

It's true for most of us Lymies that it takes longer than we'd like to recap our own stories, but at long last, here is mine.

2008

I start my story in 2008 because that autumn, things began to fall apart. (If you want to get right to the Lyme section, skip ahead to 2010). For years before that, I had been struggling, but had periods of good health and was encouraged enough by them to put aside thoughts of any large, lurking problems like disease, cancer, or immune dysfunction. In October of 2008, I had some minor surgery to repair this weird scar tissue I had on my abdomen (site of hernia repair years earlier), a cosmetic procedure that should have been simple, but something went wrong and I ended up with a major hematoma and more difficult recovery. I had a trip planned to New York for the American Indian College Fund annual gala and board meeting and was determined to go, so I strapped on a spectacularly unattractive stomach compression thingy and decided the sinus infection I had was gone enough and got on the plane. I made it through the trip, but came home exhausted and never quite bounced back to normal.

In December, I began having dizziness and trouble breathing at times when it made no sense to me (I hadn't just run a mile and didn't feel sick in the traditional sense). By January, the dizziness was worse and I had developed serious head and neck pain. I went to see my ENT, who treated me for a possible sinus infection, but the symptoms remained. My ENT sent me to a myofascial massage specialist, thinking maybe the sinus pain was really referred pain from my neck. The massage was unpleasant, but seemed to help unlock some of the inflammation and ease the pain. I also saw a chiropractor, but didn't find it particularly helpful other than some posture changes and suggested stretches. At this point, I was becoming worried about my health, but more embarrassed than anything else at what felt like a failure to just pull it together. I tried muscle relaxers, which sometimes helped. I tried drinking more, which did not help at all, and made me feel even more out of control of my situation and mental health.

In April, I had a physical with my general practitioner at which I was my usual chipper self, refusing to complain too much, which meant that I wasn't fully honest about how bad my overall state of well-being was. All of my labs then looked fine, but I'd gained weight (142 from 132). I let her know what I was doing to address what I thought were sinus problems and promised to check back in if needed. I ended up addressing pieces of my problems as I could make time and energy for appointments and investigating new specialists (my only thought about something more systemic was that I might have Celiac disease because many of my symptoms fit the profile, but my labs showed nothing on that front).

My neck and face pain continued. I was referred to an orthodontist and TMJ specialist to find out if some of the pain was jaw-related. He took a number of xrays and scans and bite impressions and showed me that I had bone wear (arthritis) just short of arthrosis, and that the alignment of my jaw/teeth could be causing facial and ear pain. He ordered an appliance (splint) to align my teeth such that the pressure on my joint would be relieved. He also put me on an anti-inflammatory diet and supplement regimen (including daily exercise, which I was sort of doing already, but not enough) to address the stress component and asked me to alter my posture, both body and tongue, and to be more aware of clenching my teeth (and how I

hold my jaw), to avoid crunchy foods, gum, etc. Then over the course of five months we monitored how my symptoms improved. My tooth pain disappeared and my joint, ear and facial pain significantly improved. My neck and shoulder pain did not, so I was referred to a physical therapist who specializes in TMJ and neck/shoulder work. She measured the motion/alignment of my jaw, gave me new stretches to do, and as the jaw improved, worked more on my neck and upper back. I saw her throughout the summer and fall, then had a setback when I discontinued my visits due to travel. The question arose: Why couldn't I find a more permanent solution to my pain, which interfered with my sleep and from there, everything?

My TMJ doc asked me if I'd ever been diagnosed with Fibromyalgia. Other doctors had mentioned Chronic Fatigue to me, but I had dismissed it due to stigma, mainly. By mid-2009, however, I found myself struggling with a mounting list of health problems and pain and decided to take a closer look at possible systemic causes. I read about Teitelbaum's book in Oprah's magazine and the CF symptoms sounded exactly like mine: Extreme daytime fatigue, poor sleep, constipation, depression, weight gain, muscle and joint pain, recurrent sinus infections/pain, difficulty concentrating/thinking (brain fog). Turns out, there was a Chronic Fatigue Center nearby that was loosely associated with Teitelbaum, which made me more comfortable about giving it a try. The doc there took my history, checked for tender points, confirmed a diagnosis of CFS/Fibromyalgia, ordered many, many tests and started me on a supplement and IV therapy plan in September of 2009.

[An aside: In the summer of 2009, I was bitten by something in the mountains in Pennsylvania. I had a raised swollen red bite, about 4 inches in diameter, which I thought at the time was a spider bite, and possibly infected due to the redness. I used drawing agents and eventually it subsided. If I had flu-like symptoms, I wouldn't have noticed as by this time I was dealing with low-grade fevers and pain on a daily basis. My thought now is that the 2009 bite may have been a tick, and may have reinfected, or newly infected me with one or more of the bacteria I'm fighting now, effectively knocking my already flagging immune system down to the point where any and all infections (viral, bacterial) were given the opportunity to flourish.]

Most of my new test results looked normal to me. Those out of range/pointed out as questionable were high Candida, questionable mercury levels, free T3 suspected to be poorly used though in range, Cytomegalovirus IGG high, EBV IGG showed exposure, Chlamydia Pneumoniae IGG and IGA elevated. A stool kit showed low good bacteria, a potential pathogen (Citrobacter) for which Cipro was suggested but decided against (I can't remember why, but probably my decision was based on overuse of antibiotics for my many sinus infections in years prior). I started on weekly IV treatments for viruses (high vitamin C and other good stuff like glutathione, mushrooms, etc.), T3 (20 mg) in late October and fluconazole (100 mg daily).

[also at the time I was taking: CoQ10, Glucosamine blend, Lamictal for mood disorder (diagnosis later changed to seasonal depression), Wellbutrin off and on discontinued 12/8/09, Provigil for energy/focus (discontinued 12/8/09), Clonazepam for sleep terrors, Nexium for reflux/sinus connection, Zyrtec for allergies (dust, cats, some trees/grasses), Sudafed as needed, Stool softeners regularly, Benefiber off and on/Miralax, Juice Plus. Celebrex (started by Dr. Yousefian) (discontinued 12/7/09), Flexeril as needed (tried taking Trazadone in May, but had paradoxical effect – I was up all night)]

The IV's were painful, time-consuming and bizarre, but sometimes seemed to help. My overall health wasn't improving enough, though, so we looked to sleep. Without good sleep, I didn't have a chance, a perspective that made sense to me (although I was very pessimistic, having never really slept well and already having had a sleep study). I started taking clonazepam in the 90s after falling down the stairs in the middle of a night terror and was terrified of addiction, so took it only after I'd had several nights of poor sleep, which meant a fairly constant cycle of bad sleep, medicated sleep, ok sleep, bad sleep, medicated sleep and so on. At my doctors' suggestion, I returned to the sleep clinic to be sure my sinuses/other breathing problems weren't a big part of my sleep disturbances. I had been diagnosed with sleep terrors/fragmented sleep in 2007 after a full sleep study, at which time the doc recommended clonazepam for regular use and assured me that sleep was more important than my fears about addiction. I took his advice back then and slept better for a time, but eventually the effect of the drug couldn't overcome everything else that was going on (that's my assessment now; then, I thought I'd just developed a tolerance for the drug at the current dosage). My second sleep study in October of 2009 showed a few apneas (when on my back), but many other awakenings not related to apnea events (somewhat better overall with the clonazepam, but still not good sleep). My sleep doc suggested switching to Nuvigil during the day and considering additional sleep/pain medications (Tegretal or Neurontin) after ruling out a current and ongoing sinus infection. I wasn't sure what to think. He seemed frustrated with my situation, so I left feeling frustrated too and worried about adding still more medications.

As instructed, I went to see my ENT 11/13/2009. She took a look at all my sinuses and said they looked good, but that my soft palate was very close to my tongue (Class 3), which could be making it hard for me to breathe at night (Upper Airway Resistance Syndrome, as opposed to Apnea) and causing the fragmented sleep. She suggested that I try a C-Pap machine to determine if increased airflow would help me sleep (and help me feel better during the day). If so, I could then look at options including surgery to adjust my jaw (something my TMJ doc had already discussed with me but I was hoping to avoid), appliances to alter the position of my jaw, or continued use of a c-pap machine. She did not think that surgery on my soft palate/uvula would be effective enough to justify a procedure, given my age and anatomy. I spoke with the sleep doc in December he agreed to prescribe a C-PAP trial. I got the machine, tried several masks and pillows of the course of the next few months, and found it at least as difficult to sleep with it on as off. Bummer.

Around the same time, I went to see a specialist to address GI concerns. She listened to my history and current complaints (constipation, pain, bloating, hemorrhoids) and suggested that I try increased use of probiotics, Miralax, avoiding soy for a week or so to see if that helped, and an endoscopy to check for Barrett's esophagus because of reflux. She didn't think I needed a colonoscopy since my irritable bowel symptoms date back to high school and I have no family history of colon cancer (said I could wait until I'm fifty). I never scheduled the endoscopy. I felt that if anyone could help with my stomach, it would be a naturopath, but that meant one more doctor and some of the therapies offered by the Chronic Fatigue clinic were naturopathic in nature. I focused my energy there, sticking with a rigorous course of anti-viral IV treatments in December of 2009, which helped, but not enough to carry me through the two weeks away over Christmas.

Early 2010:

I went to see a jaw surgeon who agreed with my TMJ doc that surgery to move my lower jaw (and possible upper) forward might help me sleep by opening my airway in addition to correcting TMJ problem. So on went the braces, with an eye towards surgery in a year or so. Teeth hurt. Lost a little weight. Road seemed long at this point, but at least I was trying. I continued the anti-viral IVs at the center, enjoyed good sinus health, but was still exhausted. That winter my neck and upper back pain seriously interfered with sleep and work. Typing was very difficult. We added new supplements (again, I went with the 'at least I was trying something' approach): anti-yeast, anti-viral, fish oil, mitomax, herbal pain formula, probost powder, coq10, b complex, probiotics. At this point, I'd been boosting the economy via supplement purchases for a solid two years and no end in sight.

Spring brought a new doctor to the clinic. We stopped the IV's, added T3, testosterone and growth hormone. I just held on. I saw the physical therapist, the massage therapist, the psychotherapist, so many appointments, propping myself up. By summer, I had to face the fact that I wasn't getting any better. The clinic doc suggested that I try Valcyte, which, unlike other anti-virals, from what he'd heard from other clinics, had some success with people like me who had improvement on the IVs and supplements but reached a plateau and didn't get any better. I said okay. Give me the magic pill. Started August 1, 2010, generally felt terrible; feverish; tired. I had cut out alcohol in July and wonder now if I might have had some withdrawal from it, a protest from the yeast I'd been feeding if nothing else. In any case, while I'm sure it did my health no favors, I didn't find that being sober made me suddenly healthy either, though over the course of months, my mental health was better for it.

I had a long talk with a dear friend around this time who was alarmed at the state of my health and the lack of answers. She pushed me to see someone great, someone who could tell me what the hell was going on. I cried when she left that day, both in thanks and despair because I had little faith that such a great person existed. Over the next weeks, I started losing my memory, began stuttering, losing my balance, fighting to find my words. It was terrifying, and maybe a bit of grace, because it pushed me to do what my friend had urged and look harder for someone to help me. I went back to my GP and filled her in on the above saga. She told me about a doctor in San Francisco who had helped a patient who reminded her of me.

I called Dr. Stricker's office after reading about him to ask if it was appropriate for me to come in given that I didn't think I was a Lyme patient, and they said yes, that he was an immunologist who treated many diseases. So I got on a plane and flew to San Francisco and on Sept. 2, 2010 saw Dr. Stricker, who works out of a historical building with nice architectural details but a dingy little office. That was fine. He was smart, absorbed my history in detail, and said he thought I had Lyme and H.Pylori. I wasn't shocked, but was surprised. I knew nothing about Lyme. Had plenty of tick bites over the years, but not for a while, I thought. And not the right kind of ticks. He said I could wait for the test results, or start on the antibiotics right away. I took the scripts with me to the lab and filled them that day. Started Biaxin (500mg) and Amoxicillin (1000mg) twice per day. Started reading like crazy, trying to understand what it meant to have had Lyme for years, potentially, what coinfections were, why there were so few Lyme docs in my state, and in many states, none. The politics behind the diagnoses, the scandals, all of it infuriated me. So much time spent on arguing and taking sides. Who to trust? I wanted to believe Dr. Stricker. I'd been looking for a good answer for years, but would I take the wrong answer in my desperation for an explanation? I waited anxiously for my test results, and made some medication changes per

his advice (subbed dexilant for nexium; tried amrix for muscle pain; did not try Abilify for sleep due to my history with anti-psychotics). In addition to the full Lyme and coinfection Igenex lab tests, a SPECT brain scan was scheduled for my next visit in October. When I started the antibiotics, I stopped the Valcyte. It's silly, but I was thrilled to find out that I had one of my frequent low-grade fevers the day I saw him. Made me feel more legitimate, though that was all my concern, not his.

The Biaxin was tough on my stomach. I became close friends with a bottle of Pepto. Got used to fevers of 99 or 100 often daily, until a break a couple weeks in. Felt good for a couple days, but lightheaded, then a series of tough days, too dizzy to drive, almost fainted in the closet, began to learn how to rest for real. Took a trip to Sedona for my sister's birthday and had to skip the hiking, but made it through. Back at home, sleep poor, very weak, hard to walk the dog. At this point, I had read all about how bad I could expect to feel before feeling better, and tried to get my head around the reality. I made notes, questions for my next visit. How long were we talking? Was he sure about the diagnosis? Sleep difficulties plagued me. I agreed to try the Abilify with no success. Turned back to the psychiatrist who I'd been working with for five years or so and trusted to be both smart and cautious (before her I'd been a lab rat for another doc who kept trying new things with crazy, pun intended, results). We came up with a new plan for sleep meds and when it was working, it really helped (more clonazepam if needed, and would try Lunesta if 2mg of clonazepam didn't work)

On 10/18/10 I had an MRI which showed no lesions or other damage. Great news. Whatever trouble the bacteria was causing in my brain would (hopefully) not be permanent. The SPECT scan I had a few days later was abnormal, showing inflammation and decreased blood flow, which made sense given the memory, verbal and spatial issues I'd been having, not to mention basic inability to focus or do anything creative.

In November of 2010, my Lyme test from Igenex was positive, even by CDC standards. I was happy, which is funny in retrospect, but I was so desperate for validation that there was a real, quantifiable reason for my sorry state. Hell, I still need that, but suppose the desperation factor is less now.

I embraced THE PLAN, which was an 18-24 month regimen of antibiotics. I realized that the jaw surgery I was planning was a long way off, and possibly would never happen, so I had the braces yanked off (hurray) and was given a retainer and a device called a splint that protects my jaw while sleeping (but does not improve my breathing; tradeoff is still questionable, but for now I'm sleeping well enough and my jaw is pain free, which is great). THE PLAN was based on my diagnosis: Lyme (*Borrelia burgdorferi*) and two co-infections (*Bartonella* and *Babesia*). Blood tests suggested the *Bartonella* was more serious, along with my neuro symptoms, so Dr. S suggested we treat that first, and explained that the antibiotic combo I was already on (Biaxin + Amox) would also chip away at the Lyme to some degree. He wanted 4-6 months, then we would switch to a regimen for the *Babesia* for another 4-6 months (maybe shorter), and then move to the Lyme. I said okay. Over time, I got used to the Biaxin, though food never did taste "right" to me. A great deal of Pepto was involved. Other drugs/supplements I was taking at the same time: Diflucan (once a week), Lamictal 100mg (down from 200mg), Wellbutrin 75mg, Clonazepam (sleep terrors), Dexilent (reflux), Armour thyroid 60mg, Zyrtec, Amrix (long-acting muscle relaxant) or cyclobenzaprine for muscle pain, stool softeners (I now know that the muscle relaxers can inhibit bowel function and don't take them, but didn't think about that then), probiotics, Juice Plus, fish oil, and an

awesome sinus spray from ITC compounding pharmacy (contains antibacterial and antifungals, plus xylitol).

In late February, my six months was up and I was still tired and spaced-out, but much, much better than I had been in the summer. We began the Babesia regimen: Zithromax 250 mg twice a day + Mepron twice per day. At first, I thought it was going okay. My stomach hurt like hell from the Mepron, but it was possible that this was also the drug doing its job and killing whatever parasite(s) I might have in my gut. I stuck it out. Continued with the same list of drugs above in addition to the Babesia/Mepron combo, but by March I was really struggling with fatigue and dizziness (serious dizziness, like no driving, feel like you're on Quaaludes sort of malaise). We had a family trip planned to Japan which we cancelled after the earthquake (a relief to me because there was no way I could have made that trip. A few months earlier, I was feeling positive, ready to give it a try and just rest a great deal if needed. By March, there was no way). Early April, my husband and daughter had the flu. I ended up with a cold that didn't go away. It felt like the bad old days of sinus infections and I wondered if going off the Biaxin had been a terrible mistake. I couldn't get anyone to answer my calls in San Francisco, so I made my own decision after spending a week dizzy, crazy weak, shaky, having difficulty breathing (probably my blood pressure was too low, but I wasn't monitoring it back then) to stop the Zithromax and Mepron and take the Biaxin I had left. It only took a few days for the sinus pressure to lift. When I finally reached my doc, he said to add back the Amoxicillin and do the old regimen until we met again. I didn't know what to think. I'd heard about a naturopathic Lyme doc in Seattle, Susan Marra, and decided to go see her and try to add to my treatment whatever complementary stuff she suggested. After a couple visits, I felt she was fully competent to manage my care (especially with the difficulty I had communicating with Stricker's office), so I turned myself over to her, cutting out the commute to California too. I began keeping a detailed calendar. I added supplements, including nebulized Glutathione, Methyl B-12 injections, additional probiotics, Vitamin D (5,000 IU/day), Phosphatidyl choline, arginine, zinc, and formulas: Neuroactives Brain Sustain, ATP Fuel, P5P, and toxi HMF, per her instructions. My pill box runneth over, so I upsized.

In late April, I wasn't sleeping, so tried, with my psychiatrist's help, Ambien CR and Lunesta. Neither worked for me. I began to panic. She kept me calm. After some experimentation, I ended up taking .5 mg of clonazepam with 12.5 mg of Seroquel (25 mg is the lowest dose made; I was nervous given my previous run-in with this class of drug, but it's a teeny dose and I SLEPT, which is priceless). Still taking this combo in late 2012 with mostly success. In April, I also tried Tramadol for pain, which I think is a great drug. It won't cut serious (say, post-surgical) pain, but makes it possible to sleep without making me feel drugged. I take it only at night, as it does sometimes make me a little sleepy, but am told this abates with regular use. [side note: Tramadol should be of concern for anyone with addiction issues. I stopped using it regularly. Also may be problematic for anyone with low blood pressure (like me) – 3/12].

In May, we added Allinia (250mg BID) to the Biaxin and Amoxicillin, which sounded good to me because I felt a little disconcerted to be back on the original combo, and making no progress re: the Babesia. The Allinia would hit the cystic form of the Lyme and possibly the Babesia too (I think). I did okay on the new stuff at first, though every week or so I'd have serious muscle pain and swelling, which became more frequent as the summer wore on. In June, Dr. M backed off a little to Allinia 4 days on, 3 days off. I needed to better detox, so she

recommended lymph massage and Epsom salt and baking soda baths. I almost couldn't believe how much time I was spending managing my illness; taking pills 6 times a day (some with food, some away in time from others, etc.), using the nebulizer, running baths, dry brushing my skin, going to therapy, massages, the chiropractor, the doctor . . . and still, every day was a maybe for plans with friends and family. I tried to be patient, but it's really tough to feel "on hold" for months with no end in sight. In mid-July, we increased the Allinia to 500mg BID, added Diflucan once per week, plant sterols, Oncoplex, liver support, NAC (my liver enzymes were getting wonky). Again, the pill cases runneth over. I bought even bigger ones. On the bright side, my nails looked great from all the gelatin in the pills! Yippee.

My liver continued to worsen and I felt terrible, so Dr. Marra decided to make a change in August of 2011. I stopped the Allinia and other antibiotics, switching to Clindamycin (600mg BID) and Minocycline (100 mg BID) with Diflucan 200mg every other day (we phased these in over the course of a week). Other changes were to my thyroid meds, from Armour to Cytomel (10mcg) and Levothyroxine (100mcg), plus a new soil-based probiotic (Prescript-pro), Licorice, Boluoque (earthworm protein for circulation), Brain sustain formula, and Oxypowder (magnesium) at night, which finally (albeit sometimes violently) got my bowels moving daily. The first day I took the minocycline, my back hurt terribly and I broke out in a rash, which lasted for 5 days or so. The next week, I was in bed and was so sick with cold symptoms, dizziness, itchy all over, feverish, sore, low bp, sweaty/faint, you name it for two weeks. I saw Dr. Marra during this time and she had me stop the antibiotics. I also added SAM-e during this time, which slowly helped my mood (and looking into Seattle's dark and rainy season seemed like a smart idea). At the end of September, I started the Lyme Inflammation Diet (kind of a silly name, as it's geared toward reducing inflammation, but a good protocol), which was hard in large part b/c food just didn't appeal to me (unless we were talking about sugar, which always sounded good). The diet was tough, but my stomach liked it. I lost a little weight. My skin looked better than it had in a long time. My new antibiotic regimen was Doxycycline 100 mg BID, Omnicef 300 mg BID and Placquenil 200 mg BID, with Diflucan every other day (other supplements the same). With this regimen, the hardest part was the Placquenil, which made me very gassy. My stomach just plain hurt, especially at bedtime. I used heat packs and massaged the hell out of my belly. It helped to some degree. Also soda water. Lots of it.

October was full of ups and downs. I drove a little. Saw a few friends here and there. Decided to buy a sauna to help detox. Increased Doxycycline to 150mg BID on November 1st. The approach here was to keep changing things to keep the bugs off balance. Sounded reasonable to me. I'm wondering now if I should have spoken up more about the bad days and done something different re: detoxification (like taking days off the big drugs to clear the toxins). Also in November we added artemisinin 3 days a week (3 on, 4 off). I felt worse while on it, but better off. In November, I had some good quality days. Over Thanksgiving, we had a bunch of family come in, so I skipped the Artemisinin, paced myself, took some Provigil (1/4) and was able to enjoy my time with everyone.

On December 2nd, we increased the Doxycycline to 200mg BID. I did okay in December, but not great. Similar to the year before, which isn't what I was hoping for by the 15-month mark. But, I was able to go to Arizona after Christmas and to Sedona, where I always feel good. I was weaker than in past years, but still went on two short hikes. Then I came back home and had a week with really great energy. Two cups of coffee was too much. I was thinking clearly and accomplishing things. What was going on? That same week, I saw

Dr. Marra for my regular monthly visit and she said she thought I might have turned a corner. Hurray! I thought, warily. Also in January, I started acupuncture, which was really helpful for my neck. And then bam, in the middle of the month, I started feeling weak, dizzy, short of breath, etc. Turns out my blood pressure was crazy low (say 79/56) which along with a high pulse (90) made me feel horrible. I'd had this before and read all about neutrally mediated hypotension. When it happened over the past year, I would eat more salt, rest, and it would pass. This time, it held on. I had to lay down to keep from fainting, meaning more time in bed, which I hate. I don't like my kids to see my like that, and I don't like how I feel being inactive – it's a vicious cycle of pain, lack of sleep, exhaustion, poor mood, pain . . . Two weeks of low bp off and on throughout the day led me to call Dr. Marra, who asked me to see a Lyme-literate cardiologist. He wasn't available until March, so I took a chance with another doc in the same practice to be sure this is a neurogenic problem and not anything structural with my heart. The bp problem was more difficult for me than most both because I was coming off such a good stretch, and because I don't know how to manage it effectively (for everything else, I have lists of things to do, whether simply lay the hell down and rest dammit, or follow detox protocols until they work, or add additional herbal remedies until I sleep, and so forth).

I had a full cardiac workup, including ultrasound, overnight monitor and blood tests for aldosterone/renin and thyroid function. Everything looked fine, structurally, so no Lyme in the heart. Good news. I was given a script for Midodrine, which raises bp, to use as needed. I tried it a few times. It does what it says, but nothing else. I found that making sure I ate small meals or snacks regularly was a key part of the puzzle (and now think the Tramadol may have been a culprit too, at least for the early am low bp).

In February, I stayed on the Doxy blend, took a big trip overseas, came back tired, of course, and fighting a tear duct problem (infection or irritation; who knows). At my next appointment with Marra, we changed my regimen to Clindamycin (600) , Monocycline (100), and Bactrim, but before I got them all phased in, I was feeling terrible again and went back in to the office. She suggested we pull back on all antibiotics and use herbs instead. We had also just done a bunch of labs to rule out other factors re: why I felt so terrible, and they showed high HHV-6 and other virus counts, so she put me on Valcyte BID with the herbs to try for the month of March. She also wanted me to try Diabetrol, an herbal version, sort of, of Metformin, which is a diabetes drug. I tried it for a few days, but didn't feel well and started researching the sugar question. Bought a glucometer and checked my levels fasting and after stuffing in 100 grams of sugar (my own home glucose tolerance test). All my numbers looked normal to me, so I put this issue back on the table for discussion, as well as what my overall plan was. I had understood Stricker's 3-part plan, whether or not it would have worked, but now felt lost.

I'm writing this in November of 2012, having been through several more changes to my antibiotic regimen, settling for the majority of the time on Biaxin, Placquenil, Diflucan and Flagyl (only a few days a week). In October, I had to stop the Flagyl to let my liver calm down, which is frustrating because I know I need it bust cysts and really fight the Lyme, but I also need my liver, so I try to be patient. For a couple months now I've been taking enzymes like Serrapeptase and nattokinase to break down biofilm (new test available showed I had high levels of biofilm), so that's one more potential piece of the puzzle now being addressed. And most recently, I was tested for mold biotoxins (not allergies), which came back positive. I'm currently using a sinus nebulizer to deliver 3 antifungals into my sinuses. Big fun. Not sure why I'm not using a chelating agent, but I think that's next. I take something like 70 pills

every day, maybe ¼ prescription. I do not yet see the end in sight, but try to stay hopeful. It's been more than 24 months, but I may have had this for a very long time, so it is what it is. I'll write more of an update when I have more to share. To everyone fighting the same battle, my thoughts and prayers are with you.

OTHER THOUGHTS

The liver: Before I even started the antibiotics in 2010, my liver enzymes were elevated (AST 43, ALT 53). Nothing to suggest imminent liver failure, but it has been informative to watch the labs and connect them with how I felt at the time. I learned that the liver does, seemingly, everything. I also learned that if it's not functioning well, I won't get the benefit I should from the medications I'm taking (I had thought the issue was all about damaging the liver, when in fact it's also about how well a medication protocol is really working, AND how well (or not) I am able to detox when the medication IS working (ridding myself of the waste when the bacteria dies), not to mention other substances like mercury. My AST/ALT shot up even higher (and alkaline phosphate) in April of 2011 when I was so sick during the Mepron/Zithromax phase. And then in June and July, higher and higher (up to 72 and 150; enough to worry us and pull back on some medications b/c, as Dr. Marra said, I didn't want to blow out my liver). To say the least. By October, levels were right about normal (only a tiny bit high), and then in early January, they started to climb a little again. Which makes me wonder, again, if I've not paid enough attention to detoxification, or if I need to look at that more closely and build in days to allow that to happen. I'm not sure how this is connected to my low bp issues, but toxins = inflammation, so maybe there is a connection.

Self-care: Throughout all of this, I have continued to see a therapist once a week, which became really important as my family started to understand my illness and we all had to adjust. I continued to walk my dog daily unless I absolutely couldn't get out of bed and to do Pilates twice a week, though my exertion level varied depending on pain and fatigue. Regular exercise, stretching and movement in particular, seem to be important, though I can't say that I've found any correlation with exercise and good sleep on a day to day basis.

Sinuses: A little more hindsight (a sinus infection isn't always just a sinus infection): Starting in 2000, I had a sinus infection every couple months. Amoxicillin was useless. I loved Levaquin. I wonder now if each course of antibiotics was beating back the Lyme, only to have it flare back up again. I remember my ENT throwing up his hands after two sinus surgeries and three years of treatment and saying he didn't know what else to do for me. He never would have suggested a longer course of antibiotics, or not long enough to cripple Lyme. He had no idea, nor did I, what we were dealing with. I can't say for sure that it goes back that far, but I wouldn't bet against it either. We moved from New Jersey to Seattle in 1999, leaving the land of deer ticks, a danger I knew nothing of when we were there. I spent countless hours in a yard frequented by deer and was often bitten by insects. I'm one of those people mosquitoes love, so I never thought much of a bite. Any one of many could have been an infected deer tick and I would have had no idea. I don't remember a bulls eye rash, but neither was I ever on the lookout for one. I don't remember anyone even talking about Lyme back then, even in New Jersey. And back even farther, in 1988 I was bitten by a tick while

running around naked in the woods around Princeton as a college student (the nurse was not amused, as I recall).

Moods and psychiatry: During the time of sinus hell, my mood suffered terribly and my therapist suggested I see a psychiatrist because my GP had prescribed a couple anti-depressants for me that either didn't work, or caused a paradoxical reaction, meaning that I should get the advice of an expert before any more dabbling in the pharmacopeia. Sounded reasonable, though she told me that the guy she was sending me to diagnosed everyone as bipolar. So, shocker, he said I was too! Though a very mild case. Now I know that this diagnosis was uber-popular at the time, and a whole host of drugs had recently been approved for use in mild cases like mine. I sat in his office in a fog and took home prescription after prescription, wondering why I felt so weird on each one. Well, the answer is that he was giving me serious antipsychotics, and they weren't what I needed. Zyprexa made me euphoric, but I stuttered and gained 20 pounds in a flash. Seroquel left me splayed out on the couch all day like a zombie. He wanted me to try Lithium, but at this point I had done some research and just wasn't convinced about the diagnosis, which was based primarily on recurrent depression, not any real manic behavior, so I told him I would focus on getting my sinus health in order (also linked to depression because when you have a sinus infection you can't think, sleep, drive, function . . .) and then see what was left. I had to change ENTs to get real help with my sinuses, taking a culture-first and treat second approach, which meant fewer antibiotics but longer courses (more effective). I found a naturopath, changed my diet, enjoyed a couple years of moderately good health (went on family vacations, hiked, etc.) and stable mood. I wonder sometimes if I look too often through the Lyme lens, but I think it's worth trying to figure out what started when. I didn't have a mood disorder as a young woman, when it most often first presents. I always had trouble sleeping, and I drank too much in college, but I didn't have clinical mood cycling. So, I think I was misdiagnosed, but it wasn't entirely the doc's fault because my symptoms were real. I think now that inflammation in my brain was already causing trouble but I had no idea that bacteria could be the cause, so I looked for something bigger and half believed what I was told. Fast-forward past the couple years of decent health, during which time I found another psychiatrist who suggested Lamictal, an interesting drug with few side effects. It seemed to help, and allowed me to take an antidepressant without having a weird reaction. I wasn't thrilled to still be facing a mood disorder diagnosis, but I did feel better taking it, and found the new doc to be so much smarter. I trusted her, and still do. What's the most fascinating is that a year or so into the Lyme treatment, I stopped taking the Lamictal. I still need something to sleep, which is either a lifelong problem or related to pain and other weird Lyme symptoms. Either way, I no longer feel out of control of my moods. I get down, sure, but I doubt many Lyme patients don't. Facing years of treatment, during which you often feel like shit for days and even weeks at a time, is tough. A lot of faith is involved, something I've never embraced but have found to be essential to healing (and, really, to living well and being the kind of person, parent, wife, friend, I want to be).

UPDATE, December, 2017

Happy to report that I have been in what I consider a state of remission for almost two years. I stayed on the antibiotic roller-coaster through 2014, stopping when my liver demanded a break and then tailoring a plan to my own peculiarities after reading Horowitz's book on Multi-systemic illness. I believe each patient has to figure out which antibiotics they can tolerate, in which combinations, and to address the biggest picture possible. For me, that meant biofilm busters. I could only make limited progress with having a cyst-buster and biofilm agent on board. What that looked like was a regimen of Biaxin, Bicillin injections twice a week, and a rotating use of Flagyl or Plaquenil. Flagyl can't be taken for months, so I did an on/off regimen, something like 5 days on, 5 days off – I monkeyed with it as I went, looking to side effects of pain, fever, dizziness and the like to tell me when to take a day off. The Bicillin injections are hell – they hurt terribly – but they allow the medication to remain in the system for several days without using the stomach to do all the heavy lifting. And in the end, it was the combo of all three of these that brought me out of the illness, so I would absolutely do it again. My brain started clearing up after a few months of this, fevers gone, pain in check, so I was able to taper off all the drugs and slowly build up my strength and immune system over the following couple years. NOTE: It takes time to rebuild! I can now make plans like any normal person and know I'll be able to keep my promises. Travel takes a toll, so I plan in a buffer of extra rest, but it's manageable. Very thankful, and very watchful for any sign things are slipping. I eat carefully, make sleep a priority, and exercise daily.

My husband and I have spearheaded some research into Lyme at the Institute for Systems Biology (ISB) in Seattle, with an eye toward figuring out accurate, reliable diagnostic tools and new ways of understanding why people like me end up in a chronic disease state while others can take a couple weeks of Doxycycline and go on their merry way. Please check out ISB, it's a great institution, a non-profit, and always in need of support. It turns out science is expensive! So, onward and upward we go. Much love to all out there suffering from Lyme and related chronic illness.