

LYME *in the* LIMELIGHT

BY RACHEL ISAACSON

Part I

CAUGHT IN THE CROSSFIRE:

How illness, ignorance and ego have turned treatment of Lyme disease into a battle zone — turning patients into victims.

Mrs. Eva Wikler* was uneasy about her daughter, Shaine,* 18, who had returned to their Midwood residence in Brooklyn, N.Y., several months into her school year abroad. In December 2013, Shaine came home from Israel following the onset of bizarre symptoms which she had never experienced before and could not deal with on her own. She needed her mother's care.

Mrs. Wikler told *Hamodia*, "I was worried because Shaine was having profound weakness, chills, overall body aches and headaches, to the point that she couldn't get out of bed. She was also having trouble with concentration and focusing, and she had always been a top student in school. I didn't know what was happening to her."

Mrs. Wikler accompanied her daughter to her family's pediatrician, who was stumped by her symptoms and referred Shaine to a rheumatologist. That physician drew a panel of blood works, including tests for Lyme disease, and sent it to a lab.

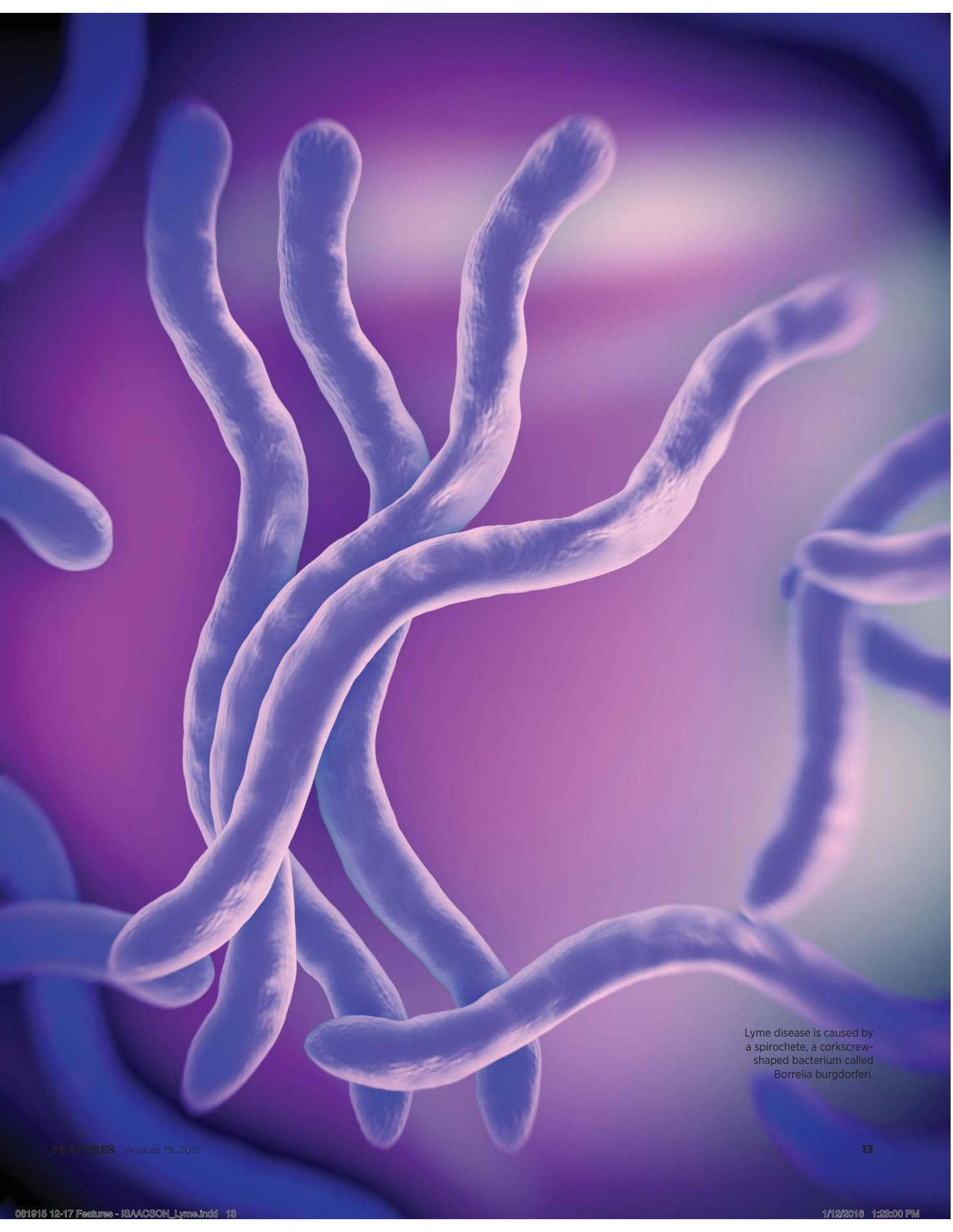
"The possibility of Lyme disease occurred to me. Although Shaine did not have the Lyme rash that doctors say appear with Lyme, I remembered that Shaine was in summer camp about four months before," Mrs. Wikler said. "But when the rheumatologist's Lyme testing proved negative, Shaine's two doctors consulted with each other and advised me not to do anything further. They suggested

to me that possibly Shaine didn't want to go back to school, and was suffering from emotional issues such as depression. I knew my daughter was popular and a high academic achiever and this was not characteristic of her. I also realized that I had to turn elsewhere for help," Mrs. Wikler recalled to *Hamodia*.

Still suspicious of a missed Lyme disease diagnosis, Mrs. Wikler was guided to a Lyme Literate Medical Doctor (LLMD) who specialized in treating Lyme disease patients. The Lyme specialist evaluated Shaine and sent out her bloodwork, this time to a specialty laboratory designed to be more sensitive and specific in detecting Lyme and other tick-borne diseases (TBD). After obtaining a Lyme positive result, the LLMD put Shaine on oral antibiotic therapy.

Shaine, who began feeling improvement after several weeks, flew back to school overseas. Six months later, Shaine was significantly recovered, and with her doctor's consent, stopped antibiotics. She has since resumed her active lifestyle and scholastic studies.

Despite the gratifying outcome, Mrs. Wikler admitted to *Hamodia* that she never confronted the pediatrician who dismissed Shaine's symptoms. "I think that doctors should be made aware of the importance of [Lyme disease] and be educated about this disease," she said, adding, "but I feel uncomfortable saying that to them directly."



Lyme disease is caused by a spirochete, a corkscrew-shaped bacterium called *Borrelia burgdorferi*.



he Wiklers were unwittingly catapulted into the crossfire of an acrimonious debate raging between two poles of medical societies who have authored conflicting guidelines regarding Lyme disease.

The Infectious Diseases Society of America (IDSA) is pitted against the International Lyme and Associated Diseases Society (ILADS). The IDSA showcases the academia of scientific research, whose studies are frequently published in prestigious, peer-reviewed publications. IDSA is composed of scientists, researchers and infectious disease clinicians, who authored IDSA guidelines in 2000, 2006 and 2009. The established IDSA guidelines govern diagnostic and treatment standards [of Lyme disease] which impose the metric of treatment for conventional physicians and at medical institutions across the United States.

Conversely, ILADS is a subset of specialty LLMD-trained clinicians in a growing multispecialty society. ILADS's ranks encompass primary-care physicians, specialists, researchers, nurse practitioners and physicians' assistants. ILADS's approach to clinical treatment is inclusive of patients' multi-systemic symptoms; these doctors evaluate and treat patients by combining their clinical assessment with diagnostic blood work. ILADS scientific research studies are denied entry into the prestigious medical journals and therefore are published online in "open access" medical journals, such as *PLOS ONE*.

The Lyme disease controversy has disenfranchised patients who describe lingering and increasingly ravaging symptoms and are rebuffed by disbelieving mainstream medical practitioners. Struggling patients who grapple with devastating symptoms consequently turn to ILADS physicians, seeking their LLMD's protracted treatment approach for Lyme disease. ILADS terms the constellation of multi-systemic lingering and debilitating symptoms as "chronic Lyme disease."

Lyme Disease

Lyme disease was discovered in 1975 when a group of children in Lyme, Connecticut, suffered from joint pain symptoms which were originally dubbed "Lyme arthritis." That moniker was soon changed to "Lyme disease" when other symptoms emerged.

In the endemic Northeast and North-central area, Lyme disease is commonly caused by the *Ixodes scapularis* black-legged deer ticks, common in wooded and grassy areas; on the West Coast it is caused by the widespread *Ixodes pacificus* tick. Lyme disease is a corkscrew-shaped bacterial pathogen, called *Borrelia burgdorferi* (Bb) spirochete.

ILADS clinicians, treating in the trenches, claim that Lyme disease can affect any body organ, including the brain, nervous system, muscle, joints and heart. ILADS believes that patients with Lyme disease have often been misdiagnosed with chronic fatigue syndrome, fibromyalgia, multiple sclerosis and various psychiatric illnesses. They dub Lyme disease the "Great Imitator" because of shifting, vague and multi-systemic symptoms that often mimic other diseases.

Uptick in Ticks

The lower Hudson Valley is a breeding epicenter for

Lyme disease. Other than permanent residents in the area, large sectors of the Orthodox Jewish population are drawn to the bucolic Catskills Mountain region during the summer season, yielding a spike in Lyme cases even once back in their city homes.

Experts warn of a surge in the tick population, which can transmit Lyme disease and other tick-borne diseases. Ticks are hatched as larvae, molt into the nymphal stage and morph into adult ticks after feasting on the blood of white-footed mice — even more than on deer, for which deer ticks are named. When the ticks subsequently bite humans, they inject the bacteria they have absorbed with their blood meals into humans, thereby transmitting the disease. Because ticks are so tiny and their bite is painless, victims are not often aware that they have sustained tick bites, and can go on to contract Lyme disease and other bacterial infections. The longer a tick remains attached to a person, the more likely it is that an infected tick can transmit Lyme bacteria and possibly other pathogens into the person's bloodstream.

Since the reporting of Lyme disease to the New York State Department of Health (NYSDOH) began in 1986, more than 100,000 cases have been documented. Despite annual variations, New York State averages more than 5,500 new cases each year. The NYSDOH provided *Hamodia* with 2013 New York State counts of confirmed Lyme cases. Rates per 100,000 in population indicate that in 2013, Sullivan County residents had 130.2 confirmed diagnosed Lyme cases, while Ulster County residents reported even greater numbers of 236 residents with Lyme disease.

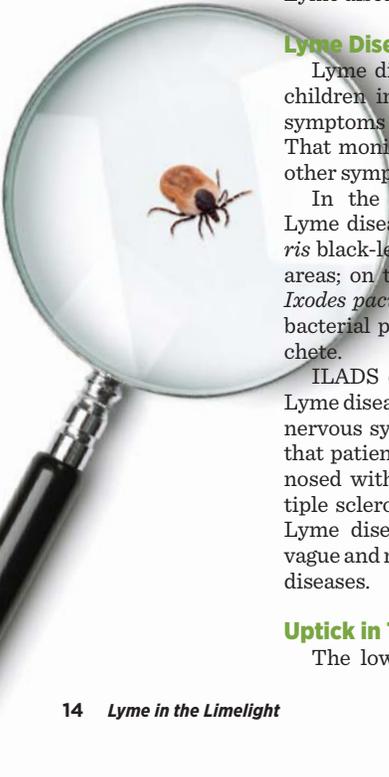
A DOH spokesperson told *Hamodia*, "The New York State Department of Health is currently collecting ticks for testing. In a state as large and diverse as New York, it is extremely difficult to make a prediction about the tick population. However, Lyme disease is endemic across New York, meaning the DOH sees cases year after year. Sullivan County [and Ulster County], because of their location in the lower Hudson Valley, has had several decades of history with ticks and Lyme disease."

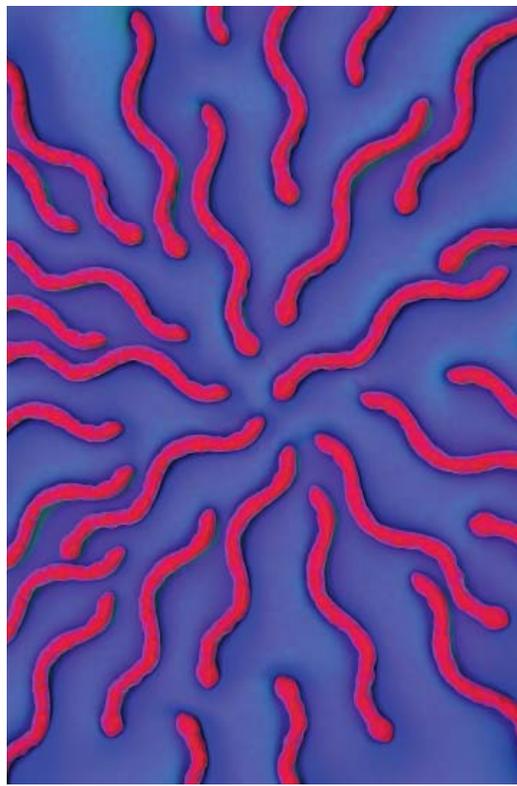
When asked by *Hamodia* if wide-scale measures would be implemented to reduce the burgeoning tick population, the DOH spokesperson responded, "Currently, personal protection is the best way to prevent tick bites."

The Numbers

The CDC has recently estimated 300,000 new cases of Lyme, upward from previous estimates of 30,000, and the controversy engulfing Lyme disease has likewise ratcheted up. According to the CDC, Lyme disease is the fastest-growing vector-borne (transmitted via insects) infectious disease. The CDC has partnered with the IDSA in adopting their guidelines in diagnosis of Lyme disease and treatment standards, although these guidelines were initially intended for CDC surveillance purposes in monitoring definitive new Lyme cases, not for diagnosis and treatment — and regardless of the fact that the CDC had earlier recommended that Lyme should be diagnosed clinically according to doctors' assessment of symptoms.

Dr. John N. Aucott, M.D., Director of Johns Hopkins Rheumatology Lyme Disease Clinical Research Center, concurred with the CDC estimate of 300,000 new Lyme dis-





ease cases. He told *Hamodia* that he had reached a similar estimate in his own studies when researching insurance claims.

When *Hamodia* asked if Lyme disease is epidemic these days, Dr. Aucott replied, “In certain parts of the country, I believe it’s reaching epidemic proportions.”

Hamodia interviewed IDSA guideline co-author Eugene D. Shapiro, M.D., of Yale New Haven School of Medicine. Dr. Shapiro disagreed with the revised CDC estimate of 300,000 new Lyme cases, and said, “There has been a slow and steady increase in Lyme disease, but the 30,000 numbers are still true. Counts in the past have been estimated by doctors submitting ‘report cases’ which are typically under-reported.

“The CDC, for the past 30 years, has always said the numbers could be 10 times higher. So they [CDC] did a study which nationally studied all positive antibody lab reports. I think that study had errors. I believe there are more than 30,000 cases, but [maybe] there are not 300,000 cases. The CDC is still counting numbers by reported cases, so it’s not a surge in numbers, if you use a different system to estimate it. I do believe that there [might] be an increase in Lyme disease, but it’s in very limited areas. It’s a slow increase but not an epidemic outbreak.”

ILADS’s board member, Kenneth B. Liegner, M.D., internist and critical care physician, has treated thousands of Lyme disease patients since 1985 and published articles on chronic and neurologic Lyme disease. Expressing views contrary to IDSA’s as to Lyme prevalence, Dr. Liegner told *Hamodia*, “Lyme disease is very common and is present in every state of the union and in many continents and countries [around the world].”

Nationally reputed Lyme patient advocate Pat Smith, president of the Lyme Disease Association (LDA), was asked by *Hamodia* about the CDC estimates. She responded, “The (CDC) finally admitted publicly in 2013 to about 300,000 new cases. [But the number] 300,000 may even still be an underestimate due to the lack of a gold-standard test, strain variations [of Lyme and tick-borne disease] and the fact that Lyme in non-endemic areas is vastly under-diagnosed and under-reported.” She added, “Some [people] think the numbers are also suppressed.”

Lorraine Johnson, chief executive officer of LymeDisease.org and nationally recognized Lyme advocate, was equally outspoken when, at a rally protesting IDSA guidelines, she referred to the CDC count of 300,000 cases reflecting the scourge of Lyme disease. She conjectured that Lyme cases can range from 500,000 to a million, if not more, as “CDC numbers are rigidly defined.” She added that many more Lyme cases are clinically diagnosed and do not meet CDC criteria. Johnson underlined, “Numbers are important because numbers drive research funding.”

Diagnostic Tests

Every aspect of Lyme disease is contentious, including its diagnosis — as there are no accurate diagnostic tools which detect the Lyme bacterium itself. The CDC recommends the two-tier diagnostic tests of [the] ELISA and Western Blot testing, which screens the body’s immune system reaction of antibodies to indicate Lyme. ILADS and their patients

“In certain parts of the country, I believe it’s reaching epidemic proportions.”

- Dr. Aucott

denounce these standardized tests as missing about 50 to 60 percent of cases, and claim that they are about “as accurate as a coin toss.”

Dr. Shapiro outlined the IDSA stance for new tick bites: “Ticks should be identified if infected [in laboratories]. If the tick is embedded for more than 48 hours, then it can transmit Lyme disease.

“If the tick is in the nymphal stage, a single dose of [the antibiotic] Doxycycline is sometimes indicated. Usually we don’t treat it. Only about 25 to 30 percent of nymphal ticks are infected and most people pull them off before 48 hours. Chances are low for getting Lyme disease.”

He stated that a well-defined case of Lyme disease is one in which the tick has been embedded for 48 hours, and [the patient] presents with an erythema migrans — or “bull’s-eye” rash — which is picked up in a known tick-infested area. “But endemic areas are contained in very limited areas [and only several] states,” he said.

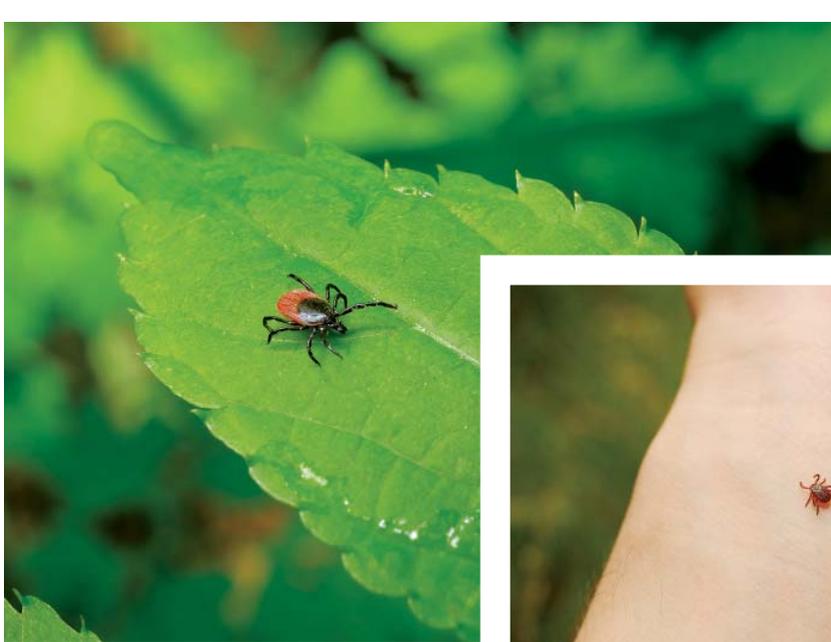
IDSA guidelines recommend treatment for a ‘well defined’ Lyme disease case, consisting of two to four weeks of antibiotics, but not more than 28 days.

Dr. Shapiro noted that “testing for early tick bites makes no sense, because it doesn’t test for the spirochetes; it tests the antibodies of the immune reaction which are too early to have developed, as it takes three to four weeks to develop antibodies, and infection occurs within seven to 14 days.” Dr. Shapiro advised, “I would just tell people to look if the tick is infected, but the risk is low [for getting Lyme disease].”

ILADS’s views on tick bites radically diverge from IDSA guidelines. The IDSA promotes the telling bull’s-eye rash as required evidence of confirmed Lyme disease. Nonetheless, up to 70 percent of patients may never have seen a rash, according to surveys conducted by Lyme advocate Lorraine Johnson of LymeDisease.org [LDo].

ILADS doctors frequently use specialty labs which are touted to be more sensitive in pinpointing Lyme disease. As IDSA-aligned doctors allege that such labs are not FDA approved, Dr. Liegner countered strongly to *Hamodia*, “Laboratories such as IGeneX and their diagnostic methods of testing have been evaluated stringently by the New York State Department of Health and found to be acceptable [by the DOH].”

Dr. Liegner contended, “The CDC-promoted two-tiered testing has been extremely deleterious to the interests of patients, although the CDC asserts it is for ‘epidemiological’ purposes [in surveillance of Lyme cases]. Many, including — and especially — insurers, use it as the gold standard for diagnoses and reimbursement purposes. Insurance companies make ‘payable’ claims disappear ... in a nice sleight of hand.”



Daniel Cameron, M.D., M.P.H., is an internist, epidemiologist and Lyme disease expert affiliated with ILADS, treating Lyme disease since 1987. He is lead author for evidence-based ILADS guidelines in 2004 and 2014, and has published articles, reviewed in peer reviewed publications and presented at national and international conferences.

Dr. Cameron commended ILADS tick bite practice. “ILADS recommends that prophylactic [preventive] treatment should be implemented for at least three weeks, with follow up after a tick bite [as Bb Lyme spirochetes have the ability to penetrate the body and cells in less than 24 hours following an embedded tick bite].” He said, “Whereas IDSA sometimes recommends a one-time 200-mg dose of doxycycline, the only study supporting a single dose of doxycycline demonstrated that it could prevent rashes but did not study whether it could prevent any chronic manifestations of Lyme disease.”

He counseled patients whose physicians balk at providing prophylactic treatment after a tick bite to ask their doctors if they would consider treatment to avoid long-term complications of Lyme disease. “If the doctor does not offer a longer treatment option, you can seek a second opinion from a doctor who might consider longer-term treatment,” he said.

Chronic Lyme Debate

The most divisive dispute between the feuding societies is centered on the contested existence of disseminated, persistent infection, which, according to ILADS practitioners, is chronic Lyme and necessitates long-term antibiotic treatment. Collaborative insurance companies typically follow IDSA guidelines and often deny payment to patients for oral and IV antibiotic treatment, despite ILADS claims that the treatment is warranted with noticeable patient response.

Dr. Eugene Shapiro, IDSA guidelines co-author, underscored to *Hamodia*, “Lyme disease is not difficult to diagnose and it’s a well-defined entity. It’s generally relatively easy to treat. It’s generally a mild disease and in some cases it’s more severe. In rare cases, it can be very severe. Symptoms of fatigue, muscular and joint pain are very common. So some people [who have these symptoms] decide they must have a disease — and chronic Lyme disease fits the bill. To be clear, I believe that these patients suffer symptoms, but it’s not causally related to Lyme, or even to another medical condition.”

Dr. Shapiro cited a national survey which demonstrated that 10 to 15 percent of the population feels either extremely tired or exhausted most days or every day, for the last three months. “These are the fatigue and aches and pains of daily living,” he maintained, echoing the IDSA position. “There have been numerous studies on Lyme disease and there are no benefits of further antibiotic treatment. There are many side effects and no reasons to take it; there are lots of reasons not to take it.”

Dr. Shapiro contended that patients with symptoms following treatment have “post-treatment Lyme disease symptoms.” If symptoms

remain, they are termed “post-treatment Lyme disease syndrome [PTLDS].”

“Chronic Lyme disease has no definition and no criteria. There is no such thing as chronic Lyme disease. First you need to be diagnosed with Lyme disease — and most people never had Lyme disease to begin with.”

Regarding the controversy, Dr. Shapiro underscored, “Ultimately, science will prevail.”

ILADS Views

Dr. Cameron, president of ILADS, is among the ILADS clinicians and scientific researchers who charge that their views are banned by the IDSA guideline panel, which bars opposing

representative relevant medical and scientific perspectives that point to evidence-based studies attesting to persistent Bb spirochete Lyme infection.

Dr. Cameron said to *Hamodia*, “There continues to be a network of physicians who push a narrative that there is no evidence of chronic Lyme disease and any illness is nothing more than the aches and pains of daily living. The narrative prevents doctors from working together to treat Lyme disease effectively. IDSA guidelines are too rigid and narrowly defined.”

Dr. Cameron debunked Dr. Shapiro’s assertions that disabling and lingering symptoms are “the aches and pains of daily life.” He described to *Hamodia* that his patients’ lives are derailed by Lyme disease, saying, “Children’s grades and attendance at school can drop precipitously. Adults might need to leave their work and families can fall apart.”

Yenty Rubin, 33, illustrates the devastation Lyme disease can cause if not given adequate treatment. Mrs. Rubin offered her account to Hamodia, after waging battle with Lyme disease in 2013. Mrs. Rubin, who resides in rural Monsey, N.Y., had been an employed, energetic wife and mother. She “suddenly” got sick in January of 2013, elaborating, “It was [as if] I had a physical breakdown.” Recurring infections, crushing fatigue, feeling faint, and intense ‘Lyme brain fog’ assaulted her in rapid succession. Her internist placed her intermittently on antibiotics for the frequent infections, and symptoms receded, but a short time later painfully resurfaced again.

Mrs. Rubin, who had formerly seen her internist only at routine annuals, now shuttled to him regularly and made two emergency room visits. Unable to care for herself or her family, her previously meticulously maintained home was in disarray. “My husband was father, mother and nurse,” she said to Hamodia.

Her bloodwork, ordered by her internist, finally yielded a positive Lyme disease result, despite the fact that Yenty Rubin never presented with the erythema migrans (circular bulls-eye rash).

Her internist placed Mrs. Rubin on 28 days of antibiotics. Concluding the internist’s protocol of treatment, her symptoms waned, but resurged again weeks later with terrifying intensity, snowballing to include a stiff neck, bilateral facial numbness, excruciating TMJ and laryngitis, among other symptoms.

Mrs. Rubin was referred to a rheumatologist who diagnosed her with fibromyalgia. When her medical condition further declined, she arrived at her own conclusion, that her symptoms were Lyme related. She found an LLMD who placed her on a combination of oral antibiotics. Mrs. Rubin improved gradually “with ups and down.” Eight months later, her health mostly restored, she ceased all treatment.

Yenty Rubin said to Hamodia, “My internist, who followed the standard protocol, treated me for 28 days. That didn’t work. I think that only ILADS-trained doctors understand how to diagnose and treat Lyme dis-

ease — and that's why I'm fine today." But she added a caveat: "I do know some people with early-stage Lyme disease who got well after 28 days of treatment. I think I had Lyme disease in my system for six months."

"Chronic Lyme disease includes a wide range of conditions such as Lyme encephalopathy, chronic neurologic Lyme disease, post-treatment Lyme disease and late Lyme disease," Dr. Cameron explained. "Chronic Lyme disease [symptoms] are often severe and chronic, and can include problems with fatigue, memory, irritability, dizziness, joint pain, tachycardia and chest pain. These are just some of the symptoms you will find in Lyme patients. [Studies show] that the symptoms are far worse than the normal population on standardized measures in NIH trials."

Dr. Cameron said, "The Lyme disease patient's quality of life is the same or worse on standardized scales as diabetes, myocardial infarctions (heart attacks), fibromyalgia and chronic fatigue. There are a growing number of doctors who recognize chronic Lyme disease who are professionals with experience in nearly every state and in a growing number of countries. I would encourage doctors who disagree to take a second look at the evidence. I also encourage doctors who disagree with the chronic Lyme disease diagnosis to engage in open dialogue."

Dr. Cameron treats a broad range of patients who respond differently to treatment. "We have patients who remain well after 30 days, and others that do not. We find most of our patients resolve their illness with oral antibiotics. We use IV antibiotics for those who do not resolve their illness with oral antibiotics. We have countless numbers of patients who have recovered and are able to stop treatment. We also have some [chronic] patients who fail treatment who require symptomatic treatment."

The 300,000 cases in the U.S.A. cited by the CDC demonstrate how commonplace it is to contract Lyme disease, Dr. Cameron said. The ILADS physician added that Krupp studies at the National Institutes of Health (NIH) trials demonstrated antibiotics were effective. The Klemmner and Fallon trials [studies which denied persistent infection] only focused on patients who were sick 4.7 to 9 years, and who had failed previous treatment.

Dr. Cameron stated, "The studies were mixed. Chronic Lyme disease remains a clinical diagnosis. The wide range of presentations makes it difficult to come to a consensus on diagnostic criteria. The only exception [in the IDSA disputation] is the post-Lyme disease syndrome proposed by the 2006 IDSA guidelines. Dr. John Aucott of Johns Hopkins Lyme Disease Clinical Research Center demonstrated that PTLDS exists and it can be severe."

Dr. Cameron explained to *Hamodia* the variables which may contribute to chronic Lyme disease. "There is a growing recognition of how complex Lyme disease and co-infec-

tions are. It is unclear what causes these lingering and disabling symptoms in individual patients. Co-infections [diseases other than Lyme which are spawned concomitantly by the tick bite], round bodies [of the bacterium], biofilms, the blood-brain barrier, variable strains of the disease, are only a few of the potential reasons for difficulty in treating Lyme disease. It remains difficult to culture Lyme disease and co-infections in any tissue other than the rash. Therefore it is difficult to prove which mechanism is at play [and the different treatments each requires]."

ILADS's protracted treatment of Lyme patients has led to state medical boards' sanctions against these physicians. LLMDs are a subset of beleaguered medical clinicians who aver that they are hounded by state medical boards. These boards investigate complaints and have suspended — and even revoked — the licenses of some of these doctors, following complaints against them which are primarily initiated by insurance companies. ILADS physicians argue that their rightful autonomy to treat their patients has been thwarted. ILADS clinicians therefore maintain a low profile.

In light of maltreatment of ILADS practitioners, Dr. Liegner stressed, "It is desirable for physicians caring for the persons who have, or might have, Lyme or other TBDs to be careful in their evaluations, to document in detail what they are doing, what they are thinking, the rationale for their diagnostic and therapeutic interventions, to be thorough in their assessments — and to be 'humble faced' with so much that we do not know, and with the many uncertainties that attend to this field."

Dr. Liegner said to *Hamodia*, "I have tried to do my best to advocate for my patients in battles with insurers and the 'mainstream' that has insisted there is 'no such thing as chronic Lyme disease.' It has been an uphill battle with heavy propaganda usage to attempt to maintain the 'status quo.' However, things are beginning to change, unfortunately not fast enough."

In his earlier years of his treating Lyme patients, Dr. Liegner had advocated to the insurance carrier for his patient with advanced Lyme disease, Vicki Logan. After consulting with Dr. Liegner in 1989, Logan was hospitalized and administered IV treatment to which she responded. Upon her own request, Logan underwent a spinal tap, which revealed Lyme spirochetal bacteria swimming in her cerebrospinal fluid, despite her prior prolonged antibiotic treatment. Nonetheless, Logan's insurance company continued to reject payment for her critical IV therapy.

In 2003, Vicki Logan died of complications of Lyme disease a while after insurance denial of reimbursement and the ensuing discontinuation of her IV antibiotics. Dr. Liegner has since publicly called for reforms in shielding chronic Lyme patients' treatment and their treating doctors.

Dr. Liegner said, "This field [in treating

COMPLEXITIES IN TREATING CHRONIC LYME DISEASE

By Dr. Daniel Cameron,
lead author of ILADS guidelines

Ticks can harbor multiple infections which can be transmitted through a single tick bite and are termed **co-infections**. When a patient's symptoms are severe, persistent and resistant to antibiotic therapy, co-infections are often exacerbating Lyme symptoms.

Scientists have discovered new ways that bacteria can survive in the human body. The spirochetes that cause Lyme disease appear to use these same approaches to survive in people.

A number of bacteria survive antibiotics treatment to form a persistor population, which can regrow after antibiotic treatment.

The spirochetes of Lyme disease can stick to each other in a matrix called a **biofilm**. A biofilm can protect the bacteria from the body's defenses and lead to persistent infection.

Lyme disease can change from a spirochetal form to a [dormant] "**cystic**" or round form that can be difficult to treat. These "cystic" forms can revert to spirochetal form, leading to a persistent infection.

Lyme disease can also survive in the brain, which is inaccessible to antibiotics [due to the **blood-brain barrier**, a filtering mechanism that only allows certain substances through]. The persistent cognitive and constitutional symptoms of LD, such as fatigue and headaches, may indicate a subacute brain infection.

Finally, there are **variable strains** of Lyme disease, some of which are more difficult to treat. There is a strain that requires longer treatment.

Lyme disease] is not for the 'faint of heart.' It's the price you pay for being a 'pioneer.' Persons with Lyme disease have suffered greatly from their illness as well as from the ignorance of many in the medical profession; they have been severely discriminated against, aided and abetted by the insurance companies."

Dr. Daniel Cameron summed up, "There are [mainstream] doctors who dismiss Lyme disease (who do not meet ILADS criteria), which leads to needless treatment delays. The delay makes it more difficult to treat. We have not been successful at getting the IDSA to begin the dialogue needed to establish diagnostic criteria. I feel a majority of physicians responsible for their patients will get involved and ignore the IDSA." ■

**Name and identifying details changed to protect privacy.*