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3 Month Progress Report on Doxycycline (Nov 2021-Feb 2022), with 2-Week Pause

Started doxycycline Nov 6, 2021 after suspicions of undiagnosed Lyme disease and the failure of four antibiotics (Bactrim, Nitrofurantoin, Cephalexin, Fosfomycin) to resolve recurrent UTIs—15 in a span of 15 months (July 2020-Nov 2021). During this 15-month timeframe, disability increased markedly: standing was no longer possible, transfers could only be completed sitting down (side transfers), it became impossible to get on/off floor without significant aid, risers were purchased for the toilet and couch, additional bars were installed in the bathroom, and a wheelchair-accessible van was purchased (July 2020).

Since initiating doxycycline, there have been dramatic health improvements. In addition to the antibiotic, 2-4 sessions weekly of in-home occupational and physical therapy were added along with 2-3 hours of daily (self-driven) therapy, amplifying physical gains. After 2.5 months on therapy, a 2-week antibiotic pause was initiated, resulting in the modest re-introduction of many symptoms. The results of the past 3 months are documented in detail on the following pages.

Foot/Ankle/Leg Swelling

Severe swelling of the feet, ankles and lower leg had been a chronic problem dating back to approximately the summer/fall of 2020. Once doxycycline was introduced in the fall of 2021, virtually all swelling resolved within one week. When doxycycline was paused for two weeks in early 2022, modest swelling returned within a week. It resolved a week after the antibiotic was resumed.

August 6, 2021, typical swelling of feet for past 2 years.

November 10, 2021, 5 days after starting doxycycline.

January 23, 2022, baseline before pausing doxycycline.

January 30, 2022, swelling resumed approx. January 29.

February 4, 2022, before restarting doxycycline.

February 12, 2022, six days after restarting doxycycline.

Leg risers and compression socks were used for a year+ to reduce swelling with only limited and transient success.

A leg recovery system with air compression was tested to see if it could reduce the chronic swelling. It could not.

Feet/Ankle/Leg Measurements

In a test of the Normatec Leg Recovery System, extensive measurements were taken October 18, 2020 and November 4, 2020 to quantify any improvement on swelling. It did not; swelling only intensified. [Note: maximum swelling was observed in the summer and fall of 2021, not measured.] Measurements were retaken February 14, 2022 after the introduction of doxycycline as a comparison. While both right and left lower extremities saw a reduction in size, in particular the calf region, it is unclear how much of the change is the product of reduced swelling, the result of muscle atrophy, or a combination.

LEFT FOOT/ANKLE/LEG

11/4/20	cm	2/14/22	Change
Ball	24.0	23.5	-0.5
Arch	25.5	25.0	-0.5
Above Ankle	24.3	23.5	-0.8
+10 cm	23.7	23.5	-0.2
+20 cm	32.5	29.8	-2.7
+30 cm	33.0	32.0	-1.0
Kneecap	37.5	36.5	-1.0
+10 cm	37.5	36.8	-0.7
+20 cm	44.8	43.0	-1.8

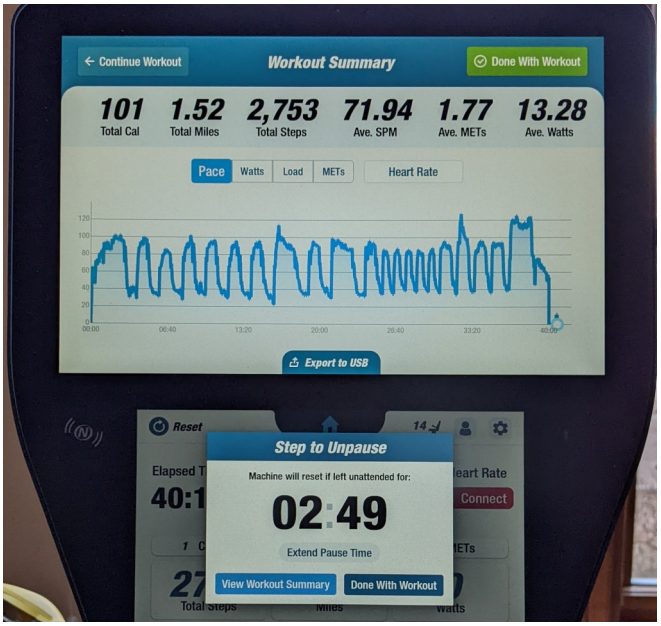
RIGHT FOOT/ANKLE/LEG

11/4/20	cm	2/14/22	Change
Ball	24.0	23.0	-1.0
Arch	25.3	25.0	-0.3
Above Ankle	25.1	23.4	-1.7
+10 cm	25.6	24.5	-1.1
+20 cm	34.0	31.0	-3.0
+30 cm	34.7	32.5	-2.2
Kneecap	38.3	36.5	-1.8
+10 cm	37.8	37.0	-0.8
+20 cm	44.0	44.0	—

Lower/Upper Body Strength

Weakness, particularly lower body weakness, has been a chronic symptom dating back to diagnosis in 2005. Leg strength slowly deteriorated until the spring of 2009, when a cane, and then walker, were required for mobility in 2009 after a series of UTIs. A wheelchair became necessary for distance in 2010. Leg strength returned after HSCT in 2010, only to slowly fade in following years. A cane was last used in 2015, forearm crutches last used in 2017, a walker last used in 2018. A wheelchair has been used full time since 2018, resulting in significant muscle atrophy. Upper body strength had also decreased markedly, particularly on the right side. After the introduction of doxycycline, upper body strength returned dramatically and swiftly while lower body strength is being regained steadily with the help of physical therapy. The doxycycline pause affected strength gains only minimally.

In the first week on doxycycline, it was not possible to move the pedals a single full stroke on the NuStep using only leg power. After the second week, that improved to one minute, then after week two, two minutes, then five. This was accomplished in 30 to 60 second intervals.



Steady improvement in leg strength has been notable, increasing with every passing week. After three months of doxycycline, 15 minutes of leg-only power, in intervals, can be observed here (the troughs). A 5 minute leg-only interval has been the maximum interval to date.

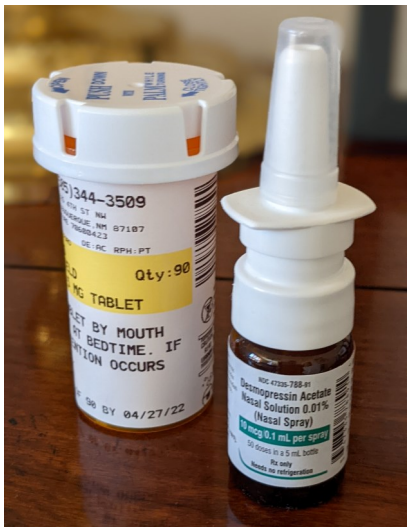
Before the introduction of doxycycline, a set of 10 reps of bicep curls was limited to 4lbs (L), 2 lbs (R) maximum.

After one week of doxy, it was possible to complete a set of bicep curls using far heavier weights: 20lbs (L), 15lbs (R).

Bladder/Bowels

In addition to leg weakness, bladder issues have been the most debilitating. Urgency, retention, leakage, and nocturia have been chronic and unrelenting since 2009 as medications have been only modestly effective. Incontinence was frequent, averaging once or twice a month, necessitating protective undergarments and mattress pads. Bladder issues were most acute in 2009/10 after a series of debilitating UTIs or UTI-like symptoms and in 2020/21 after 15 confirmed or suspected UTIs in a span of 15 months. Self catheterization was initiated in the fall of 2021 but UTI-suggestive symptoms persisted (accompanied with or without a positive culture, usually skin related). Days after the introduction of doxycycline in the fall of 2021, bladder problems have virtually resolved in full. There were no significant bladder issues during the 2-week pause of antibiotics in January 2022.

For the bowels, constipation has been the most significant challenge despite significant dietary modifications, with urgency a frequent issue accompanied with occasional incontinence (1-2 times per year). A portable toilet transportable by vehicle had to be purchased for emergencies. After the introduction of doxycycline in the fall of 2021, constipation problems have decreased markedly. (Note: there have not been any diarrhea/loose stools during this time; daily probiotics are taken.) During the 2-week pause of antibiotics in January 2022, constipation gradually returned within a week, and resolved a week after resuming antibiotics.

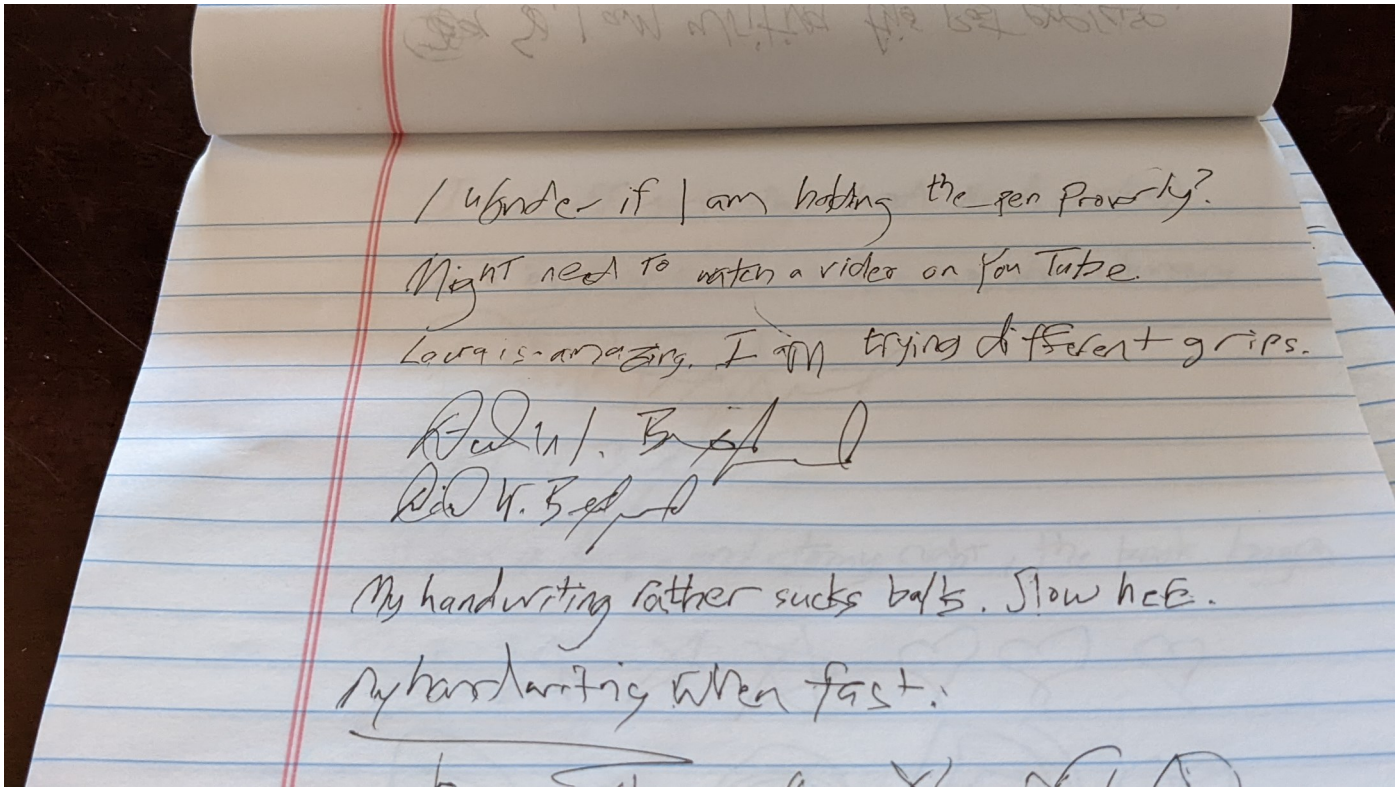


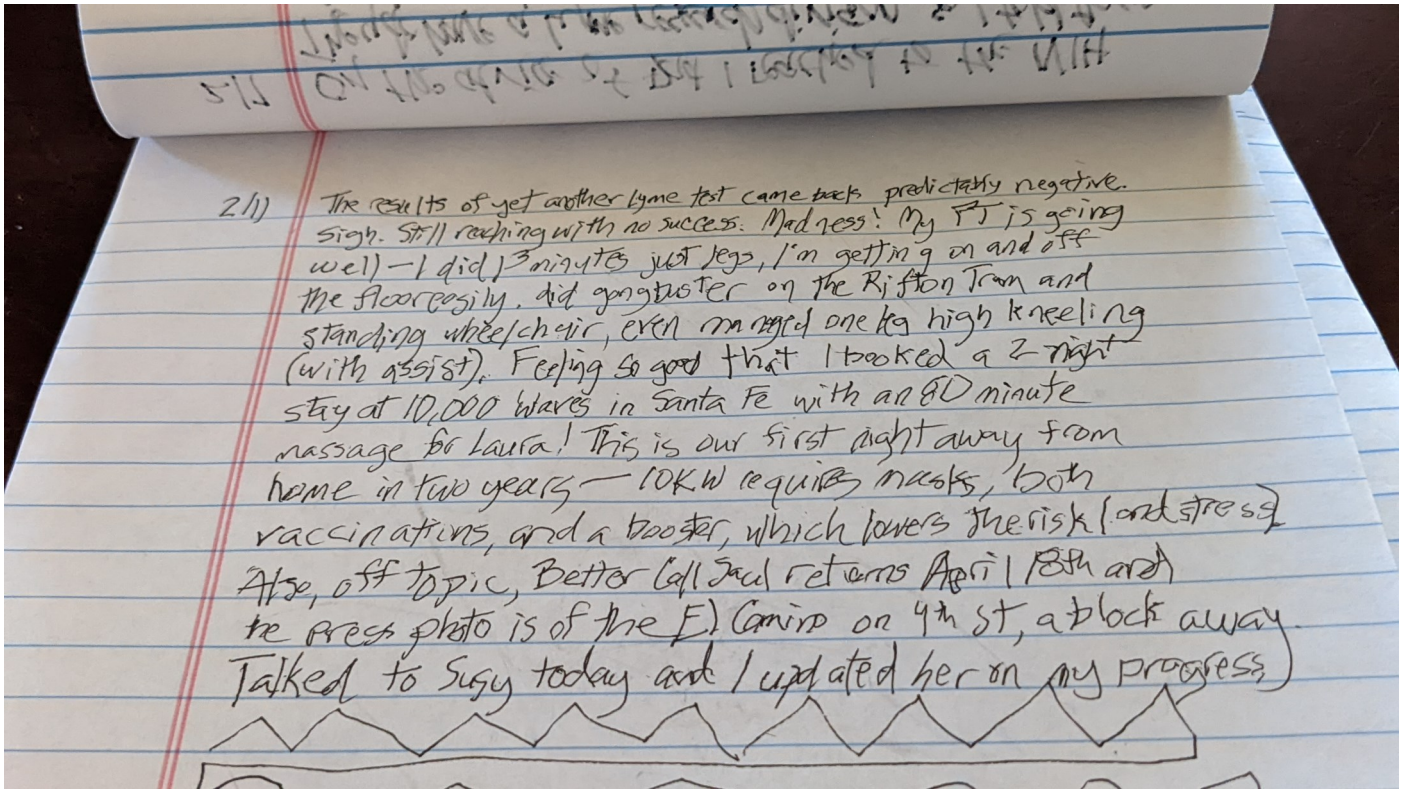
After the introduction of doxycycline, all bladder medications have been stopped (oxybutynin and desmopressin). All self-catheterization efforts have ceased. Urinals and disposable underwear are no longer needed. Breakfasts heavy in fiber are no longer required. Laxatives are no longer used and any fiber supplements are now taken as needed for predictable regularity for someone in his or her 50s.

Because of urgency, clothes below the waste had rarely been worn in the last year; blankets and towels served as cover-ups when entertaining house guests. Velcro skirts were purchased but only worn twice before doxy rendered them unnecessary.

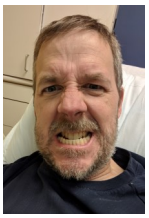
Hand Dexterity/Fine Motor Control

Due to illegible writing and inability to hold a pen, all handwriting ceased in 2019 with the exception of barely legible signatures. Most kitchen duties requiring coordination (cutting, turning, etc.) were ceased and aid has been needed for dressing, from shirts and pants to socks and shoes. After doxycycline, all areas involving fine motor control have improved dramatically. The clearest example is demonstrated in handwriting—the top example is from mid November, the bottom from three months later.



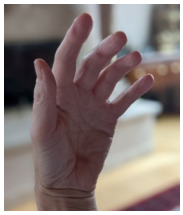


Spasticity



Spasticity emerged as a significant symptom in 2015 and has required muscle relaxants since: Baclofen, 20 mg, 3x a day, at times more (the maximum oral dosage is 80 mg daily). A week after initiating doxycycline, legs became uncontrollably floppy at the full dose of baclofen. Slowly tapered baclofen to 45 mg/day, then 30 mg/day, then 20 mg/day. During the antibiotic pause, forced to increase baclofen to 40-45 mg/day. Currently at 30 mg/day. Changes in spasticity, which were notable, have been documented by OT and PT therapists.

Neuropathy

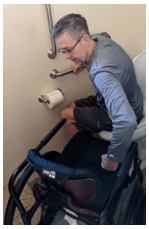


Lack of feeling along with pins and needles in the lower extremities has been a near constant since diagnosis. The lone exception was after HSCT (followed by a year of antibiotics) when feeling markedly returned. Numbness gradually resurfaced after 1.5 years. Issues are most pronounced in the feet and lower legs as well as the hands (right in particular). The recent addition of doxycycline has had a mixed effect on this symptom, with tactile awareness improving with the hands, less so with the legs and feet. The antibiotic pause had little effect.

Sexual Performance

Before the introduction of doxycycline, bedroom activities were challenging, time consuming, and frequently unsuccessful. Erectile dysfunction and sensitivity are ongoing issues, necessitating Viagra or other ED drugs. After doxy? Medication is still used as an aid, but timing can be measured in songs rather than full-length albums. The antibiotic pause proved (temporarily) detrimental in this department.

Transfers

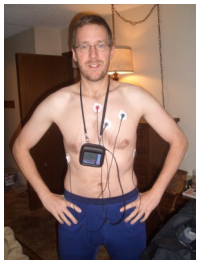


For the last year, transfers on and off the toilet, chairs and other furniture have been side transfers out of necessity due to the inability to use legs. With doxycycline, standing transfers can be accomplished, permitting the far easier removal of pants/shorts. More care was taken during the antibiotic pause for safety.

Self-Rescue

Prior to doxycycline, it was not possible to self-rescue after a fall or voluntarily sitting on the floor (last done in 2019). Additional help was necessary. By 2021, using a mechanical lift (or calling the fire department) became mandatory. Once doxy was introduced, getting on and off the floor can be accomplished unassisted.

Cardiac



Tachycardia was an early symptom in late 2005, early 2006, with resting heart rates at 100 bpm, cresting to 130 bpm with minimal effort. While that acute symptom faded after several months, random cardiac issues have surfaced at times, most typically in the form of a racing heart, which tended to last 24-36 hours. Since the fall of 2020, maximum heart rate numbers recorded during exercise, have dropped from the mid 150s, to 140 bpm or lower. Also during this timeframe, both lower legs were chilly, even after a hot shower. Once doxy was introduced, legs were once again warm to the touch. Other cardiac progress is unclear at this point.

Pain, Cognition, Fatigue, Headaches

With rare exception, none of these symptoms have been present or problematic since diagnosis. This extends to joint pain, which occurred once, 3.5 months after the suspected tick bit (the wrist was so painful it was documented). The addition of doxycycline, predictably, has had no effect on these symptoms.