A Summary of J.'s Lyme Journey
By her parents ☺

Having lived in Africa for 10 years, we were used to being alert for signs of illnesses like malaria and filaria; but in April 2008 when our 11-year old daughter, J., was having more and more difficulty finishing her homework assignments on time, we had no idea we were not looking at a behavioral issue, but rather the start of a long journey with Lyme disease.

We didn't think then that 4 weeks of mono-like symptoms (fever, malaise, no appetite, leaving her thin and weak) in February was connected. But in the first part of May when J. started making a pattern with her foot before walking, then doing the same when she picked up a dropped pencil, we knew something was going on. Things progressed rapidly from then on – until by the end of May she could not walk by herself, had problems picking up objects or putting them down, could not physically concentrate enough (eyes shifting and hands not cooperating) to work her math problems on her final test although mentally she knew how to do them, and could no longer feed herself. At that point, we traveled 5 hours to consult with two western doctors. They told us to return to North America immediately, suggesting the possibility of a psychiatric condition and starting J. on anti-psychotic medication.

Arriving in Canada the first part of June, J. was examined by a medical doctor and a child psychiatrist (who continued the treatment of anti-psychotics), and had extensive lab tests. J. was still able to walk with help, but otherwise not able to do anything except sit and talk, though sometimes talking was difficult because she would repeat sentences 3 or more times. It was getting harder to feed her, and she would react against everything we were trying to help her with – we would try to put on her socks and she would try to stop us and then pull them off (all the while insisting that she really did want our help getting dressed). Through the rest of June and July 2008, J. had exams at the Children's Hospital (neurological, MRI) as well as a visit to a homeopathic doctor, all without answers. J. was admitted to the Children's Hospital mid-July for extensive testing including neurology and psychiatry, but after a week she was discharged, as they could not find anything physically wrong with her. Conversion Disorder was mentioned as a possibility.


J.S. – July 2008

At this point J. could still ride a bike if someone got her started, and she could move from place to place if someone got her started and provided external incentive (such as suggesting a footrace), but daily activities like getting her bathed & dressed were getting harder and she was jerking/twitching a lot more when sitting down as well as having a lot of problems with fine motor skills like picking up a spoon or pen. During one neurological exam she was asked to fold a piece of paper, and it took her probably 5 minutes to make one fold, using the palms of her hands instead of her fingers to manipulate the paper. She was extremely sensitive to touch – didn't like her hair being brushed; yet she wanted to touch food (with her tongue, nose, or chin) before it went into her mouth; the easiest way to feed her was through a straw. We had to start using the child lock on the car door, as she would try to open the car door and attempt to get out even while the car was in motion (irrationally). At times she unintentionally hurt her siblings when they tried to help her, throwing them to the floor. She also started drooling, and showed discouragement, whereas up to this point in her illness she had been very detached emotionally.

In August we were interviewed by a psychiatrist from the Children's Hospital who was able to get J. admitted to the mental health ward (lockdown) at the Children's Hospital the day before J.'s 12th birthday. The hospital staff suggested Post-Traumatic Stress Syndrome with OCD components, and J. was discharged 10 days later with a doctor's diagnosis of OCD and Movement Disorder. J. started school with first her father and then an aide helping her move from class to class and taking notes for her. She was able to listen to information, but reading and writing required help. The psychiatrist from Children's continued to meet with her, and in January 2009, J. entered the Dr. Gordon Townsend School, once again in the mental health ward at the Children's Hospital. As parents, we had done extensive internet research on J.'s symptoms and possible causes, and had suggested a few possibilities to the various doctors but hadn't found anything likely. In January 2009, a friend suggested the possibility of Lyme disease. Further research led us to neuro-Lyme , where a significant list of symptoms correlated with what we had observed in J.. We took our information to the doctors at the mental health ward and requested that they explore this option. After a detailed interview with the infectious disease authorities from Children's, they reluctantly agreed to do a blood test for Lyme and gave permission to put her on antibiotics (doxycycline) for 2 weeks; they said it could take 6 weeks to get a result from the lab tests (several months later, we asked one of our doctors to check up on this test - and, as the infectious disease doctor had predicted, the lab results were negative). After 4 weeks in the Gordon Townsend program, J. was released by a very puzzled staff whose best conclusion was OCD with Tic Disorder. She later had an appointment at a Tourrette's clinic. Throughout this time, she was on various anti-psychotics that either had no observable effect, or seemed to put her out of touch with reality.

J.S. – August 2008

We had continued our own research, finding help in places like canlyme.com. Hearing about the difference in various Lyme tests, we sent for a blood test kit from IGeneX labs in California and arranged with a local doctor to have him receive the results. We saw a marked reduction of symptoms in February, beginning around the 10-14 day point, as J. continued taking the doxycycline (we had requested and received a longer-term prescription after the initial positive results), and in mid-March you can imagine our mixed emotions as we received a clear POSITIVE result for Lyme Disease from IGeneX; now we at least had a name for what we were dealing with.

Since J.'s positive diagnosis (after more than 6 months of no answers), J. has been on a range of medication – various antibiotics, anti-parasitics (J.'s Lyme had attacked her central nervous system, so the blood/brain barrier had to be considered), and an anti-inflammatory (as well as LOTS of probiotics and many lab tests). Her initial improvement on the doxycycline lasted around 4 months, then the symptoms began returning, with new tics added. This led to another seven month hiatus of trying differing antibiotics before we found an antibiotic/antiparasitic combination that began the healing process again (azithromycin and atovaquone) Now, almost 2 years after the start of treatment, she is able to do anything she physically wants to do, her mind is able to focus, and she is almost totally weaned off all medications. A few tics remain, surfacing mostly in times of stress. Though only time will tell if we are really done with Lyme, we are SO thankful for the doctors who were willing to treat J. for Lyme disease, and for God Who has brought us through this difficult time.

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