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Beyond the Bull's-Eye: Advocates Take Aim at Lyme Disease

By Yvonne Bokhour

How much do you know about Lyme disease? Are you aware of its symptoms? Do you believe blood tests are reliable? How quickly do you think Lyme can be cured? Many of my neighbors have discovered the answers to these questions the hard way. They are ill, or their children are ill, or both. As they try to cope, they find themselves immersed in two battles: the fight to be well and the fight to be heard.

Lyme disease is an illness shrouded by uncertainty and controversy. Disagreements abound within the medical community, leaving patients caught in the middle. Their anguish, especially as Lyme proliferates nationwide, points to the urgent need for research.

In 1997, a tiny group of neighbors met in Wilton, Connecticut. We were all victims of the illness, and we were all worried by its spread. We were especially troubled by the threat Lyme posed to our children, who were exposed to ticks every day. To prevent more cases and help those afflicted, we arranged a seminar. Although we knew Lyme was prevalent, we were astonished by the turnout: 650 people filled Middlebrook auditorium. Volunteers soon found themselves fielding desperate calls from patients throughout Wilton, the tri-state area and indeed the nation. The Wilton Lyme Disease Support Group was then established to comfort those in need. Three years later, we launched a group for young people. Today, both are committed to providing emotional support to adults and teenagers in Fairfield County and beyond. Five hundred victims have now passed through our doors.

Lyme patients have an illness that is not only mysterious but also the focus of heated debate. As we contend with a wide array of frightening symptoms, we are trying to prove our illness is real.

The Controversy

At issue: whether Lyme is easy to spot and easy to cure. Many doctors believe it is. A fair number of patients see a bull's-eye rash, the best diagnostic marker available. It seems most diagnosed at this point do quite well.

But how often does the rash occur, and how often is it missed? How reliable are testing methods? Are standard antibiotic doses sufficient? What should be done when symptoms persist after treatment? All of these questions and more are in dispute. The implications—medical, financial and emotional—are enormous. Surveys in some communities show as many as 54% of households affected. The Centers for Disease Control and Prevention (CDC) states that national incidence rates nearly doubled from 1991 to 2000. In fact, an analysis of recent CDC data reveals rates climbed 39% between 2001 and 2002.

Need for Research

Dr. Douglas Bunnell, psychologist and president of the National Eating Disorders Association, offered to facilitate our adult support group because he, too, developed Lyme disease. Dr. Bunnell is quick to point out, for this article and at every meeting, that the group represents a skewed sample of patients. We tend not to see those who have recovered. Still, significant numbers develop ongoing symptoms despite standard treatment. Why? In his own case, Dr. Bunnell developed a bull's-eye rash he recognized immediately. He received two weeks of antibiotics, a common prescription in 1993. Despite early detection, he later found himself in the emergency room with Lyme meningitis.

Although Dr. Bunnell is not sure antibiotics are the ultimate answer (noting other therapies might alleviate symptoms), he feels treatment is more likely to be inadequate than excessive. Unfortunately, he says, the efficacy of different

regimens is contested: some physicians insist four weeks is adequate, while others see the necessity in some cases for years of treatment. Unless a foolproof test is developed—to assess both infection and cure—the controversy will continue.

Brian Fallon, MD, MPH, M.Ed. (Associate professor of clinical psychiatry, Columbia University, and Director, Lyme Disease Research Program, New York State Psychiatric Institute), agrees a definitive test would quell the debate. While most infections are easy to culture, the bacterium responsible for Lyme disease—a corkscrew-shaped spirochete—is more elusive. Doctors rely most often on antibody tests, such as the ELISA and Western Blot, which measure the body's response to an infection.

But results vary from lab to lab. Dr. Fallon says a single blood sample may be positive according to one lab, but negative according to another—a phenomenon that has been studied by the National Institutes of Health but is not widely known by doctors.

The CDC recommends two stages for testing. The ELISA comes first; if results are positive or equivocal, the Western Blot is next. But does the ELISA have the sensitivity needed for screening? A significant number of patients are negative on the ELISA but positive on the Western Blot. Interpretation of the Western Blot is also problematic. The CDC has established a standard that is debated by researchers and laboratory directors. Dr. Fallon thinks these disputes, too, are unfamiliar to many clinicians.

Tests administered at the first sign of a bite or rash may be negative, since antibodies need time to develop. Diverse immune system responses, antibiotics received prior to testing and bacterial strain variations may also affect outcomes. Both false positives and false negatives are possible. It is essential to consider that ticks are now known to harbor other illnesses such as babesiosis

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and ehrlichiosis. One tick may even carry two or more infections. Since testing for emerging pathogens is also unreliable, diagnosis is likely to become more troublesome than ever.

Diagnosis

According to the CDC, Lyme should be diagnosed on the basis of clinical symptoms. Lab tests may support the doctor's conclusions, but should not decide the matter. Nevertheless, Dr. Fallon has seen doctors rely exclusively on negative results from one lab, even with clear-cut clinical evidence to the contrary.

Without a bull's-eye rash, what difficulties do patients encounter in the diagnostic process? Disseminated Lyme can affect many systems in the body. Dr. Fallon says this may be problematic when patients visit specialists, who tend to concentrate on symptoms that fall within their realm of expertise. Patients with multiple complaints—and Lyme can affect the brain, heart and musculoskeletal system, among other things—may struggle to find a doctor who recognizes a possible interrelationship. In addition, Lyme's multi-systemic nature makes evaluation extremely time-consuming. Insurance constraints may leave physicians little time to unravel a medical mystery.

Basic signs may well be missed or misinterpreted. Lyme rashes do not always form a bull's-eye and may be identified as spider bites or fungal infections. Even classic rashes are easily overlooked when they present on the scalp or back. Late-stage Lyme has many variations and may be confused with numerous illnesses. Support group attendees have been diagnosed with multiple sclerosis (MS), arthritis, chronic fatigue syndrome, fibromyalgia, early menopause, Alzheimer's disease, psychiatric illness

or ADHD before finding relief under the care of Lyme specialists.

Paige

In October, 1999, while taking a shower, 12-year-old Paige noticed an odd rash. She didn't think much of it. Her mom, Marcy, thought it was a simple insect bite, nothing to worry about. Three months later, Paige found herself with a sore throat, a stiff neck, flu-like symptoms and a massive headache. Because a strep test was faintly positive, her doctor administered antibiotics. Paige is prone to strep and usually recovers quickly. This time she didn't improve. She was in terrible pain, confined to a dark room, acutely sensitive to light. Her doctor tried other antibiotics, and eventually some of her symptoms subsided. But the headache, stiff neck and fatigue "just wouldn't quit." A CAT scan of her sinuses was clear; the next step was a scan of the brain. Marcy and her husband Andrew were "flipping out," since doctors were looking for a tumor. That test, too, was negative. Next, a neurologist diagnosed migraines due to muscle spasms in the neck. He was not willing to pursue the matter further, nor would he return Marcy's calls. Their pediatrician thought Paige must have a post-viral syndrome and said he was out of options.

Marcy felt abandoned by the doctors, afraid "no one really cared." Paige had by now missed weeks of school (her mother, a psychotherapist specializing in chronic illness, had stopped working to care for her). She went on to experience episodes of disorientation and confusion. A gifted, well-organized student, she tried her best to attend school. But she missed so much she had to be tutored at home. Paige began losing things and forgetting assignments. She developed numbness, light sensitivity

and other "weird" symptoms. Her parents were worried and exasperated by memory issues they did not understand. Marcy says, "When she was ...forgetting to bring her books home...we didn't realize it was from the disease, so we were fighting...I'm sure people diagnose ...behavior problems that have nothing to do with behavior; they have to do with cognitive deficits."

An old friend suspected Lyme disease. At Marcy's insistence, despite the pediatrician's objections, Paige was tested. Her ELISA was positive and antibiotics were prescribed. Shortly afterwards, though, a negative Western Blot arrived. The doctor concluded Paige must not have Lyme and asked Marcy to discontinue the medicine. Marcy, however, read the lab report, which stated Lyme should be diagnosed clinically, not on the basis of test results. She kept Paige on antibiotics and consulted several specialists. All denied the possibility of Lyme, providing other diagnoses including depression, chronic fatigue syndrome and MS. Marcy, whose profession required knowledge of all these illnesses, was positive Paige did not have them. As a psychotherapist, she was also quite sure Paige was not depressed.

Four months after Paige became ill, her parents found a doctor who interpreted the Western Blot quite differently. In his opinion, her symptoms and even her lab testing pointed clearly to Lyme disease. He convinced Paige's pediatrician to begin intravenous (IV) antibiotic therapy. She had an intensely difficult initial reaction. (Many support group members report feeling worse during treatment. This phenomenon occurs because, as bacteria are killed, they release toxins. Marcy says, "I felt like I was having an exorcism in my house.") Paige had seven weeks of IV and three months of oral antibiotics. Three years later, she remains symptom-free. "Since hearing our story," Marcy says, "I can't tell you the number of people who've come out of the woodwork with horror stories about their father, their uncle, their little boy."

Neurological and Neuro-Psychiatric Effects

Dr. Fallon estimates that, even in Lyme-endemic areas, 75% of doctors are unaware Lyme may mimic MS and other neurological conditions, although severe neurological complications caused by similar spirochetes are well established

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Editor: Lucy Schmolka, MA.

Program Director: Marsha Hurst, PhD.

Production: Riverside Resumes

Email: health@slc.edu

For information about Dr. Fallon's study or the Wilton Lyme Disease Support Groups, Yvonne Bokhour can be contacted at kos1@earthlink.net.

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in European medical literature. Syphilis, another spirochetal infection, has been known for decades to incite neurological symptoms in untreated patients. Studies conducted by Dr. Fallon himself have examined the connections between Lyme and several neurological and psychiatric conditions, including depression, ADD, autistic-like syndromes and many cognitive and memory disorders.

Jane

In 1990, Jane, a pediatric intensive care nurse, woke from sleep and realized "I could not feel the right side of my body at all." She was tested for Lyme among other things; her ELISA was negative, and her neurologists diagnosed a post-viral syndrome. She lost seven weeks of work. In 1993, she had another episode: this time, she could feel nothing from the chest down, her speech was slurred, her vision was blurry and she had word retrieval difficulties. An MS verdict was issued following a brain MRI. Years later, Jane saw a copy of the MRI report and was shocked to discover Lyme mentioned as a possible cause. Jane had never been informed of this possibility nor sent to a specialist. Numerous symptoms continued to plague her. In 1997, an acquaintance mentioned her illness resembled Lyme disease. Although tests were equivocal, Jane received 7 1/2 weeks of IV antibiotics and follow-up orals. Her neurological manifestations diminished, although some flared later and were retreated.

Once Jane discovered she might have Lyme, she wondered whether her son, whom she had carried while symptomatic, might have acquired Lyme congenitally. He had been placed in special education at age two when diagnosed with Asperger's syndrome (a developmental disorder in the autism spectrum affecting communication and socialization). Jane had him tested for Lyme; his results, like hers, were equivocal, and he was treated. Eleven months of antibiotic therapy dramatically improved his ability to socialize. One year later, he was fully mainstreamed with minimal assistance.

Jane was unable to work during her thirties because she was afraid her recurring cognitive problems would endanger her patients. Happily, she now considers herself cured. "It's part of the Hippocratic oath to keep up with research," she says, "and it was all over the research in the 90's that Lyme... produces an MS-like illness.... Hey, if I can find it in the research, why can't the

doctor?"

Depression

Depression may be the most common diagnosis support group members receive prior to learning they have Lyme. Dr. Fallon says distinguishing between the two may perplex doctors without psychiatric training. Depression has physical features—such as fatigue and sleep disturbance—that characterize several illnesses, including Lyme. Without a definitive test, diagnosis may be confounding.

To complicate matters, depression can occur on its own, as a symptom of Lyme, as a result of Lyme-induced symptoms like fatigue and pain, or as a consequence of going from doctor to doctor for an explanation. Dr. Fallon also suspects Lyme may aggravate a predisposition to psychiatric conditions.

Assessment may be further confused by emotional factors. Dr. Fallon says patients may arrive at his office feeling anxious or hostile because they have been "turned away, rejected or pushed aside" by other physicians. The last thing they want is to be sent to a psychiatrist. Others want a guarantee they have Lyme, which he cannot provide. He says patients may well be traumatized by doctors' reactions. Dr. Bunnell agrees: "If the doctor in whom you have placed your trust does not recognize your experience, if you arrive feeling powerless and sick and leave without acknowledgement you are ill, the results can be devastating." Without a doctor's support, family, friends and co-workers may also be skeptical, compounding feelings of abandonment.

Dr. Bunnell says Lyme patients may well be told to seek a psychiatric evaluation—a problem since "the eyes of subsequent doctors tend to go straight to this referral." Despite the growing awareness that "there's a tremendous physiological base we can apply to brain functioning," some doctors see depression as an underlying cause rather than as a symptom of physical illness.

Patients with Lyme tend to look well, adding to such suspicions. Drs. Bunnell and Fallon agree symptoms tend to wax and wane. Dr. Fallon has seen family members become enraged when loved ones attend work or school one day, but are bedridden the next. Such issues may profoundly alter relationships, says Dr. Bunnell—at home, at work and at school—especially without absolute proof the illness exists. He notes Lyme

patients may not be excused from everyday expectations because they are not perceived as ill.

Memory and Cognition

As Paige's neurological symptoms progressed, her parents were able to serve as her advocates. Unfortunately, Lyme patients without advocates may find the diagnostic process further hampered by cognitive and memory impairment, symptoms Dr. Fallon's research has explored in depth. Patients can be disorganized when they recount their histories, even forgetting their own symptoms. Dr. Bunnell says, "Having a patient who is cognitively limited, often in terms of language, trying to articulate a complicated phenomenon loaded with subjective assessments (Am I anxious? Am I thinking clearly?) to someone who doesn't have the time to listen is a setup for failure."

Complaints about memory may be attributed to stress, depression, menopause or Alzheimer's disease. Deficits may be especially troublesome to assess in children and the elderly. Doctors have screening tests they employ during office visits to gauge memory loss, but, Drs. Bunnell and Fallon agree, these can miss significant disabilities. Neuro-psychological testing explores all aspects of memory in detail, but, according to Dr. Bunnell, can also be traumatic for the impaired—a "psychological spinal-tap."

Treatment

Patients who fail to respond to standard antibiotic doses challenge physicians, since the nature of ongoing symptoms has provoked contradictory interpretations. Some researchers believe persistent problems are caused by an active infection. Others theorize they represent an immune or inflammatory response to an infection that has been cured. Patients who research their illness find themselves thrust into a complex medical argument. Dr. Bunnell believes patients must educate themselves, but knows that is terribly difficult to do without medical training—especially while sick with fatigue, pain and/or cognitive limitations.

For example, treatment guidelines issued by the Infectious Diseases Society of America in 2000 (accessed at its website 11/03) recommend 14 to 21 days of oral antibiotics for early Lyme and two to four weeks of intravenous therapy for neurological disease. The report states: "Response to treatment is usually slow and

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may be incomplete. However, unless relapse is shown by reliable objective measures, repeat treatment is not recommended." Dr. Gary Wormser (Chief, Division of Infectious Diseases, New York Medical College, Valhalla), co-author of the report, noted: "The consensus reached by the expert panel was that, to date, there are no convincing published data that repeated or prolonged courses of either oral or intravenous antibiotic therapy are effective....We also concluded that there is insufficient evidence to regard 'chronic Lyme disease' as a separate diagnostic entity."

Conversely, the International Lyme and Associated Diseases Society (ILADS) states on its website (accessed 11/03): "A preponderance of evidence indicates that active ongoing spirochetal infection is the cause of persistent symptoms....There has never in the history of this illness been one study that proves...30 days of antibiotic treatment cures Lyme disease." ILADS contends "uncomplicated chronic Lyme...requires an average of 6 to 12 months of high-dose antibiotic therapy...until the patient is symptom-free."

Thousands of patients believe long-term antibiotics have been essential to their recoveries or to their abilities to manage incapacitating symptoms. However, probes have been conducted in several states, threatening clinicians who treat Lyme aggressively with the loss of their licenses. Patients are upset by these investigations, worried doctors will not feel free to find treatments that work.

Insurance companies—not all, but some, according to Dr. Fallon—prefer not to pay for long-term treatment. Negative testing can be used to deny coverage; Dr. Fallon has even seen positives dismissed as false positives. He believes many doctors are now wary of prescribing IV—although studies point to its efficacy—and are using orals instead, because they fear being flagged by insurers or conservative colleagues.

Connecticut Attorney General Richard Blumenthal received so many complaints that in February, 1999, he held a hearing. He stated then: "My office has received scores of...moving, incisive accounts of health insurers denying coverage...or rejecting doctors' diagnoses....The number and severity of complaints—some extraordinary horror stories—suggest there must be a complete review so as to assure acceptable coverage." The hearing did in fact result in a protective legislative mandate. The law provides specific treatment

guarantees; additionally, long-term therapy is covered if recommended by certain specialists. Unfortunately, patients have had difficulty obtaining such opinions on the basis of clinical symptoms alone.

Financial impact

Financial stresses add to the burden of patients already overwhelmed by illness and controversy. Marcy quit her job to care for Paige. Jane's family incurred hundreds of thousands of dollars in medical expenses. Dr. Fallon has seen "enormous numbers" of Lyme patients struggle financially due to disability, lost productivity or rejection of coverage by insurers; some sufferers have even lost their homes. Economic implications extend beyond the family to the community, as schools face rising special education budgets and employers cope with impaired workers.

Mary

A nurse in Fairfield County, Mary was well aware of Lyme when in October, 1999 she removed an engorged tick. Within 48 hours, she developed flu-like symptoms and a bull's-eye rash. Her doctor immediately prescribed one month of antibiotics. By January, however, Mary was ill with migratory joint pain, fatigue and chills. Antibody tests were negative but her doctor, convinced Lyme was the culprit, treated her for eight more weeks. Months later, Mary developed cognitive and memory impairment. Tests were again negative. She began having tremors, muscle weakness, numbness, balance and coordination problems, neck pain, headaches and stammering speech. She was unable to work or drive. "I would know to stop at a stop sign, but I would forget to look both ways....I kept getting lost in town, going to places I go all the time." An emergency room physician believed she had MS, but Mary insisted that Lyme be ruled out. Brain-imaging techniques showed Lyme-like changes (although these tests, too, are not definitive). Mary improved with more orals, but was still so ill she received 23 weeks of IV.

Despite her medical training, the experience was extremely difficult. Although normally confident, she was afraid to assert herself. While pleased with her care overall, Mary was incredulous when doctors failed to classify her plight as an emergency. She asked them, "If this was your wife, what would you do? I'm trying to raise three children

here....I can't remember their names, I forget them when...I have to go get them....I don't understand how you can feel this is not important."

Today, Mary is "95% better," although she struggles periodically with headaches, numbness and word-retrieval issues. Nevertheless, she handles her demanding job and will soon obtain a master's degree. Despite losing her gallbladder to IV treatment, she uses her nursing position to promote long-term treatment for symptomatic patients.

Research

Dr. Fallon hopes to put many of these controversies to rest with his research. With \$4.7 million in funding from the National Institute of Neurological Disorders and Stroke, he is studying long-term antibiotic treatment. His investigations will likely clarify diagnostic issues, too. He urges patients to apply for "the best neurological Lyme work-up in the world."

Patients, too, are working toward scientific solutions by supporting various non-profit initiatives. For example, the Lyme Disease Association is funding a Lyme center at Columbia University. The Lyme Disease Foundation sponsors an annual scientific conference. The National Research Fund for Tick-Borne Diseases awards grants to researchers at preeminent academic institutions.

Conclusion

Every month, we have new visitors to our support group. Recently, we saw a friendly young man in a wheelchair, unable to walk; a 20-something woman with such severe cognitive problems, she was accompanied by her parents; and a mother whose entire family is ill with a multitude of symptoms. In fact, it is not uncommon in Fairfield County to see several family members chronically affected. Dr. Bunnell is perhaps most moved by parents who come on behalf of their children. Youngsters have a fundamental need to feel safe. Having Lyme violates that need: "You mean, something in my backyard can make me sick?" It has "long-standing ripple effects" that impact relationships, inhibit experiences and threaten cognitive impairment. "The most tragic thing is seeing a kid whose life may now be forever affected by a tick bite."

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