretty anti-social, hurty and blindly. . tired and. .sick. So, we talked about my special drug combo. It was nice to hear him say "I've been through this and survived and you'll get through it to."

As number 23 (or 21 maybe?) on the Alinia, and one out of three at my doctor's office, there is some issues with finding the right combo of drugs. Right now, it's probably a little too much. So, some of my meds have been reduced. I have to go back on hormone therapy, it'll help with life.

I have to check in with him on Friday, which will lead to one of four options:

1. I need to see a Lyme-approved nuro-eye doctor (he's in Lancaster, PA) because I might be losing my vision - at least in my left eye.
2. I need an IV therapy protocol (either once or twice a month, not another PICC) to help my body deal with the die-off caused by the drugs.
3. Nothing happens. Life goes on as normal.
4. A combo of 2 and 3.

November 25, 2008:

Got sick over the weekend. Started at 2am on Sunday. Felt my normal crappy but didn't eat much all day. Then I puked. Mostly a cookie and some blood. I ended up with a half sick day on Monday and slept a good 14 hours. I had a max 102.1 temp. I did call the doctor about my medications and all that, but, they won't give advice (meaning any information) without me seeing the doctor and waiting 10 hours to see him was out of the question.

It's Tuesday and I am starting to feel better. I have a sore throat that won't go away, though. I did eat solid food today.