

The law of the universe – things change. And, they did. March, 2015.

While taking a course of antibiotics for a non-Lyme issue, at the two-week point I had a massive herx reaction. I almost never get headaches, but this reaction was characterized by a crushing one-sided head and eyeball ache, brain fog, wooziness, and that old sensation of not having slept for a month. I thought, well, good! This will clear out in a few days and I'll be all the better for it. Days passed. Weeks passed. Every day was the same. I continued working – my bread and butter for the last year and a half has been as a medical hospitalist at a psychiatric hospital – and as awful as I felt, my intellect remained intact and the demanding work distracted me from my sensory misery. When off work and home, symptoms were relentless and my usual life activities weren't compelling or distracting enough to pull my attention from my new hell state.

Two months came and went and every day was the same. I was lost for a new strategy but I assumed I had awakened dormant bugs that my prior treatments had failed to eradicate. Or perhaps it was immune system cytokine dysregulation? For lack of anything better to do, I restarted the same antibiotic (Ketek) and by the fourth day, my symptoms cleared. Mostly. For a while...

Since then, and it's been almost a year now (as of 2/16), I've done many things to dig out of this Lyme misery. And by misery, I mean a variety of symptoms including (not necessarily all at once) wooziness, brain fog, insomnia, sense of sleep deprivation despite adequate sleep, sense of 'toxic intoxication', pounding pulse and other arrhythmias such as paroxysmal atrial fibrillation, multi-sensory 'buzzing' – my coined term 'total sensory tinnitus', myofascial pain and stiffness (back, SI joints, hip musculature, ribs), dry eyes, and probably several others that don't come to mind at the moment. Treatments I've used include pulsing or cycling antibiotics such as telithromycin and tinidazole, ozone (DIV and mucosal), exercise with 100%O2 (a la www.liveO2.com), detox with many of the usual approaches/binders, various herbals, and Rife treatments with my Doug Coil Machine and GB4000. Everything induces herx reactions – evidence of die-off – and I am not as sick as I was a year ago, but I have no sense that I'm really getting anywhere. I have no really good days. Parts of days, yes. Only parts...

On bad days, or bad parts of days, wearing clothing hurts. One of my 'opiate substitutes' after a hard day of 'keeping up with the herd' is getting into my jammies and sandals, luxuriating in relief from my belt and shoes. Then, there's getting off my feet on to my recliner couch in the evening. That can relieve a lot of back pain nearly instantly, sometimes. But mostly my days are uphill both ways. It takes everything I've got to 'act normal', stay positive, do my work as a physician, work out to keep my body ready for wellness, and try to be the best husband and father I can be while running on fumes. Sometimes cranking my guitar rig and making a rock/blues racket thrills me, but too often just standing with a strat around my neck is impossible because of back pain. So, I postpone for another time. It is difficult to impossible for those close to me to even begin to relate to my life and suffering. I

neither need nor expect them to identify with this bizarre existence. My wife knows more than anyone, but no one knows like another Lyme sufferer. Ours is a strange lot. I used to be so normal. I used to be so healthy. Coping was something that I would have to do from time to time, like most other people – not every second of the day. Fortunately, I do not have any tendency to depression. There's a world of difference between misery and depression. I never allow myself to suffer more than necessary. I refuse to go down that sinkhole.

As of this (part of) writing, I'm intrigued by the results some Lyme docs are getting using IV daptomycin, as there is compelling evidence that it uniquely has the ability to destroy the forms of *Borrelia* that are resistant to other antibiotics. Stay tuned and I will update when I feel that I have something worthy to share. In the meantime, good luck to all of us with this horrid infection. We need all we can get.

Next update (4/16). Today I began my third week on oral Ceftin + Doxycycline and 2 days with tinidazole added. Though I've taken Ketek and tinidazole on and off during the past year, I can't say that it's done much. But this - I've had some of the worst days of die-off/herxing ever. I could barely stand being in my skin. Working was beyond difficult. But for the past couple of days, parts of my days have been remarkable. I have felt more normal than in years. It doesn't last – the next round of neurotoxic herxing comes on, but just to taste a bit of that foreign, forbidden fruit called *normal* gives me a lot of hope. Even happiness. And when the next round of die-off floods my brain with woozy, buzzy toxin, I cheer it on. Go get those fuckers!! Die *Borrelia*!! So, we shall see... My intention is to stay on these antibiotics until I come to a plateau – one hopefully better than the one on which I've been stranded for the last year (or ten years, depending how far back one stands), then per Joe B's recommendation, stop, and restart another cycle either when symptoms recur or at some arbitrary interval. Best laid plans.....

And it's now May, 2016. I've been cycling Ceftin, doxy, and tinidazole about 3 days a week. I get die-off/herx reactions within 24 hours, often as soon as 6 hours after starting. I try to time my cycle for days off work to minimize the impact on having to be 'on' and productive. Some parts of some days are OK. The rest sucks.

Paroxysmal atrial fibrillation has hounded me for the past year. I'll be having atrial ablation with one of the gurus in the field in a week. Fingers crossed.... My game plan is to have a successful ablation and then to begin to arrange for an IV daptomycin protocol. I should need a PICC line only for 3 weeks, which is good. I'm told that most patients on this protocol just gradually feel better without intolerable herxing, but with my history of die-off reaction intensity and frequency, I'm a bit pessimistic that it'll be a walk in the park. Thus, the need to plan work scheduling, which must be done months in advance. Then there's the challenge of buying these drugs (daptomycin and ceftaroline) in Tijuana where they're affordable. Apparently

there are contingents of Lyme patients doing this all the time. It makes the difference between daily med costs of ~\$100, vs ~\$1,000. Great system we've got here, huh.....

Mid June, 2016 now. Had my atrial ablation a month ago and although a.fib has continued, each episode lasts for only minutes to a few hours at most vs. the 20-40 hours it used to last. I'm told this is not unusual for the healing phase – a three-month period. I was told to not have a PICC line until the surface of the atrium is healed – at least 6 weeks.

When I got home from the hospitalization, a friend with Lyme contacted me to share his initial experience using Stevia to kill Bb. Eva Sapi's paper from last year described the ability of a Stevia extract to kill ALL forms of Borrelia, including persister and biofilm forms – better than daptomycin with a cephalosporin and doxycycline! This study was in vitro only – not in a human body. Nobody really knows how well the multiple constituents of Stevia extract are absorbed or react in vivo. My friend said that within an hour of taking ten or so drops, both he and his wife, who also has Lyme, experienced symptom worsening consistent with a die-off reaction.

I took that ball and ran with it. I bought some store-available Stevia drops and started consuming large quantities. I then bought the brand that was used in the study from Nutramedix, and threw caution to the wind (after reading all the literature I could find on safety and absorption of Stevia extracts) and have been taking about 500 drops a day in four divided doses. Within the first week, I had some better-than-average symptom days and some worse. I had severe, horrid exacerbation of my brain-toxic symptoms about 12 days ago. Since then, each day has been a bit better to the point where three days ago, I had almost NO neurotoxic symptoms – something that just never happens - certainly never since my relapse last year. Since that day, I have stayed mostly well and so much better than my prior baseline. If I never get better than this, I'll be fine. But, it's early in the game. I am reservedly ecstatic about all this. I have no way of knowing if anyone else is getting real, durable results, and whether anyone else is trying the amount I'm taking. I don't think I'm having side effects other than die-off reactions, to date. I'm not quite one month into this experiment, but my optimism is stoked. Does Stevia have the capability to make us well? Stay tuned. In the meantime, I'm holding off on my prior plan to pursue IV daptomycin.

It's July 1 tomorrow. I continue to have some better and some awful days. Am I getting anywhere? Damned if I know. I'm certainly better than I was a year ago, and far from well. Nothing happens quickly in this realm. I'm hoping to draw some conclusions, or at least get an impression, by the 3 month mark – mid to late August, coincidentally when I turn 70. I use my coil machine periodically. I'm restraining my

desire to take antibiotics so that I can know what Stevia might be able to do on its own, +/- Rife.

I get contacted by fellow sufferers who are under the impression that I found a cure for myself based on the prior entry about Rife and getting my life back. So it seemed. I really must contact my Webmaster and get this update online.

It's a month past the solstice (2016) and 2 months into my adventures with Stevia. The past week has been a quantum change for me. I have had almost no brain toxicity. I do get some fatigue and pounding heart sometimes, but the incessant sensory buzzing is pretty much gone. This NEVER happens. I'm sleeping better. I haven't felt this well in years. Have I found salvation? The keys to the kingdom of normal? A Lyme doc once told me that you're not better until you've been better for a month. During the worst of my illness a few years ago, I had a couple of one week breaks from symptoms when I took something, or stopped something, but symptoms always returned with a vengeance by about a week. I've learned to keep my expectations low. This time seems different though. The two-month course has been more typical for a treatment that actually works. Slow progression, plenty of herxing especially early on, and requiring a similar amount of time that prior antibiotic induced remissions have taken. If I was taking a pharmaceutical antibiotic, I'd have no trouble concluding that this IS working. But an inexpensive herb extract? I've taken tons of different herbals in the past without any benefit. Is this my turn? I'll be turning 70 in a month and I can't imagine a better BD present for this battered bluesman. Do I get to step down from the cross? I don't know, but for now, I have to constrain my enthusiasm and stay braced for the next fall from grace. That doesn't mean I can't revel in my own abandon from time to time, squeezing each moment for whatever goodness might drip out. As always, stay tuned....

.....

3 hours later - a typical late morning neurotoxic rush came on.... Of course.... I did a coil session last night so I suppose I had it coming. Not time to cash in just yet. But, it's never like that with this plague, is it? Two steps forward, one back, rinse and repeat. My long term optimism isn't clouded, but I remain hunkered for the journey.

.....

End July.

It's been a very rough last week. Very neurotoxic. I added aggressive use of O2 therapy (a la my liveO2.com rig) and a lot of exercise, so that could be stirring things up. Today isn't as bad. But really, day to day status means nothing. One Lyme doc friend and fellow sufferer would say that he measures progress in three month chunks. I'm not even at my first 3-month mark, so I really need to cool my jets. I AM

(somewhat) better than I was 6 months ago, 12 months ago, and 17 months ago, so... Onward, through the fog →

August 11, 2016 – Acknowledging my lack of progress with very few good days in the past several weeks, I took 1g of cefuroxime (Ceftin) this morning and after about four hours, I had a massive brain herx reaction that put me down for hours. I have to accept the reality that this Stevia experiment may be headed for the box containing all the other failed herbal trials. It's a big, deep box. Not having taken antibiotics for a while, perhaps this is a good time to hit the bugs hard with this heavy hammer. But it's basically back to the drawing board.

I'm on the surgical schedule mid-October for a repeat atrial ablation as I remain plagued by daily runs of a.fib, a.flutter, and PACs. Life with bodies.....

August 15 – Last night I dusted off my old GB4000 and did a run of channel 466 with the intention of doing a second session using channel sweep mode but by the end of the 25 minute run, I was very neurotoxic – both woozy and unusually edgy (a symptom that was prominent years ago, but not so much this era) and so stopped for the evening. The edginess eased after about 90 minutes, but woozy/buzzy brain symptoms persisted until this morning. I hadn't used the GB for a long time, having been depending on my coil machine. The fact that I got significant toxic reactions to that and to Ceftin reinforces my view that my journey with stevia has been unproductive and I've got plenty of spirochetes just hanging out, doing what they do and displaying susceptibility to Rife and beta lactams. So, the plan of the moment is to hammer away with the GB and the coil while intermittently pulsing Ceftin. We shall see. I still have two cases of stevia extract should I get a sweet tooth...

September 24th – First day off in a while. I've been running the GB4000 consistently and having fewer die-off reactions.

.....

And now it's Sept. 28th.... I've been working a crazy number of hospital shifts the past 10 days, rendering writing a fleeting thought. I found my old documentation of my first months' Rifing with the GB, now almost 4 years ago. It looks like everything I did, all the channels I ran, produced horrid die-off reactions both immediately and during the days following, so I only did sessions once or twice a week back then. It's nothing like that these days. I've had fewer days that are completely neurotoxic and more days that are 'livable', for lack of a more descriptive term. When doing my hospitalist work, I am so engrossed with the pressing tasks at hand that I barely notice the sensory buzzing and other brain toxic symptoms that occur – analogous to ignoring tinnitus. Although my game plan was to Rife and also take an occasional cefuroxime, I haven't done the latter. Just the GB and rarely the coil. I do the GB

about 4 evenings a week. Sometimes when I'm on hospital call, I won't do a run as finger swiping on my iPhone doesn't work when the GB is running (usually one electrode on my right forearm, the other tucked in my left sock). Electrostatics and all....

I do best when I eat very little until early afternoon, and as little fat as possible. Yesterday, my first day off after a long work stretch, I put some butter on one piece of raisin toast, and some coconut oil on another, for breakfast. [I followed this with a heaping tsp of cholestyramine] Like clockwork, about 2 hours later, I had an intense neurotoxic rush, consistent with my theory that the late morning neurotoxicity I endure is from enterohepatic recirculation of Lyme biotoxin loaded bile. What was different yesterday though was that instead of my prior pattern of 4-8 hours of 'seriouslyfuckedup' after the morning sensory toxic rush, I was much better after a couple of hours. That does NOT tend to happen. I regard it as a little data point that reinforces my optimistic sense that I'm indeed getting somewhere better than I've been. I mean that in a strictly secular sense ☺.

Since my prior update on August 15th, I turned 70. Whoop dee doo. What a weird freaking life – as only my fellow Lymies understand. But I'm on a mission to get my life back before my race is run and the lights go out. I'm optimistic that this year will be the one. Looking back, I'm MUCH better than I was when I relapsed 3/2015. What I'm doing now seems to be working albeit at the typical rate any Lyme treatment works when it does – VERY DAMN GRADUALLY. Progress is measured on timeframes of months – hopefully punctuated by a good day, or at least a good string of hours. Or less sleep derangement.

The not so great parts are:

1. Occasional diplopia. Very disturbing. It usually resolves in a couple of minutes, but is momentarily disarming, if not disabling, to say nothing of unsettling as I understand a bit about how the brain(stem) works. I've had this occasionally for about 6 years, but it seems to be happening more often now. Lovely....
2. I think my guitar playing is suffering. Maybe I'm just tired of the same old worn out licks that always sound like me and are littered with 'clams', but I feel less nimble on the fretboard. This could simply be from not playing and actually 'practicing' enough, or it could be that I'm losing it. I'm trying to be consistent with recording everything I do, random noodling and all, just to leave to my progeny who I won't be around for when I face plant into the dirt for the last time. It's a form of me talking to them.
3. Despite having a bit less brain wooze/buzz, I still have plenty, and it takes everything I have to both endure and ignore it – sort of like ignoring 95 decibel tinnitus – it's a learned skill. When I'm not distracted by the demands of work, it's trial by fire. When sitting in my counseling practice where ONE thing is happening vs 17 things at once at the hospital, the buzzing can be overwhelming. I'd like to put that practice on hold, but I have too many patients that need me. So it goes...

4. I put everything I've got (the leftovers, it seems sometimes) into being a good husband and father (of very grown kids), but often I'd just as soon crawl under a rock and die. I don't do things they'd like to do if/when I just feel too damn shitty. I really, really look forward to being more available. I'm good with listening and communicating, but going places, not so much. Lots of catching up to do....

The days are getting shorter and as of today, a bit cooler after the insane heat of northern California summers. I always look forward to late fall (early fall can still be roasting) and winter. I crave less sun, cold weather, and hopefully some more rain – that rare commodity around here. I really belong in Seattle or Nome or Siberia – some place where one has to bundle up. As always, a stranger in a strange land and a stranger body. And so it goes...

October 7th: more better days, less neuro noise – reinforces optimism.

October 20th: Had my repeat atrial ablation on the 14th. It went OK. I had one day a few days ago with persistent PACs, but the old ticker has been mostly quiet since. I took one Ceftin dose a couple of days after the procedure and had a mild herx from that. All in all, Lyme brain symptoms are a bit improved. I don't seem to be having the post-prandial neurotoxic rush as much that I've been so plagued with. Got a flu shot today. My eyeballs already ache (4 hours post injection). Hopefully it'll forestall influenza this season.

November 27th – so much has changed! After my ablation procedure, I had to have a urinary catheter, which was less painful than the one I had previously as it was a bit thinner. I had typical discomfort after catheter removal but by a week later, the discomfort had morphed into something deeper and I realized that I had a complication of catheterization – prostatitis. Uggh.... So it was time for antibiotics. I started Septra and by the next day, I developed one of the most intense herx reactions I've ever had. Shaking chills, intense myalgias, pounding heart, stiffness, eye pain and profound malaise put me to bed at 1:00 in the afternoon, wrapped in three layers of clothing, and other than to pee, I didn't get up for 14 hours. Symptoms gradually faded over the next few days, drifting a bit above my prior baseline. Recall that 8 years ago, when much sicker with Lyme, I took 3 months of Septra and Rifampin and after a horrid 2.5 months, my brain cleared and I was pretty symptom free – at least for neuro symptoms. Unfortunately, the 'Lyme doc' I was seeing at the time thought it would be a good idea to stop [what was working!] and start a different antibiotic, on which I relapsed and have never been the same since. I re-tried Sep/Rif a year later and though it induced intense herxing, it never cleared my neuro symptoms.

A week after starting Septra, I added Rifampin and had deepening neuro symptoms (woozy, buzzing, edgy, 'toxic intoxication) for the next week. By the third week, I was having some parts of days that were remarkable. I felt better than in years, but, of course, it didn't last. I had some very bad days and parts of days, but now, past my 5th week on Septra/4th on Rifampin, I have more clear days, or at least hours, than in a very long time. Also, more of my bad days are what I view as 'cytokine' days when I'm just profoundly wiped out, but not necessarily with the neuro symptoms flaring. Sometimes, if I kick back on my recliner, I can drift off into a semi-conscious/semi-sleep state and feel much better after an hour or two. My optimism has been refueled.

I've spoken to the head of a hyperbaric oxygen center an hour from my home. She claims to have had great success treating ~100 Lyme patients over the past number of years. I'm going to check it out, though my enthusiasm is tempered by the enormous price tag and travel challenges [I work, for starters]. But at my age, I really can't afford to leave any stones unturned. I have had significant herxing from intravenous ozone and exercising breathing 100% O2. My bugs clearly don't like that molecule. Stay tuned.

Since the ablation, I had 2 episodes of a.fib, the first one lasting one hour, and the second one lasting 20min. I had a few days of misery with frequent and very symptomatic PACs, but it's been awhile since any arrhythmia has happened. I'm very happy about this.

And so it goes, for now. Onward ~~~~~>>

A month later – Dec 28th - Things are changing

I'm now well over 2 months on Septra + Rifampin and a month with Doxycycline added to the mix. As these are am and pm dosed, at mid-day/lunch, I take my calcium and magnesium supplements to be far from doxy dosing, as well probiotics – VSL3 and Prescript-Assist Pro – the soil organisms prep from Researched Nutritional. I also take S.boulardii at any time. I have no untoward GI symptoms, though for the first month or so I was moderately dyspeptic and it was hard to eat much. That has passed. Although I take a lot of other supplements, none of them are specifically for 'detox' purposes. For me, detox approaches have never done anything that I can tell. *For me*. The ONLY thing that has ever gotten me anywhere is bug killing with antibiotics and/or Rife (and maybe O2, O3). As always, ymmv.

I have some days that are as close to symptom free as I can imagine. Sometimes several in a row. That NEVER happens. When I'm not symptom free, I'm not bad. Not nearly as sick as I was on a daily basis for most of the past 2 years. As of the last 2 weekends, I began pulsing – 4 days on, 3 days off. I checked my blood count and

liver functions to monitor antibiotic use and they were fine at about 6 weeks in. I'm due for another check soon.

I'm putting pursuit of HBOT on the back burner for now. I want to see what 3-6 months of the current approach does. If I have too many variables, I can't know what's doing what. I might do '10 pass' ozone sooner though as it's convenient for me. A prominent O3 doc is just down the street.

Something I took OFF the back burner is using my liveO2.com rig – exercise using 100% O2, alternating with oxygen depleted air (equivalent to 14,000 ft elevation) to induce vasodilation, using an elliptical trainer (15 min sessions at a time). I fell off that wagon last winter, or perhaps it was early spring, and as it so often goes with exercise inertia, I hadn't fired up the concentrator in quite some time. I've been having patellar issues that have limited my power walking, and the elliptical trainer seems pretty tolerable. So, I do this. I continue strength training every other day. I'm sleeping better. I think feeling better fueled my drive to 'do more' and my willingness to tolerate more discomfort for a goal. I know my bugs hate oxygen, so I'm stickin' it to them.

There you have it for my last entry of 2016. What a farcked up year in Lymeland. But hope springs eternal.... so far, anyway. Onward~~~~>>

It is mid February, 2017 and as of last week, I have 'cried uncle'. Outa bullets. My attempts at knocking down this plague, or rather, the life destroying symptoms I live with every day – the brain fog/buzz/wooze/misery – have failed. I still begin nearly every day feeling normal, but by noon or so, the symptom complex begins and the long uphill trek through the blizzard of brain noise (+/- cardiac, myofascial pain, headache, scattered fasciculations, etc.) make my day miserable. There are, of course, many more details but I'm drawing the line here on relevance for this communication. I thought I was getting somewhere after 3 months of continuous antibiotics and then pulsed/cycled antibiotics (mostly ceftin + sepra) approximating five days on, 3 days off, depending on my hospital work schedule, but it has come to naught. Perhaps 6 months or a year would work? Who knows. It's not like I'm a newbie on the antibiotic merry-go-round – I've just run out of confidence that this will do it.

Rifing doesn't seem to do much anymore either.

And so, I have asked for help. This is the first time since 2012 that I'm investing in 'fresh eyes' on my case. I have a track record of 100% failure accomplishing anything good with this. I've had one consultation now so far, new testing is pending, and I have a good feeling about her.

I have a counseling patient who is dying of complications of Lyme disease. Once a successful professional, she is now destitute from her disease and cannot afford the out-of-pocket costs of a TBD pro – which I am NOT and wouldn't have the bandwidth to do even if I thought I had the chops. Even if she had some spare change, she's not well enough to get to most appointments. It's a crime against humanity – a medical system that cannot give her the best care possible – in the richest country in the world – but as of this writing, maybe the sickest....

I am no longer responding to those looking for help with their Lyme disease. Unless or until I get past this neurotoxic mess, I don't feel that I'm in a position to help others, beyond bearing witness as a fellow sufferer. I do this in my counseling practice, but am even pulling back from that as I must preserve my limited energies for my bread and butter – my hospital work. In the future, who knows? The good part remains – I still have my intellect and can make a living, despite feeling like dog shit. I endure.

Stay tuned, fellow riders of the storm.