

Current diagnoses and symptoms write up for: March 31, 2012

Current diagnoses and symptoms:

1. Generalized chronic tendinosis, experienced as a whole-body RSI (Repetitive Strain Injury). This is a well known and well described direct effect of Fluoroquinolone Toxicity (FQT), and most, if not all FQT victims experience this to some extent. Tendons affected include tendons in the knees, ankles, Achilles, feet (plantar tendon), toes, fingers, wrists, elbows and shoulders, and probably all other tendons in the body as well, which may well be contributing to my muscular pain. Level of pain ranges from about 1-4 to 7-10 out of 10, depending on what additional symptoms I'm experiencing and if I've tried to exercise. What this basically means is that as long as I don't move too much or utilize my body in any way too much, the pain level is minimized to a baseline 1-4 level out of 10. If I attempt exercise or movement, in particular anything with repetitive motion or weight bearing strain, the pain level will escalate proportionately. Examples include kicking my legs during swimming, riding a bike, or using the elliptical exerciser for more than a few minutes at a time will increase the pain the following days and week. If I try to do these exercises on subsequent days, usually by Day 3 or 4, I have to stop completely any exercise or movement for several weeks, due to severe pain. "Recovery time" for my tendons after any form of exercise is increased proportionately to how many minutes of exercise I am trying to do daily. I cannot kneel, crouch, stoop, or crawl more than a few times in a row for the same reasons. I cannot stand for long, or do any weight bearing or isometric exercises, for the same reasons. Sitting with knees bent for longer than 30-60 minutes at a time stresses the knee tendons and causes subsequent pain also. Holding a book up with my arms to read for longer than 30 minutes also will cause additional pain. I am able to type up to several pages daily now on the computer, except during the worst of setbacks. I am able to care for myself in the home, and I can drive. I can walk on level ground, sometimes up to 2.5 miles at a time. However, during more severe setbacks, I will not walk outside for exercise at all, will limit any movement within the home, and won't type at all, and will try to lay flat for several days to allow my tendons to recover.
2. Autoimmune (Hashimoto's) Thyroiditis. This is an endocrine autoimmune disorder where antibodies continually attempt to destroy the thyroid gland. Current statistics from informal polls are that at least 20% of FQT victims develop thyroid abnormalities after taking the antibiotic, with this particular disorder being quite common among that group. Symptoms of Hashi's include both hypothyroidism (low thyroid hormone) as a generalized state because the gland isn't working well, and hyperthyroidism (high thyroid hormone) during severe antibody attacks on the gland, which release boluses of the hormone. I have had severe symptoms of both, starting with my first thyroid storm which landed me in the ER at about Month 8 post. However, I was not appropriately diagnosed until about Month 16 post, as none of the doctors and specialists I saw throughout that time recognized it. I finally figured it out and demanded the appropriate testing myself. Symptoms of hypothyroidism that I experience include chronic fatigue, painful joints, muscle fatigue, exacerbation of tendon pain, peripheral neuropathies in feet, hands, and face, bradycardia (slow heart beat), heart arrhythmias (palpitations), tinnitus, sore throat, air hunger, insomnia, hot flashes/sweating, decreased energy and stamina, long recovery time, "brain fog", inability to concentrate, severe physical and psychological depression, severely dry eyes, skin, mouth and hair, severe constipation, achlorhydria (low stomach acid) and poor digestion/absorption, food sensitivities, severe hair loss, brittle nails, vitiligo, borderline high cholesterol, and Raynaud's syndrome (cold and

purple hands and feet due to vascular issues). During thyroid storms and hyper periods I have experienced tachycardia (fast heart rate), heart arrhythmias (SVT/VT's), high blood pressure, "adrenaline – like" feelings and rushes, extreme headaches, extreme eye pain, blurry vision, severe anxiety, severe hot flashing/sweating, insomnia, tremoring muscles, extremely painful upper arm tendons, increases in tendon pain overall, Interstitial Cystitis-like bladder pain, severe muscular weakness and severe fatigue. All of these symptoms are usually experienced at one time or another by FQT victims as well, and some to many of them chronically in the most severely affected. So it's unclear to me how much of my symptoms are due to FQT vs. Hashi's. My current hope is that by treating the thyroid condition, many of these symptoms will clear up as well eventually. Thyroid hormone is necessary for almost every cell of the body for growth, maintenance, and repair, and this includes tenocytes (tendon cells). Unfortunately, I was deficient in this hormone for the first 16 months after being floxed, when I needed it the most, so I lost a lot of potential healing time as a result. Additionally, I suspect the combination of being floxed along with the Hashi's is probably what contributes to the severity of my symptoms overall. Hashi's can be difficult to adequately treat due to the fluctuating hormone levels between the hypo and hyper levels (ie, treating a "moving target" with a static dose of thyroid hormone), and so far I've found this to be true in my case. However, this condition is the only diagnosis that I have a hope of controlling or influencing, so I continue to try various approaches in my quest for resolution of these debilitating symptoms.

3. Severely Dry Eyes. This occurred with the initial insult of FQT, but slowly improved somewhat over time. Then, within a two week period about Month 8 post, when all the thyroid symptoms started in earnest, I lost all basal tear production. For me, this particular symptom is every bit as debilitating as the tendonitis. Currently, my eyes wax and wane between zero tear production (confirmed at university ophthalmologist), and a fraction above zero during better times. With zero tear production, my eyes are extremely painful, red, and feel like there is gritty sand in them at every moment, whether my eyes are open or closed. My vision is blurry, my eyes ache, and I develop severe headaches. I am unable to read, use the computer, watch TV, be outside in the wind and light, or use my eyes at all. I have spent entire days, and some weeks, in bed in the dark simply putting artificial tears in my eyes every 1-3 minutes in a desperate attempt to gain some comfort. At times I have lost reflex tears as well, leaving me with no tears while crying, an especially painful condition, as there is no relief from the suffering. Thyroid treatment appears to help somewhat, but a few micrograms of hormone either way (such as during the antibody fluctuations or dose adjustments) can make the difference between "intolerable" and "tolerable" status. On good days, I can get by with putting drops in my eyes once or twice an hour. This includes waking up at night throughout the night to treat. Computer time is often dictated by how much my eyes can tolerate. Eye treatments, whether over the counter or prescription, are very expensive. And none of it remotely comes close to natural tear production in terms of comfort and protecting from infection. Many FQT victims suffer from this, developing this symptom within a 6-9 month timeframe post insult, so my experience is once again fairly classic for this toxicity. This condition can also be caused by an autoimmune disease called Sjogren's Syndrome, which I am at increased risk of since being diagnosed with Hashi's. There is an overlap of many of these symptoms between the Hashi's, Sjogren's, and FQT, so these have been my top three differentials in terms of possible diagnoses. I have tested seronegative for Sjogren's at least three times, and will continue to monitor, as blood markers for this disease tend to start appearing 5-7 years after symptoms start.
4. Trigeminal Neuralgia / Facial Neuropathy. This is a tingling/numbness around my eyes in particular: just below the eyes on the cheek, just above on the brow, across the bridge of my nose; also my upper lip.

Right side is worse than the left and a small area on my right cheek seems to be the nidus or focal point. Basically, the symptoms seem to follow the ophthalmic and maxillary branches of the trigeminal nerve, and are like a trigeminal neuralgia. At its worst, the symptoms continually move around this area, waves every 10-15 seconds, round the clock, often initiating on the right cheek area and spreading to the left side. Symptoms tend to be less in the AM, progress throughout the day, and worst in the PM. Symptoms seem to be exacerbated by eating. Very very rarely have I experienced a mild tingling around the lower lip, essentially, that area hasn't been of concern yet. At the height of the symptoms, I experience numbness across the bridge of my nose and in the sinus area. Although there is decreased sensory to the skin in this area, the numbness and symptoms are "deep" to the skin as well, and particularly present in the sinus area. At times, at the height of the symptoms, I experience bilateral earaches, sharp pains through my ears, as well as moderate to severe tinnitus, and numbness to my gums above my back upper molars. Also during the worst of these "flare ups" I experience "brain fog" and disorientation and "headache". Additionally, these symptoms seem to either cause, exacerbate, or correlate with my severe dry eyes, and "eye pain". Neurology workup and MRI of my head revealed no abnormalities and no brain tumor, and no explanation for the symptoms. These symptoms can be indicative of Sjogren's, Hashi's, or FQT. I have found that correct thyroid treatment can help these symptoms substantially, but I have not found the optimal dose yet, and symptoms continue to wax and wane. These symptoms contribute greatly to my "non-functional days" – days where I cannot read, type or write, walk, drive, run errands, or do much of anything other than stay in bed.

5. Peripheral Neuropathy , Peripheral Artery Disease, and Raynaud's Syndrome. Within the last 6-8 weeks or so, I've developed additional peripheral neuropathy, mostly in my feet and lower legs, but a little bit in my hands and fingers, and scalp as well. It feels like a chronic painful bad sunburn on the surface of my feet and legs, along with tingling and numbness and the feeling of "water trickling down my legs and across my scalp". Even with this burning feeling, my feet and legs are very cold "from the inside", chronically white and pale except for purple areas; this is due to the vascular issues of Raynaud's. These symptoms developed as I was changing my thyroid meds, so perhaps that is one cause. However, they again are very common in victims of FQT, and also can be caused by Sjogren's. It remains to be seen how much of this will resolve as I optimize my thyroid meds. I didn't have this symptom when I was initially hypothyroid, so this does feel like a new development. I hope it's not permanent or progressive, because if it gets bad enough, according to other Sjogren's sufferers with PN of their legs, it can affect and limit my ability to walk.
6. Adhesive Capsulitis ("Frozen Shoulder"). I went through a flare up of my arm tendons in August 2011. Both upper arm tendons were very painful and felt "loose". One day, I moved my left arm to my right side, and felt and heard a loud "pop". From then on, the biceps tendon in my left arm has been extremely painful, and I estimate I initially lost about 80% of the use of that arm. Within a few months, I then developed "frozen shoulder", most likely secondary to this trauma. This has severely limited the use of my shoulder as well. MRI and ultrasound revealed no abnormalities; however MRI will miss about 15% of intra-tendon tears, and the ultrasound had limited views because of the limitations with my range of motion with my arm. To this day (approximately 7 months later), the tendon in my left arm is still very painful, and the frozen shoulder persists. Frozen shoulder usually is a self limiting condition, healing within 1-3 years, unless a person has thyroid problems or diabetes (both of which I now have), in which case it may take longer or never heal 100%. I estimate I currently have about 50% of the use of my left arm. I can't reach up above my head or stretch my arm or reach behind my back. Although it's somewhat difficult, I have learned to compensate, and use my right arm for most of my daily tasks, such as washing

my hair, showering, dressing, driving, cooking, etc. However, the corresponding tendon in my right arm is also very painful, and feels similar to how the left tendon felt before it “popped”. The right shoulder also has some incipient pain, and I feel like that shoulder also “wants to freeze”. I try to guard my right arm as best I can, as it’s really the only good functional limb I have left. I estimate I have about 80-90% of the use of my right arm for daily functions. The orthopedist recommended waiting at least a year to see if the left frozen shoulder will heal on its own. We both agreed steroid injections into the shoulder would not be wise for me, as steroids of any kind tend to make the tendinosis and other symptoms in FQT much worse for most victims.

7. **Dysglycemia/Type 2 Diabetes.** I discovered severe blood sugar abnormalities (dysglycemias) were occurring about Month 7 post. My blood sugar was spiking to 250 after eating, taking 8 hours to return down to 130, and plummeting to 50 or below in between. This is quite typical and characteristic of FQT, and although it can occur quite acutely while taking the drug, it tends to develop within months to a year of stopping the drug. Diabetes is not in my family history, my DNA test revealed I don’t have any increased risk for this, and I don’t have the body type. Differentials therefore include: direct result of FQT, metabolic syndrome due to extreme inactivity and chronic illness, hypothyroidism, Addison’s disease - clinical or subclinical, hormonal, inflammation, autoimmune, or other. When I saw my original PCP about this, she didn’t believe I have diabetes because my fasting and A1C, the typical screening tests for this, were within normal limits. However, this is the same doctor who decided I didn’t have a thyroid problem based on the typical screening tests for thyroid. I requested a more comprehensive glucose workup, but she refused. However, I saw no reason to wait until I developed permanent peripheral neuropathy, lost a leg or an eye, or ended up in the ER with dangerously high or low glucose levels, before being appropriately diagnosed with this, so I’ve taken action on my own. I changed my diet radically to a low carb diet, and have spent hundreds of dollars on diabetes strips to characterize these swings, trying to correlate them with my other symptoms. I do regular lab work to rule out autoimmune and adrenal issues, and aggressively monitor my thyroid to objectively track treatment changes. So far, treating the thyroid has eliminated the severe lows, but not the high blood sugar spikes and the insulin resistance. Despite this, I am managing to keep my glucose under acceptable control so far with a very controlled limited diet and the little bit of exercising I can do. Of course, exercise is one of the best things to do for Type 2 Diabetes and Metabolic Syndrome, but that’s the one thing I can’t do aggressively with any kind of consistency. I have yet to do the comprehensive diabetes workup on myself, but plan on doing that when I’ve gained hormonal control in other areas first to get a more accurate idea of this issue in isolation. If, after optimizing all other conditions, I can’t control the glucose with diet, then I will consider traditional medication. However, I consider this a last resort; there’s simply no reason to jump to medication (many of them with their own serious side effects) first before addressing a number of other potential causative issues I’m experiencing.
8. **Severe chronic fatigue.** I have waxing and waning severe chronic fatigue. This usually occurs with many of the above symptoms as they flare up. When I’m hyperthyroid, I feel weak, shaky, trembly, and “out of gas”. When I’m hypothyroid, I feel extreme fatigue, sluggishness, and like I’m “wallowing in syrup”. This is separate and in addition to the tendonitis and hypothyroid physical pains I experience. I think the inability to move and exercise contributes to this, along with the chronic insomnia and additional symptoms. I continue to walk for exercise as I’m able, but I have spent days and weeks housebound due to the combination of this fatigue along with the other symptoms. Sometimes, simply going to grocery store can be incredibly fatiguing.

9. Chronic insomnia. I am always tired, but am unable to get a good night's sleep. I never wake up refreshed. I wake up every hour or so to put drops in my eyes. I also wake up to move or roll over carefully, as it's painful to do so because of my painful arm tendons and frozen shoulder. I'm unable to sleep on my left side because of the frozen shoulder. Chronic hot flashes and sweating occur when my thyroid, adrenal, and sex hormones are imbalanced, and when blood sugar is high or fluctuating, and this contributes greatly to my insomnia. I do take a benzodiazepine (sedative) 1-3 times a week when desperate to get a good 3-4 hours sleep at a time. I limit this, as these are addictive and contribute to my fatigue and grogginess the following day.
10. Tinnitus. This occurred with the initial drug insult, but slowly went away over the subsequent months. It then returned with a vengeance when the thyroid issues escalated Month 8 post. It definitely increases in volume when I am either hyper or hypo with the thyroid meds. At times, it has been borderline intolerable, contributing to my misery.
11. Food sensitivities. Most FQT victims develop this to some extent within the first several months to years of exposure, and I am no different. For whatever reason, just the act of eating worsens the "head stuff" (trigeminal neuralgia and facial neuropathy, headache, dry eyes). In my case, I suspected and hoped that it was related to the Hashi's (ie, food stimulating the antibody attacks) as this was something I could control. I experiment with different foods in an effort to determine what, if anything, stimulates the antibody attacks, and if there's any way I can prevent the attacks or lower the antibodies. I have done an elimination diet, and eat an extremely limited diet now, between this and the diabetes. This has been a slow process, as is everything else involving the thyroid gland, but I do feel I've achieved some success with determining trigger foods. The hypothyroid state also affects my digestion quite a bit by decreasing the acid in my stomach, and I just can't eat much anyway as food just "sits there" and doesn't digest.

Why I have out of pocket and out of network expenses:

In April 2010, a few weeks after taking the antibiotic, a rheumatologist did a "massive workup" (in his words) to rule out autoimmune, infectious, and inflammatory conditions. Out of the numerous test results that came back, only one was out of range: the TSH test for the thyroid. Interestingly enough, only 3 weeks earlier I had had a random TSH thyroid screen done during a wellness check, and it was within normal limits. So within a 3 week period, during the acute phase of my antibiotic reaction, my thyroid was obviously affected, and the test result showed that. Despite the fact this test result came back abnormal, the rheumatologist did not follow up on this. Additionally, the bulk of a rheumatologist's job is to check for antibodies which act as a marker for autoimmune conditions. Unfortunately, for whatever reason, the rheumatologist checked for antibodies to almost everything but the thyroid gland. In hindsight, it is obvious to me, both from a clinical perspective as well as based on test results, that I was having a thyroid problem in April 2010. Not only did the rheumatologist miss this, but every subsequent doctor and specialist I saw after this, all the way up through the Neurology consult and MRI one month before diagnosis, missed this as well and continued to write on my reports that "Thyroid axis is normal". Thyroid hormone is absolutely necessary for almost every cell in the body for growth, maintenance, and repair. It is absolutely crucial and fundamentally necessary for the body to handle any physical as well as emotional stress. For the next 16 months, until I finally figured it out and diagnosed myself, I was deficient in these hormones while attempting to deal with an incredible physical insult (FQT due to Ciprofloxacin) to my body. Not only was there not a lot of "repairing" going on, but I continued to decline into a variety and severity of symptoms I never thought

possible during this time, both physically and emotionally. From my perspective, I suffered much more than I would have, and lost a lot of potential healing time, as a direct result of the negligence of these doctors.

Consequently, I've done what many people in similar situations before me have done, when the "system" fails them: taken charge of my own health and turned to independent physicians with an alternative, complementary, or holistic approach who will work with me. The doctors I have chosen are traditional licensed MD's, but with an interest in holistic health, so I get the best of both worlds. Unfortunately, insurance companies tend to only cover synthetic patented drugs, and not natural, unpatented medications or supplements. I therefore pay for the out of network consults and natural medications and supplements myself. I am a good clinician, and there is no one more willing and motivated than me to find some answers, if any exist, to my current health problems. I can certainly research my own case as well as or better than the traditional physicians I've seen so far. I've been proactive and the driving force all along anyway for requesting or demanding the testing that's been done. Every workup I've had done, I had to suggest or demand. I was the one who requested physical therapy. And I was the one who eventually diagnosed the one condition I do have at the moment. This has all been documented through my letters to my physicians. Having health insurance and the traditional medical system has been important and lifesaving for me in times of catastrophic acute health crises and typical wellness screens. However, it turns out it's quite different if a chronic problem exists: if the problem, solution, and treatment isn't one of their "top forty" 15- minutes diagnoses, these doctors have no answers, other than to prescribe pain killers such as opioids, NSAID's and steroids, or synthetic drugs with a long list of side effects. I'm not interested in spending my life half asleep or addicted to drugs that only mask the problems. I'm already experiencing the long term horrific side effects of the supposedly benign antibiotic I was prescribed, and am understandably pretty wary of additional risks from additional drugs. I initially was rather shocked at the incredible lack of interest, curiosity, or any motivation what so ever of these doctors to dig a little deeper into actually diagnosing my health issues and trying to solve them. However, it turns out my situation is not unique; I've since learned that virtually every person with a chronic illness has to be extremely proactive in their own health care, as the system as a whole is just not designed to deal with these types of patients. I accept it for what it is, however, I am not willing to compromise my health and refuse to let insurance companies, for-profit drug companies, and frustrated overworked doctors dictate my health care based on limited diagnostics and time constraints of the system.

Unfortunately, traditional medicine has had little to nothing to offer me, and therefore no hope. If I can avoid it, I'll do everything I can to prevent the slippery slope down into permanent disability. I continue to choose to believe that there are actions I can take to improve my health, but it will take time, effort, and probably most of my savings. Most FQT victims spend between \$10,000 - \$100,000 of their own money in the quest to heal from this toxic event, and it looks like I'm not going to be any different. Whether I succeed or fail in my attempts remains to be seen, but at least I'll know I tried.

Top three differentials and treatment approach:

1. Fluoroquinolone Toxicity: Proposed mechanisms of damage include cellular DNA damage, mitochondrial DNA damage, and severe oxidative injury and cellular death. If I choose to believe these proposed mechanisms of damage as the cause of my symptoms, then there is very little I can do to help myself heal. Symptoms may mitigate over time, but the damage is done. Although this may be the case, I don't focus on this for the time being, as it's not helpful to my healing.

2. Autoimmune, in particular Sjogren's syndrome: If I choose to believe my symptoms are autoimmune in nature, then there are powerful immunosuppressive drugs available to help mitigate these symptoms. Some of these drugs take 3-9 months of usage before knowing if they are going to work or not. This includes the very expensive cyclosporine eye drops "Restasis", which only work in about 15% of the people who try it, burn upon application, are incredibly expensive, and can make my eyes worse when stopped. These immunosuppressant drugs have equally powerful side effects, and I see no reason to start taking these drugs without an actual diagnosis. Additionally, once I start taking these drugs, there's "no going back" in terms of trying to ferret out root causes of additional symptoms because there are so many side effects (which often require additional drugs). I have frequented a number of autoimmune boards on the internet, and the list of drugs these people are on are astounding. Doctors have offered me "trials" of steroids and immunosuppressive drugs to "see if they help" (instead of doing the appropriate testing). Again, I will not take these drugs unless and until I have at least one marker of a positive diagnosis. To date, I remain seronegative (no antibodies in the blood work) for a number of autoimmune conditions I am monitoring. I have been diagnosed with one autoimmune disorder (of the thyroid gland), so I am at increased risk of developing more within my lifetime. I will continue to monitor this by checking antibody levels for a variety of autoimmune disorders once or twice a year. If I can get insurance to cover this, I most certainly will go this route. However, insurance companies are only interested in getting to a diagnosis with the least amount of testing possible, which usually requires a person already have severe symptoms before justifying ordering the tests. As with the diabetes and Hashi's, I'm not interested in waiting until it's too late any longer to discover I have a serious disorder. If I have to pay for the tests on my own to be proactive and provide adequate monitoring for myself, I will.

3. Endocrine and hormonal. If I choose to believe that many, if not all, of my symptoms, are due to endocrine imbalances, then this is the only differential so far that I have some control over, and can possibly affect a positive outcome. In my mind, this is the "only card I have to play" at the moment, so I'm "playing it" for all it's worth. I have found that thyroid hormone can have profound effects on my tendon pain, as well as all the other symptoms provided above. On occasion, I hit "the sweet spot" and for a few hours, sometimes a couple of days, can almost feel tantalizingly "normal". Complicating matters is that it takes a good 6-8 weeks with any adjustments or changes I make with thyroid meds to determine if improvements or failures occur. This means that overall this is a very slow process. I also am choosing to use bio-identical natural hormones (exact replicas of what my own body would produce) instead of the synthetic drugs that traditional medicine and the pharmaceutical companies have to offer. Sadly, but not surprisingly, insurance will only cover the synthetic drugs, which increases my out of pocket expenses quite a bit.

Regarding PRP/Prolo or stem cell treatment – I am interested in this, but it's not prudent to do unless I've gained hormonal control and there's no evidence of autoimmune. I also doubt I'll have the money, if that time ever arrives. At times, the hormones must have been optimal, as on occasion I've been able to walk 2.5 miles, and bike up to 6 miles at a time. This suggests to me that hormonal influences are greatly affecting my symptoms and overall status, and that gaining control of this aspect would be more productive than PRP/Prolotherapy. However, it seems that for every step forward, it's about 5 backwards. As of today, I am coming out of a severe setback from the past several months. I did try riding my bike again for a few days several weeks ago despite this setback, but I wasn't able to keep it up and had to stop all activity again.
