

Lyme article No. 4

Living with Lyme - May 22

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Grand Rapids Herald-Review

Editor's note: The following is the fourth of a five-part weekly series on Lyme Disease in Minnesota to be published Sundays this May during Lyme Disease Awareness Month.

Dozens of pills in various colors and sizes, IV bags, and shots are strewn across the kitchen table. Like a collection of supplies a medic might carry into the field, the lot looks as though it could treat more than a dozen wounded soldiers. Yet it's just one day's worth of medication for just one person. But it really is a war - a war she's staging with Lyme disease; a war she must live with every day and night; a war with limited medical support.

Her story is sad; her pain very real as she copes with this seriously debilitating, tick-borne illness. She's "struggling" and feels "isolated." This beautiful, strong, and confident woman who "could work as hard as three grown men," haul heavy hay bales, mount her horse with ease and precision, and guide national bird hunts, is left crippled physically and emotionally by the deteriorating effects of late-stage, chronic Lyme. It has completely changed everything about her life.

Unfortunately, this is also the case for many, many more like her. This number of people who know by experience that Lyme can develop into something much more painful than a simple tick bite and rash is growing - especially among those in north central Minnesota, including Itasca County.

While the stories of those who suffer with Lyme sadden our hearts, they also bring heightened awareness in hopes of greater understanding and, in turn, increased precaution among the population at risk. However, those who choose not to listen are not just those who don't read newspapers or those who want to remain blissfully ignorant. This group also includes physicians - the very people charged with finding ways to help those who are ill become well. Itasca County residents who live with Lyme are starting to speak out with a common intention to foster more discussion, more research, and more understanding among the local medical community. However, with patient-physician relationships so intimate and Lyme needs so extensive, these people fear backlash that could jeopardize their care. For this reason, the source reported in this article will remain anonymous.

A life with Lyme.

At 56 years old, she's lived in Grand Rapids for the past 16 years. It wasn't until just recently that her Lyme was discovered and rapidly progressed. Her diagnosis came via a path of discovery that was most unfortunate. Looking back over more than 30 years, she told of how her daughter had been a sick child all her life since she was five. In

consultation with doctors, they were told the girl suffered from various ailments from psychiatric issues and swelling of the brain to an erroneous diagnosis of cancer and prognosis that she would never have children.

“After suffering two miscarriages, she finally became pregnant - and, with many complications, the baby was born.” Despite the goodness that comes with a new grandchild, she still worried about her daughter who was constantly sick and in bed most of the time. “She had gone to doctor after doctor; been called a hypochondriac, a malingerer. Then, three years ago, she saw a nurse practitioner who said, ‘I think you have Lyme, have you ever been tested?’”

The Lyme tests on her daughter came back glaringly positive, so they began treatment and the symptoms started to get better. Then a few months later the young mother took a turn for the worse. It was Easter and her daughter was visiting Grand Rapids when the concerned grandmother decided to take her daughter to the local emergency room. ER doctors’ questions about medical history and current medications prompted them to explain that the young woman had late-stage, chronic Lyme disease. “[The doctors] both rolled their eyes.”

Unwavering, the two women remained committed to learning more about Lyme, its symptoms and its link to past experiences. Remembering back 26 years ago, they were in Pennsylvania (a hot bed for ticks) when they remember taking a tick off the girl’s back hairline. “We just picked it off and didn’t think of it anymore.” But the girl did suffer from what they thought was the summer flu not long after being bit. “And, at six, her knees were stiff. All the symptoms over the years fit.”

That’s when she began to seriously research this disease that had incapacitated her daughter and been passed on in-utero to her granddaughter. Driving her daughter to numerous doctor appointments in the Twin Cities, she began to reflect on her own health history. “For years, I had major joint pain; I mean real pain. And I was treated for years for rheumatoid arthritis but none of the drugs would work.” Then two years ago, she started experiencing absent-minded spells that scared her into worrying that she might have early Alzheimer’s disease which her doctor dismissed.

“I started thinking, of course, I have Lyme. I’m an outdoors person, a hunter, I’m always trail riding.” Her Lyme doctor has since told her she may have been living with the disease for 20 years. She started oral antibiotic medications last April yet her symptoms did not improve. After switching doctors and trying other forms of antibiotics, she now has a PICC (peripherally inserted central catheter) line to receive four doses of IV antibiotics a day.

“I feel like I’m getting my energy back.” She likens the process of finding medications that work to a lock smith tumbling to unlock a door “with different medication combinations to find that magic place. And each person is different.” Tears come to her eyes when she thinks about her three-year-old granddaughter who lives with the same infections.

"I've had a lot of long talks with God not just for me but for my daughter and granddaughter; I used to pray that He take it from them and give it to me. Now, I have to ask what part of that did He not understand."

Sense of humor is something she works to maintain as tough as that can be at times. "The pain of Lyme is nothing you can explain. When you are at your worst, you want to die because every part of your body - even your skin - hurts."

Describing herself as "not a pill taker," she said, "even if I take a narcotic, it doesn't do anything" to numb the extreme pain. "The first thought, when a Lyme patient wakes up is 'what hurts the most?'"

She says her legs feel like she's been walking all day at the Mall of America on spiked heels, "and that's in the morning." And the fatigue caused by Lyme is also unparalleled. "It's much different than sleepy tired." A person who has always been particular about maintaining a clean home and entertaining guests properly, she is now left so unmoved by the great fatigue even when company is expected and things needed tidying. "It leaves me feeling like I just don't care. That's not me." It's also affected her passion in life. "For me, to not go see my horses for weeks, that's sick."

The isolation caused by Lyme is something that hinders quality of life, "because it becomes your world." Socially, Lyme makes it difficult for her to go out with friends. She may appear fine but the hidden pain has her focused on the disease at all times. "I don't want to burden my friends with all Lyme talk all the time."

Financially, Lyme can be devastating on a family as certain medications are very expensive. "You never know what insurance will cover. I hold my breath before opening my insurance statement wondering 'did they cover it or not?'" There are also incredible costs involved with traveling to see specialists - or simply "Lyme-friendly" primary care physicians.

Generally speaking, she says the number of Lyme-friendly physicians, or those who will not judge a Lyme patient, are "few and far between." She says there are many compassionate physicians here, however many do not know a lot about Lyme. She believes the doctors that need to know more about Lyme the most are primary care physicians "because they are in the trenches; they see you at the first sign," but "they know the least."

And she's met doctors that totally disregard Lyme, brushing it off as insignificant in the light of other problems prevalent in Itasca County such as teen pregnancy, obesity, heart disease and alcoholism. This troubles her particularly when looking at the current statistics released by the Minnesota Department of Health showing record numbers of Minnesotans ill from tick-borne disease in 2010. "Minnesota is No. 8 in the nation for confirmed cases and Itasca is in the top four counties in the state. How can they say it's not here?"

When state and nationally-recognized Lyme expert Dr. Elizabeth Maloney was invited to Grand Rapids to lead an educational seminar on the disease, “only one physician came out of 156 people there.” “[The doctors] don’t want to hear what makes them uncomfortable. I don’t get it. Lyme takes them out of their comfort zone.” Because Lyme patients often require longer visits with physicians as well as constant monitoring and trials with various medications, she believes doctors can shy away from accepting such patients.

“But, if they don’t want to look at it with a humanitarian view, why not financially? If Itasca County had a team of specialists on Lyme, we’d have people flying in, staying in hotels, spending money locally.” She views recent Minnesota doctor protection legislation as a step in the right direction. However, this is not permanent as it allows a five-year moratorium on discipline based solely on long-term prescription oral administration of antibiotic therapy for chronic Lyme disease.

“Often doctors willing to treat Lyme patients are ostracized by their peers and leaders. So people have nowhere to go.” Crediting her current Lyme doctor for working with her to find the right treatment, she says it’s best when patient and physician weigh the risks and benefits together as a team with the patient making the final decisions. She wonders why so many other doctors will not demand more research to help them help their patients.

“I wish doctors would go to the websites and really do the research. Lyme is like AIDS was before. It’s not going away.” Remembering back years ago when she was a young nursing student she said, “I learned to listen to the patients because they will tell you what it is the diagnosis is - that’s stayed with me all these years.” For those who discredit her condition, she points to that table with the myriad of medications and sighs. “Why would I want to live this way?”