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## My Lyme Story

My Lyme story started in the spring of 1991. Every spring, I would go mushroom hunting in rural Illinois. I never found an attached tick or had a bull's-eye rash, but that year I had the "flu" three times and had severe knee pain which I thought was related to an injury.

In the spring of 1992, over a period of three days, both arms and legs began to tingle. Initially, it was one-sided and my physician ruled out a stroke. I was only thirty-four at that time. My physician sent me to a neurologist who very quickly wanted to diagnose me with MS. We, as a Lyme disease support group, have found that the specialist you see determines your diagnosis. I was able to convince the neurologist to try me on the antibiotics for Lyme, as I felt I had more symptoms of Lyme than MS.

With the antibiotics, I had the classic Herxheimer reaction where my symptoms became much worse for a few days, then I'd begin to improve. By then, my symptoms included fatigue, headaches, nausea, weight loss, joint pain, dizziness, muscle aches, and blurred vision.

In September 1992, I had a short course of IV antibiotics. I then switched doctors, because the neurologist would not treat me further unless I went to Iowa City Hospital or Mayo's to confirm the diagnosis since three blood tests were negative. I was involved with the Quad Cities Lyme Disease Network and knew neither of these medical facilities give a fair evaluation for Lyme disease. I stayed on oral antibiotics until the spring of 1993, when symptoms became much worse. Again, my physician began to talk about MS. I had a MRI, which was normal. My Lyme tests were still negative. I found a Lyme clinic in Indiana, six-and-a-half hours away, and there my Lyme test confirmed Lyme disease.

I was put on twenty-one weeks of IV antibiotics. I improved, and went back on oral meds - but in the spring of 1993, I again relapsed. I could no longer see the doctor in Indiana, but found a doctor in Missouri. My physician told me he was at the end of believing I had Lyme disease. This was while I was sitting in his office looking like death warmed over. I was extremely ill at that time, and he offered no help but giving me my records.

The physician in Missouri tested me for Lyme, and I had a very positive test. He changed my antibiotic, and for the first time someone addressed possible yeast problems.

In the fall of 1994, I started the Mississippi Valley Lyme Disease Network. We have drawn people from Missouri and Iowa who have similar stories. Most of us go out of state for treatment. Most physicians in Illinois do not recognize Lyme as a problem, even though

the Illinois Department of Public Health has identified ticks with the Lyme bacteria since the late 1980's.

In the fall of 1994, I went off antibiotics, but was not symptom free. In the spring of 1995, I began to have problems again and went to the state of Louisiana, because the doctor who treats me for Lyme had moved there. A long drive to see a doctor, and something that should not have to occur.

By fall, I had relapsed and was back on antibiotics. The symptoms settled down, and by January 1996, I was off antibiotics. I did well until the fall of 1996, when my symptoms returned with a vengeance. I tried three different oral antibiotics and none of them worked. I tried IM shots of Bicillin and had an allergic reaction. So, again, I had a central line inserted and had several weeks of IV Vancomycin. I still was only doing fair.

By February and March 1998, I had heard of the hyperbaric oxygen study (HBO) in Texas. I did not meet all of the criteria for the study and did not want to wait to see if I would receive treatment. I and two other individuals went to Tampa, Florida, and received hyperbaric oxygen treatments. We were the first Lyme patients they had treated. I received forty-eight treatments over five weeks, with significant improvement.

I returned to Tampa for forty-eight more treatments over four weeks in October and November. By the time I returned to Tampa, I was slipping. I was on IV antibiotics during the HBO. The second set of treatments helped and I feel the best I have felt in seven years. I really feel if I were able to receive two or three months of HBO I would be cured of Lyme. I cannot afford more HBO, and I have used up all my sick and vacation time with the last two trips to Florida.

I have been lucky that my insurance has paid for IV antibiotics and my oral antibiotics with out question when I needed them. But, my insurance is changing and I hope I do not have to test it again. I have spent a lot of my money on alternative treatments for Lyme. Some have helped and some have not. But, I do not believe mainstream medicine has all the answers to Lyme disease, unless they treat early. I have changed local physicians five times, as they tend to loose interest when you do not get well on schedule. My current physician is supportive of my Lyme treatment and does not object to the alternative treatments. I pray he does not loose interest as the other did.

I still go to Missouri to see a doctor for Lyme, as he has treated hundreds of Lyme patients. Over the years a fraction of my symptoms have included: fatigue, headaches, sinus problems, blurred vision, ringing ears, fluid in the ears, neck pain, joint pain, hurting head to toe, arthritis, knee problems, dizziness, nausea, weight loss, yeast problems, ankle/foot pain, abdominal pain, memory problems, sleep disorder, numbness/tingling, tooth pain, choking problems, low body temperature, palpitations, sweats/chills, depression, irritability and colitis. The changes in lifestyle, loss of some friends and lack of understanding by others goes without saying.

I am currently trying IV vitamin C and IV hydrogen peroxide to clear up the last of my symptoms. I know the IV Hydrogen Peroxide is controversial, but it does give me a Herxheimer reaction, so I am hopeful it is killing more of the bacteria. I will never give up until I am

totally symptom free.

I continue to have a lot of support from my family, my church, my faith and my friends. Never give up, as there are caring medical professionals who are willing to help. Join a support group. They can be a wealth of information and support.

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