the great imitator

Lyme disease can masquerade as a host of psychiatric ills, confounding doctors and driving patients to question their very sanity.

By Pamela Weintraub

Photographs by Karjean Levine

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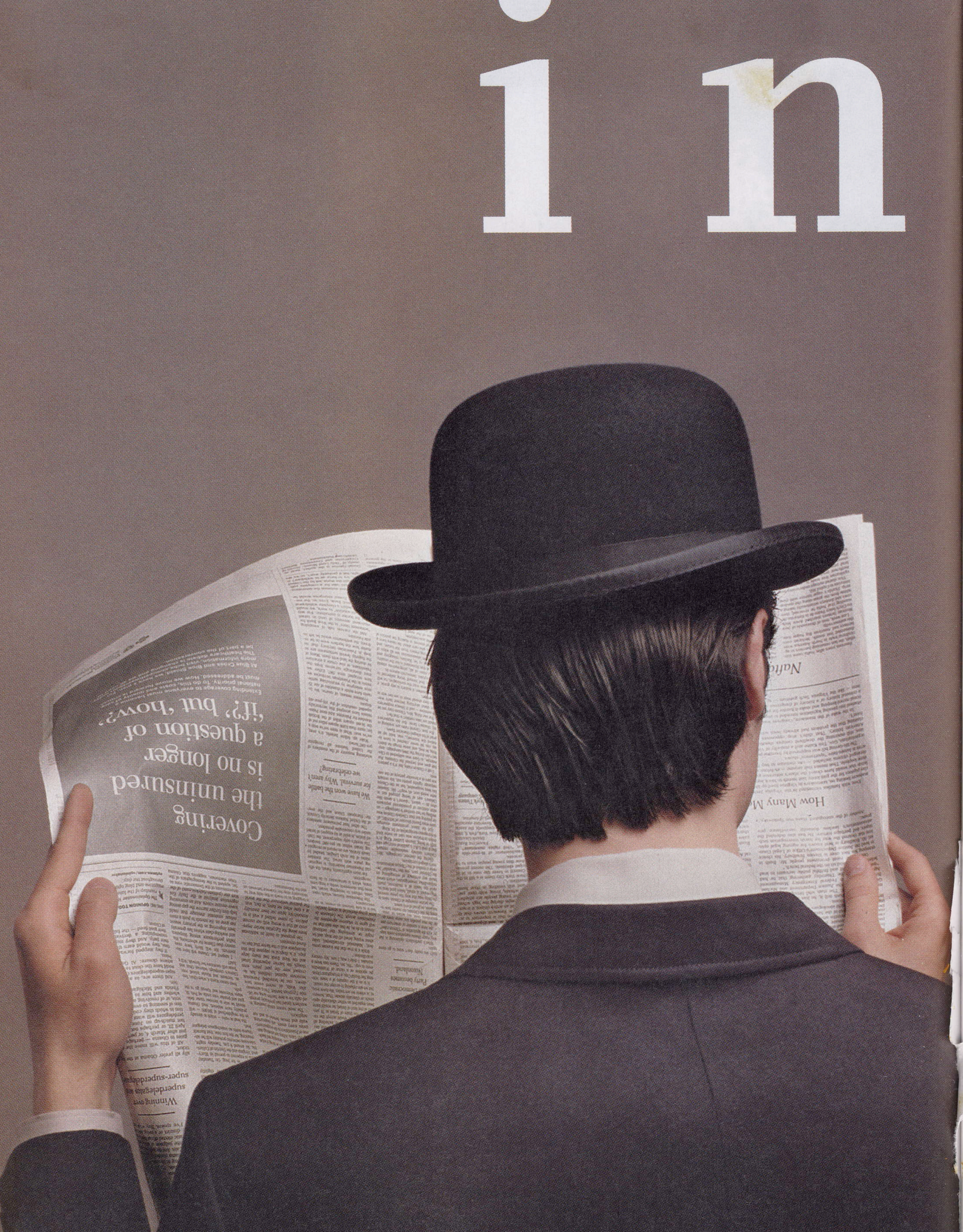

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the year 1993, I spread a map across the living room of our apartment in Forest Hills, Queens, and marked a bull's-eye at Grand Central Station, where trains come in from the 'burbs. I drew a 50-mile radius around the mark, and spent the next three months searching, with my husband, Mark, for a house. We sought top-rated schools for our two boys, proximity to a train en route to Manhattan, and an ample yard. As chance would have it, we ended our hunt at the most devastatingly beautiful spot, a winding country road abutting a spruce forest in the tony suburban hamlet of Chappaqua, in Westchester County, New York.

It would be the biggest mistake of our lives. If only we'd known how infected we'd get living on that land and how much skepticism we would face as we sought treatment, if only we'd understood that we, ourselves, would be the bull's-eye. We never would have left Queens. It took years for us to understand that the vague headaches, joint pain, and bone-weariness we initially experienced were more than just symptoms of our busy suburban lives: Instead of receiving early diagnoses and treatment for what really ailed us—Lyme disease—our infections were allowed to smolder, eventually becoming neurological and eluding the simple cure that could have worked at the start.

It was all so gradual. In the fall of '93, I began to feel ill. Though I never took a day off work, I functioned for years through an avalanche of impediments. Migraines with nausea had become my steady companion. I had intermittently sore and swollen knees, and the buzzing in my left hand was so intense my fingers sometimes formed claws. My vision, at 20/20 for most my life, had begun a sudden, precipitous decline.

Mark, meanwhile, was teetering. An avid tennis player with great coordination, he began stumbling and bumping into walls. Formerly affable, he began exploding at offenses as slight as someone spilling water on the floor. He was an award-winning journalist with a love of literature and a vocabulary so vast he was our stand-in dictionary. But gradually he began struggling with memory and groping for words. He left his job as an editor after realizing, one day, that he'd spent hours trying to read a single, simple paragraph.

Our younger son, David, began to sleep—first so long that he could not do his homework or see friends; eventually, so much (15 hours a day) that he could not get to class. Violating the strict attendance policy at his prep school but without a medical diagnosis, he was asked to leave. Hardest hit was Jason, the elder, who suffered fatigue and shooting pains starting at age 9, the summer we took up residence in our fairy-tale house. The doctors called these growing pains normal, but by age 16 in the year 2000, Jason was essentially disabled. He couldn't think, walk, or tolerate sound and light. His joints ached all day. On medical leave from high school, he spent his days in the tub. As his condition worsened and doctors at the teaching hospitals of Manhattan eliminated one diagnosis after the next, I began to wonder about Lyme disease. Yet throughout most of Jason's decline, our pediatrician dismissed the notion out of hand.

"There are too many symptoms here and he's way too sick for Lyme disease," he said. Instead, the interpretation he came to favor was psychological: This great collapse could be in Jason's mind. How lucky we were when he referred us to a psychiatrist, who said there was no psychiatric illness that could do this to a child. No, he insisted, this had to be a physical illness, and the pediatrician had better go back to the drawing board.

The chastened pediatrician drew 14 vials of blood, testing for hormone imbalance, mineral deficiency, anemia, and a host of infections, including Lyme. A week later he contacted us, baffled. Just one test, a Western blot for antibodies against Lyme disease, had come back positive—in fact, so off-the-charts that almost every band was lit. Jason was quickly reported to the Centers for Disease Control and Prevention (CDC) as an unequivocal case of Lyme. We had an explanation for Jason's illness and an inkling as to what might be wrong with the rest of us, at last.

Our nightmare had just begun. As with the quest for diagnosis, almost everything about Lyme disease turned out to be controversial. From the type and length of treatment to the definition of the disease to the kind of practitioner we should seek to the microbe causing the infection (or whether it was an infection at all), Lyme is a hotbed of contention. It was the divisiveness surrounding the disease that had caused our pediatrician and the specialists we'd consulted to hold back diagnosis as Jason and the rest of us became so ill.

For patients with early stage Lyme, the illness tends to be mild and a month of antibiotic treatment usually offers a cure. But for those who miss early diagnosis, for people like us, infection can smolder and progress, causing a disabling, degenerative disease that confounds doctors and thrusts patients into the netherworld of unexplained, untreatable ills.

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THE FIRST TIME I met a group of severely disabled Lyme patients I spent hours listening to their stories, some of them heartbreaking, and mourned with them their lives of frustration and pain. A month later, when I met the same patients again, several could not recall me. At first I was insulted. Had I been that forgettable, my empathy that banal?

Then I realized: Many of the sickest Lyme patients were cognitively impaired. Despite my research, despite my own Lyme disease, I still hadn't gotten it. To

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this day, popular perception holds that Lyme disease is an affliction of the knees, characterized by swollen joints and an inability to serve in tennis or descend a flight of stairs. Musculoskeletal symptoms can be a hallmark of Lyme, but the early rheumatologists who first defined the disease had recognized just one part of the elephant—it would take more time, and a broad array of specialists, for the widening picture to emerge.

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One of the first to realize the psychiatric implications of Lyme was Andrew Pachner, a Yale neurologist who moonlighted at psychiatric hospitals. On one such gig, he was asked to evaluate a 12-year-old boy who, prior to admission, had pedaled his stationary bicycle constantly, barely stopping to sleep or eat. Before the start of this behavior, the boy had been an excellent, hard-working student with a talent for soccer. But his soccer days were disrupted when he developed swollen knees and was diagnosed with Lyme arthritis. The child was treated and seemed to get well. When his obsessive pedaling began years later, his prior Lyme was already a distant memory, and no one saw the relationship between the two.

Except for Pachner. Given what he knew about syphilis—another spirochetal infection that gravitates to the brain and causes neuropsychiatric disease—he wondered whether Lyme disease and the obsessive cycling might be linked. In a leap of insight, he moved the boy to Yale and began infusing him with 20 million units of penicillin for 14 days. It was like a miracle. Within days the child started to improve, interacting with staff and eating food. Two weeks later he returned home and went back to school.

In 1989, writing in the *Archives of Neurology,* Pachner, by then at Georgetown University School of Medicine, described six cases of central nervous system Lyme disease, of which his bicycle boy was just one. Another patient, a 21-year-old man, had violent outbursts and wild laughing, attributed to herpes virus thought to infect his brain. But he tested positive for Lyme disease and, treated with antibiotics, was finally cured. A 6-year-old girl, so afflicted with vertigo she staggered, tested positive for Lyme and was treated; she, too, got well.

Neuroborreliosis, Lyme disease infecting the central nervous system and brain, appeared almost protean and could be mistaken for a host of other ills. Lyme disease was "the new great imitator," Pachner declared. Reports of bizarre complications now flowed into the medical journals. A group from Stanford described a 25-year-old woman with hallucinations, hypersexuality, nightmares, and a rash. Scientists from Germany found Lyme could cause Tourette's. Researchers even found a link between Lyme and the motor neuron disease amyotrophic lateral sclerosis (ALS).

If one were to describe all the macabre presentations of neuroborreliosis, it would fill a book. But the far more common problem—the confused state known as encephalopathy, or brain fog—was bad enough. Brain fog includes a disorienting lapse of memory, an inability to concentrate, difficulty falling asleep, and profound fatigue.

Though my family and I were more coherent than the sickest patients, we suffered, too. There were so many ordinary things that confounded us, hounded us, in the course of everyday life. Take our taxes, for instance. Every year since 1978 we had done our taxes together, filing receipts in neat manila folders, calculating the deductions, and sending it to our accountant, Irwin. But now we were stymied. Sitting together with hundreds of receipts we had stashed in trash bags, with credit card bills and cancelled checks, we found it impossible to do the sorting. We ignored Irwin's calls and didn't do taxes for years until my brother, a tax attorney, swooped down, demanded our mess, and took care of it for us.

Mark almost burned down our house by tossing ashes from the fireplace atop bags of dried-out leaves he had moved into the garage. The pre-Lyme Mark knew to store dried leaves outside and that hot cinders added to piles of dried leaves meant inferno and possible death; but Mark-on-Lyme did not stop to consider the consequences. Our garage was ablaze while we blithely watched a TV show upstairs. Passers-by called the police. Our family room exuded the stench of burnt wood and plaster for years.

Brain fog was new for us, formerly the family of fast thinkers. Now we were the family of stumblers and bumblers, making conversation and parsing the details of life under the psychic din of an ocean roar. I started to think of us as Dumb and Dumber.

Lyme encephalopathy was hardly undocumented. In one study, the neurologist John Halperin, now at North Shore University Hospital in Manhasset, New York, found white matter

protect yourself!

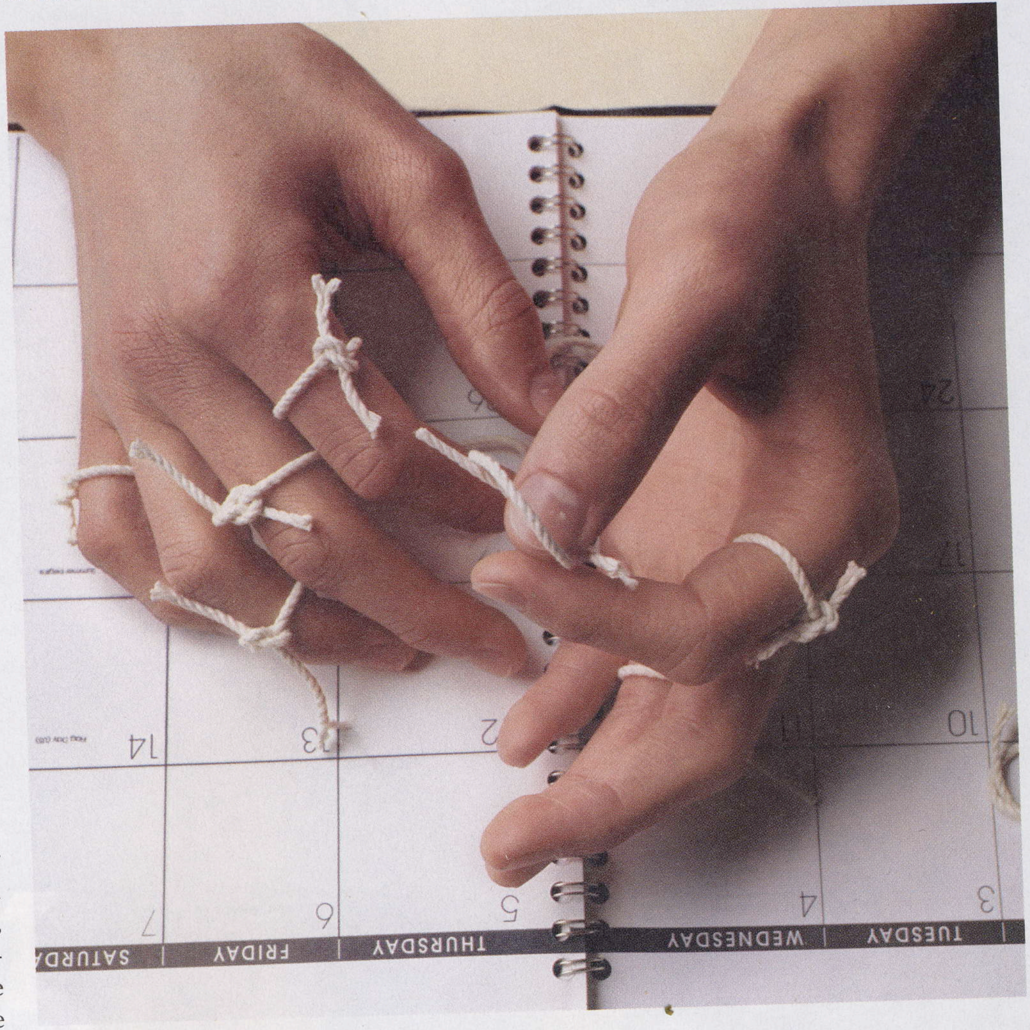
The best way to avoid neuroborreliosis is through early diagnosis and treatment for Lyme disease. Remember, Lyme in its initial stage is usually easily treatable; however, delayed diagnosis or inadequate treatment can lead to serious brain, heart, or joint problems.

- When in a Lyme-endemic area check yourself, family members, and pets for ticks. If you live in such an area, check daily. Remember that deer, mice, birds, and other small animals—found right in your backyard—carry ticks. Nymphal ticks are the size of a poppy seed in early spring and are particularly hard to see.
- Remove the tick properly with fine tweezers. If you are not equipped to do this, go to an emergency room and have the doctor remove the tick.
- Store the tick in a jar and take it to a Department of Health laboratory or testing facility to have it tested for Lyme disease.
- Keep in mind that a single tick bite can transmit more than one tick-borne illness, such as babesiosis or ehrlichiosis. These may need to be treated with alternate medications.
- Treat Lyme early and prophylactically with antibiotics. Don't wait for a positive test—antibodies against the organism will not convert to give a positive test result for about six weeks, placing you at greater risk for neuroborreliosis if you turn out to be infected.

lesions, much like those seen in multiple sclerosis, in the brains of 7 out of 17 encephalopathic Lyme disease patients. The lesions represented brain damage. Sure, Lyme patients were not usually as impaired as those with bullets in their brains, but the brain fog, the deficits in language and organization, the psychiatric leftovers of anxiety, depression, and OCD, could still disrupt lives. Adults lost houses, marriages, and jobs and were compromised as parents. Children lost their childhoods when cognitive or emotional disabilities forced them to homeschool. The impact was major, but neurologists often characterized such symptoms as minor, nonspecific, and vague.

The professionals finally able to understand the cognitive and psychiatric fallout of Lyme disease in patients' lives were the psychiatrists. One of the first was Brian Fallon, whose interest had been sparked in the late 1980s while helping a close relative overcome a serious case of Lyme. He had just finished his psychiatric residency and secured a gig as a fellow for the National Institute of Mental Health, stationed at the New York State Psychiatric Institute at Columbia University in New York City. The young doctor—whose kempt long hair, neat beard, and energetic demeanor made him look like he'd marched off the album cover of *Abbey Road*—specialized in anxiety disorders, with a focus on hypochondria. But news of his interest in Lyme disease had traveled through the grapevine to Lyme patients in southeast Connecticut. Some of them had developed psychiatric disorders after having Lyme disease. Could Fallon follow up?

Fallon drove out to Old Lyme, where the disease had first been recognized, and spent the day meeting with an afflicted group. Fallon was well aware of the single-case studies and series of anecdotes continually published in medical journals. One researcher had even staged the psychiatric manifestations so that they paralleled the neurological disease signs recorded before: In the first stage, mild depression could parallel a fibromyalgia-like illness. In stage two, mood and personality disorders often emerged alongside meningitis (swelling of the brain's lining) or neuropathy (tingling or numbness from damaged nerves). Finally, in stage three, with the onset of encephalomyelitis (inflammation of the brain and spinal cord), the clinical picture might include psychosis or dementia.



Conducting interviews with the Connecticut patients, Fallon learned that depression or panic could worsen after the start of antibiotic treatment, suggesting a kind of psychiatric Herxheimer reaction, an exacerbation of symptoms that can occur when bacteria are killed. Conducting formal interviews with the patients, he found that neuropsychiatric Lyme disease and regular psychiatric disease appeared much the same. This was of particular concern since so many patients failed to notice a rash or register positive on standard tests. Without a correct diagnosis, they might be treated with psychiatric drugs but not the antibiotics that could bring a cure.

Children with Lyme disease can be mislabeled with a primary psychiatric or psychological problem, while the root issue might never be addressed. Take Seth Statlender of greater Boston. At 12, he was so ill he couldn't regularly attend school. He bravely played soccer but felt so sick he threw up in front of his team. One doctor suggested bulimia. "I'm a psychologist," his mother, Sheila Statlender, said. "Throwing up in front of his team and a crowd of spectators doesn't fit the profile. Bulimics purge in private."

Seth's sister, Amy, also started getting sick. First it was a cough, something the pediatrician thought might be an allergy. But the cough continued, taking on a chronic, croup-like quality that was not relieved by nebulizers or other treatments. Finally, a pul-

monary specialist suggested cognitive-behavioral therapy for the cough. But Statlender pointed out that if you cough throughout the night in your sleep, it's not a cough habit, which is what behavioral therapy would treat.

Time and again, Fallon, an expert in hypochondria, had seen frustrated doctors dismiss medically ill patients as psychiatric cases due to their own inability to diagnose the disease. With Lyme, the mistake was especially damaging since a delay in treatment could turn a curable, acute infection into a chronic, treatment-resistant disease.

The solution, Fallon knew, was to gather objective evidence of physical damage to the brain. Working with radiologists at Columbia, he found that one useful tool was the SPECT (single photon emission computed tomography) scan, which generated a moving picture of the brain. A radioactive solution was delivered intravenously, then tracked to measure blood flow through the brain. SPECT could show something amiss even when MRI scans appear normal. After treatment, many patients showed improvement on the SPECT scan.

"Doctors can destroy patients by telling them that a true, physical disease is all in the head," says psychiatrist Virginia Sherr of Holland, Pennsylvania, and suicide can be a result. In the Lyme hot zone of Bucks County, she sees a new case of Lyme encephalopathy every week. "I am a psychiatrist. These are not people who are referred to me because they have Lyme disease—they are sent because they have panic attacks, hallucinations, obsessive-compulsive disorder, and depression. They are in agony—not only neuropsychiatric pain, but physical pain as well. They have never been hypochondriacal in their lives, but that is how they are labeled. They are encephalopathic, but they have been told they are not by physicians who wouldn't know a case of encephalopathy if they fell over it. They are physically sick, but are blamed by doctors who say: 'You belong to a cult if you think you have Lyme,' or 'You look okay to me.'"

Three decades after Lyme disease was identified in southeast Connecticut, its neuropsychiatric fallout remains misunderstood, not just by local doctors but also by many of the rheumatologists, dermatologists, and neurologists who defined the disease at first. Patients with this controversial but common outcome, most often a consequence of late diagnosis, may negotiate arduous paths back to health. Yet once the problem is recognized, aggressive treatment can help. Now, my son Jason, the sickest in my family, is about to graduate from Brown. His brother, David, will be a junior at Vassar. As for Mark and me, we work long, hard days as writers and editors, in a place we love, Manhattan, as far from the tick-infested forests of Westchester County as we can get. **PT**

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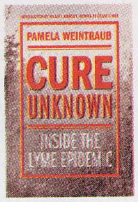

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