

Ticked off

This SELF contributing editor endured a decade of exhaustion, body aches and brain fog—plus accusations she was making it all up. By Tula Karras

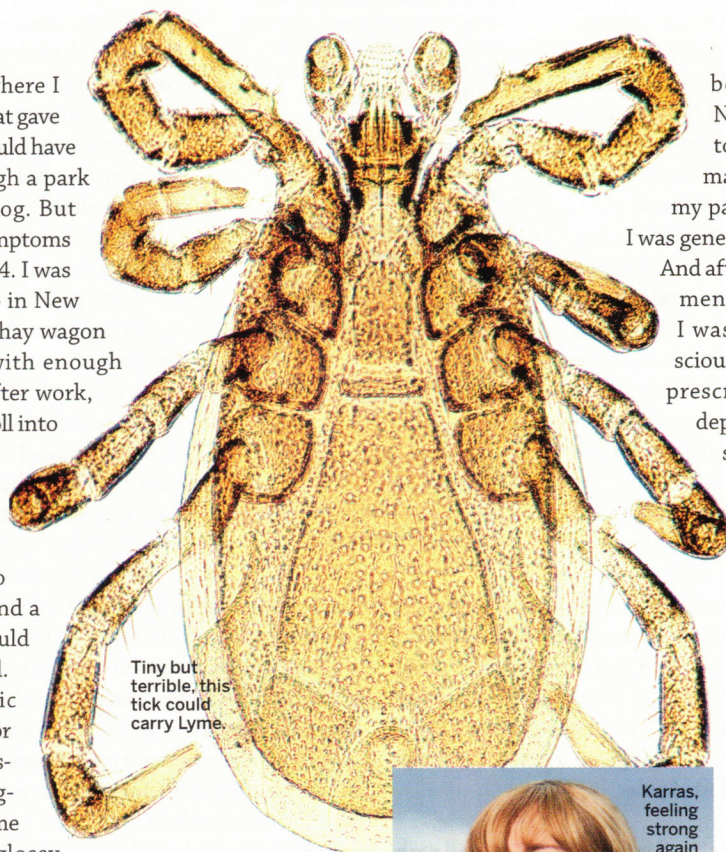
I don't know when or where I was bitten by the tick that gave me Lyme disease—it could have been during a stroll through a park or even while petting a dog. But I do remember when my symptoms first struck: November 1994. I was 26, with an entry-level job in New York City, straight off the hay wagon from Texas and replete with enough energy to go to the gym after work, play pool until 3 A.M. and roll into the office the next day with a clear head. My illness began like the flu, but when the fever lingered for a month despite two weeks of antibiotics, I found a doctor on my plan who could see me before the weekend.

A specialist in chronic fatigue syndrome, the doctor ran a few tests and then christened me with a CFS diagnosis. In practically the same breath, she pointed to a glossy women's magazine on her desk and said proudly, "I'm in this month's issue." I nodded, impressed. Armed with a vial of pork liver extract that I was to self-inject weekly (an experimental CFS treatment), I left feeling relieved. There was a name for what had been plaguing me for more than a month, and it wasn't lethal.

Several weeks later, fatigue became the least of my problems. My muscles began to seize up, a constriction like being on the starting block at a race, waiting for the gun to go off. Worse, I had heart palpitations and dizzy spells several times a week. I was afraid I was having a heart attack, but my doctor assured me the spells were typical of CFS. Was that supposed to make me feel better?

Amid all of this drama, I started dating a guy I was crazy about, although he wasn't as crazy about me. "Maybe your feelings of rejection are showing up in physical ways," one friend suggested. It got me doubting my own sanity. True, my thoughts were often so jumbled I couldn't focus on a simple TV sitcom. At work, I faked it through the day, using brief moments of clarity to perform my most complex tasks. I frequently called my parents, crying, "What's happening to me?" They had much sympathy but few answers.

Determined to find help, I sought out several second opinions during the next few months. An Ayurvedic healer instructed me to have more sex. (Would that I had the energy! Plus, my new



Tiny but terrible, this tick could carry Lyme.

boyfriend had dumped me. Not that I blamed him: I'd tried to hide my symptoms—which made me seem flaky.) A doctor my parents recommended implied I was genetically prone to feeling crappy. And after spacing on several appointments with a Freudian analyst, I was diagnosed with a subconscious desire to avoid therapy. She prescribed drugs for anxiety and depression, and they helped me sleep. But my symptoms waxed and waned, and inevitably I returned to my default condition: sick and tired.

Lyme came up the first time in 1996. I visited a rheumatologist, who'd had the disease himself. After hearing my symptoms, he ordered a blood test to look for signs of the Lyme bacterium. "But I've never had a bull's-eye rash," I said. He explained that only 60 to 70 percent of sufferers develop the tell-tale redness around their tick bite, and he promised to call with the results.

The test was negative, so the doctor tried to ease my symptoms with treatments, including dehydroepiandrosterone (DHEA), a hormone



Karras, feeling strong again

used experimentally to treat CFS. But my body aches worsened. After months of no improvement, I quit taking prescription pills—and seeing doctors—altogether. I lost faith in Western medicine.

Meanwhile, my social life was all but nonexistent. I constantly canceled plans, and while friends were mostly supportive, one practically rolled her eyes every time I bemoaned being sick. "Are you angry with me?" I finally asked during a phone call.

Her response shocked me. "You'll hate me for saying this, but I think you're using your symptoms to get sympathy. I can't feel sorry for you anymore." I hung up and sobbed, afraid that my friend had blurted out what others were thinking. Did everyone believe I'd been milking or even faking my illness for two years?



>>> So I began to lie, saying I felt fine and wishing I had something, anything, that would show up on an X-ray to prove I was sick. "If I had cancer, at least then I'd either die or recover, and there'd be an end or a new beginning," I wrote in my journal. Somehow I managed to land and keep a great job (at SELF!), shoring up all my energy on weekends and pushing through Friday as if it were the last mile of a marathon.

In January 2003, after a seven-year hiatus from doctors, I decided to see one more. My pain was so overwhelming that I had considered moving in with my parents—the kiss of death for a single woman in her 30s. As I chronicled my symptoms to Leo Galland, M.D., a chronic-illness specialist in New York City, I broke down in tears. "I think I can help you," he said. He didn't accept insurance, and the cost of the specialized tests he ordered was about \$1,500. My health is worth going into debt for, I rationalized. I pulled out a credit card.

"Your Lyme test came back somewhat positive," Dr. Galland said, calmly delivering the news in his office a few weeks later.

"That's unbelievable! I tested negative for Lyme years ago," I reminded him. "Yes," he said, "but it's possible to get a false negative or even a false positive." He explained that few tests detect the actual Lyme bacterium. Instead, blood tests look for antibodies to the bacterium, and these measures aren't foolproof. "Given your test results and history, it's pretty clear you were exposed to a tick at some point," Dr. Galland concluded. More than eight years after my symptoms started, I was given a prescription for Zithromax, an antibiotic used for Lyme.

My future was bright, I told myself as I washed down the pill each day. I had escaped the serious memory loss and rare but crippling arthritis that can accompany chronic Lyme, and now I was actually starting to improve. After nine months of taking Zithromax, I went off the drug with Dr. Galland's blessing, feeling better and energetic enough to do mundane things like clean and cook. Right before Thanksgiving 2003, however, I was leveled by what



Once bitten:
Lyme's calling card

What Lyme disease looks like

EARLY-STAGE SYMPTOMS

- ☐ A red, sometimes bull's-eye-shaped rash (but note, the rash might be a solid red circle, and only 60 to 70 percent of sufferers develop one)
- ☐ Fatigue
- ☐ Low-grade fever
- ☐ Headache
- ☐ Flulike body aches

LATE-STAGE SYMPTOMS

- ☐ Joint pain and swelling
- ☐ Migrating symptoms (e.g., a sore elbow for a few weeks, then a sore knee for weeks)
- ☐ Confusion
- ☐ Twitching or tingling in the extremities
- ☐ Headaches
- ☐ Visual changes
- ☐ Memory loss
- ☐ Facial paralysis (Bell's palsy)
- ☐ Irregular heartbeat

I thought was a flu. It confined me to my bed for days. Back at work a week later, I suddenly found myself wondering why I couldn't feel my left eyelid moving when I blinked. I hurried to the bathroom and looked in the mirror. My left eyelid *wasn't* moving. Neither was the left side of my mouth when I smiled. I went cold: By now I knew that partial facial paralysis (aka Bell's palsy) was a sign of Lyme. I rushed to see Dr. Galland, who took one look at my face and confirmed my self-diagnosis, then explained that the Lyme bacterium had invaded my central nervous system. I felt devastated but also oddly vindicated: I finally had proof—on my face, for all the world to see—that I had Lyme.

Oral antibiotics resolved my Bell's palsy after a month, but other symptoms came and went. So in late summer 2004, Dr. Galland brought in the big guns: Rocephin and Claforan, two potent intravenous antibiotics that can better penetrate the central nervous system and fight the Lyme bacterium where it hides. Within days of being hooked up to the IV—administered via a 24/7 pump housed in a fanny pack—I saw huge improvement. I was so giddy, I was able to brush off the horrified looks from women in my office elevator, who eyed my IV bag as if I

had a dead rat attached to my body. (Truth be told, I *would* have strapped a dead rat to my body if it would have cured me.)

For months, I trotted around with my beloved life-support system at my side. In January 2005, I had my IV port removed, and after taking an oral antibiotic for a few more weeks, I've been fairly healthy ever since, knock on Formica. (I don't spend much time in the woods these days, for obvious reasons.) I'm no longer fighting mad at the doctors who could have spared me years of turmoil with the right diagnosis and simple antibiotics. Heck, I was lucky to find a doctor versed in chronic Lyme, considering many don't even believe in it. (See "If I Knew Then What I Know Now..." below.) My best advice to women suffering from any long-term, unexplained symptoms is to find a doctor who perseveres with you until you're on your way to wellness. You'll know when you're getting the brush-off: Your body may be sick, but you can always trust your gut.

"IF I KNEW THEN WHAT I KNOW NOW..." Lessons from a Lyme survivor

I would have found a Lyme-literate doc. My ordeal landed me in the middle of a controversy: Not everyone believes in chronic Lyme disease, so care varies wildly depending on which doctor you see. The Infectious Diseases Society of America (IDSA) in Arlington, Virginia, asserts that there is no medical proof the Lyme bacteria persist long-term. "But dozens of studies have found evidence of Lyme infection from biopsies and body fluids of chronically ill patients who've had far more than 30 days of antibiotics," counters Steven Phillips, M.D., former president of the International Lyme and Associated Diseases Society (ILADS) in Bethesda, Maryland. If you suspect you have chronic Lyme, find an M.D. through TurnTheCorner.org who will fully investigate your hunch. **I would have sought the best test.** Guidelines from the Centers for Disease Control and Prevention in Atlanta suggest doctors order an enzyme-linked immunosorbent assay (ELISA) first and

use a Western blot test only to confirm a positive or inconclusive ELISA. But the Western blot is much more accurate, so ask for it, recommends Joseph J. Burrascano Jr., M.D., director of ILADS. Try to get a full-spectrum Western blot, which reports on all 16 antibody bands linked to Lyme. (Certain antibodies are more specific to Lyme.) But note: Only 50 to 70 percent of people with Lyme have a positive blood test at all—another good reason to seek out a doctor who is trained to recognize its symptoms. **I would have insisted on at least four weeks of antibiotics.** The IDSA advises against taking antibiotics long-term to treat Lyme—particularly when the drugs are being used for an unverified infection—and warns that it can unnecessarily foster side effects such as drug resistance or bloodstream infection. However, Dr. Burrascano and other Lyme experts maintain that anything less than four weeks is linked with higher rates of treatment failure.