

The challenges of diagnosing Lyme Disease (Published Sunday, May 8, 2011)
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Grand Rapids Herald-Review

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

She wants physicians to recognize the science that shows people with Lyme disease are not hypochondriacs. Dr. Elizabeth Maloney has become known throughout Minnesota for her expertise in the field of Lyme disease. Five years ago, she dove into leading scientific research on the condition to learn more about what some of her patients in Wyoming, Minn., were experiencing. What she discovered is a very complex, surprising and even controversial science surrounding the tick-borne disorder caused by the spirochetal bacteria, *Borrelia burgdorferi* or *B.burgdorferi*, spread through the bite of what is commonly-known as a deer tick.

At present, Dr. Maloney has shifted her focus from family practice to educating medical professionals on Lyme disease. She has developed accredited continuing education programs and serves as a medical advisor for the Minnesota Lyme Association (MLA). Her papers on Lyme disease have been published in national medical journals. And she has been invited to speak in Grand Rapids by the local MLA chapter.

With the full import of Lyme incomplete among much of the medical community, those who have it are left with few to turn to with their questions. And many are misdiagnosed. According to the International Lyme and Associated Diseases Society, Lyme disease is one of the fastest growing infectious diseases in the U.S., and Minnesota is listed as a high-risk state with Lyme concentrations in east-central, central and northern counties, including Itasca County. However, because there are many who do not receive a confirmed diagnosis, Dr. Maloney knows there are many more people living with the disease in Minnesota and throughout the U.S. making the reported prevalence of the disease misleading.

The Centers for Disease Control and Prevention (CDC) definition for Lyme Disease is: "A systemic, tick-borne disease with protean manifestations, including dermatologic, rheumatologic, neurologic, and cardiac abnormalities." For surveillance purposes, the CDC bases diagnosis on specific criteria. A red skin rash called erythema migrans (EM), is recognized by the CDC as the most common clinical marker for surveillance cases. The rash is typically circular and expands over a period of days to weeks. According to the CDC, other accompanying acute symptoms are fatigue, fever, headache, mildly stiff neck, arthralgia or myalgia. These symptoms are typically intermittent. For late manifestations, the CDC identifies attacks to the joints, nervous system and cardiovascular system.

With diagnostic testing, it's often difficult to confirm Lyme because the criteria used is designed to be so specific for the surveillance case, explained Dr. Maloney. "Because physicians often lose sight of the fact that the surveillance case is so specific, we miss so many people." In an article titled, "The need for clinical judgment in the diagnosis and treatment of Lyme Disease," published in the Journal of American Physicians and Surgeons (Fall 2009), Dr. Maloney points to 2006 Infectious Diseases Society of America guidelines for Lyme Disease as having "limited scientific support," and "if implemented, limit the clinical discretion of treating physicians and the treatment options available to patients."

According to Dr. Maloney, diagnosis of Lyme is supposed to be a clinical diagnosis with determination based on patient history relative to Lyme Disease such as exposure history or known tick-bite and a physical exam. What makes Lyme diagnosis even more challenging is only 35-59 percent of patients develop the EM rash. For those who do find a rash, Dr. Maloney said there have been studies

that found many of these people never remember a bite since it is thought that most Lyme is pass on by the tick in the nymph state which is no bigger than a poppy-seed. "Right there, the doctor can get led astray," she said. "I remind physicians often to make diagnosis based on pattern." If physicians haven't been exposed to patterns common with Lyme, "all they are going to see is a whole bunch of symptoms." When those symptoms are gathered and compared, diagnosis can be narrowed, explained Dr. Maloney. However, if the symptoms are non-specific to the surveillance case, they can be of no value to some doctors.

"With Lyme Disease, unless you know what to look for, it is easy to mislook," said Dr. Maloney. With Lyme Disease exams, Dr. Maloney advises physicians look at skin, joints and the nervous system. But progressions are often "all over the board," and other things like genetics, the bacteria strain, and family history can factor in. Once history has been considered and the exam completed, there is a blood test. However, if it is early-stage Lyme, testing is not effective because the *B. burgdorferi* bacteria is difficult to culture "so it won't show up," explained Dr. Maloney. If the lab test is completed, the results are still not definite because certain antibody bands can show if a patient was exposed to a bacteria similar to Lyme.

"A person can have a positive test but not have Lyme so the antibody test only tells of exposure," said Dr. Maloney. This missing test of cure, as Dr. Maloney described, likens Lyme to Parkinson's Disease, Multiple Sclerosis and Lou Gehrig's Disease. "Really, my goal is not to have every patient diagnosed with Lyme Disease but to have people diagnosed correctly," said Maloney. Labeled hypochondriac.

At 15 years old, one local girl from eastern Itasca County knows what it's like to be misdiagnosed. Wishing to remain anonymous for fear of stigma, she lives with the real pain of Lyme disease every day. Her friends, teachers, even people who are supposed to help heal her, have questioned her pain.

During a telephone interview on Friday, her mother explained how they finally discovered her daughter's ailments were caused by Lyme five years after she was first tested. At age 10, her daughter was given the first lab test which came back negative for Lyme. Since then, they've learned this can be common with early stage Lyme Disease. "She saw one rheumatologist who gave the diagnosis of fibromyalgia. Then no one wanted to look further. The doctors said it had to be fibromyalgia even though there were so many other things." Besides pain in her joints, this young girl also experiences fatigue, confusion, depression and tingling. The pain causes her to miss many days of school.

"She gets teased a lot because the kids say she's skipping." Her family found a doctor in the Twin Cities who did further testing and was treating her for Lyme but this physician has reached a limit of expertise and suggested they find a specialist - perhaps as far away as the east or west coast. "And then we'll be getting into the realm that the insurance won't cover."

After seeing the doctor on Tuesday, she was in so much pain from the ride, she still hurt Friday and couldn't go on a special field trip to the Fest of Nations in St. Paul. She's been on antibiotics for a year as well as other unique supplements such as a product made from Venus Fly Trap - "things I wouldn't want to take," says her mother.

A once energetic child and competitive swimmer with the YMCA swim team, she was hit with incredible fatigue out-of-the-blue and extreme pain that prevented her from finishing races she used to win. Like a third of all Lyme patients, she did not get a rash nor did they find a tick. But Lyme made sense after they thought about the Lyme her father experienced. Refused three times by doctors, he wasn't diagnosed

until he developed Bell's palsy (facial paralysis common with Lyme). "Then we thought about it - she's out with him on the four-wheeler all the time and we read you don't have to find a tick nor a rash." When local doctors brushed off possibilities it could be Lyme, the family pursued their own research. But they've found little help in their quest for answers and treatment. "We've been told by so many doctors that it's all in her head. And it's frustrating because she looks like a normal teen but then you see her try to get off the couch and she looks like she's 85 years old because her hips and knees hurt so bad."