

always thought that I was a most unlikely victim of the affliction called Lyme disease. As a born-and-bred urban New Yorker, I never envisioned that my quality of life would be eviscerated by a tiny deer tick. Nonetheless, it was a tiny tick bite that broadsided me with the elusive and debilitating symptoms that would propel me into the frightening landscape of chronic Lyme disease. Prior to that I had had a fulfilling life as a wife and mother, coupled with a stimulating career as a freelance writer. I did not know that my life would soon spiral downward in a malignant way.

My saga began on a warm summer day in August 2003 when I traveled from the city to see my children on visiting day in their sleepover camps. Together, my children and I ambled through the grassy fields, enjoying an excursion in the countryside. That would be one of the few remaining days that I would later recall being healthy. Unbeknownst to me, at a fleeting moment on that day, I was bitten by a minuscule deer tick (ticks pictured in these pages are greatly maginified) that I never even saw but which unleashed a virulent bacterial infection that would devastate my life.

Two weeks later I began to experience symptoms. Flu-like chills and extreme fatique made me slump in my recliner, too weak to move or to perform simple tasks. I started experiencing insomnia, often waking in the middle of the night and unable to return to sleep. My neurological symptoms ratcheted upward and I soon began to have vertigo and a bizarre numbness and tingling in my hands and feet, along with a constricting pressure in my head. This was in concert with the perception that my body felt "heavy," as if solidified with cement.

But worst of all was the disabling brain fog, which felt like cotton balls stuffed in my head, removing my ability to concentrate or think. I began having unexplained breathing problems and suffered migrating pains in my joints. Unmanageable gastrointestinal symptoms surfaced, and overall muscle aches and fever chills served to complete my misery.

My writing projects were at first hindered and subsequently dismantled, as was the seamless operation of my home. I had become very ill and didn't know what was happening to me.

I began seeing doctors, launching my search for an answer with a local internist. I had never previously needed an internist, so this physician wasn't aware of what an active and productive individual I had been. I visited him twice, initially when he drew blood for numerous tests. On the following visit, after all the blood work returned with negative results, the doctor, to my consternation, derisively branded my symptoms as "anxiety." Despite his misguided diagnosis, I was certain that my declining condition was not an outcome of anxiety but had an underlying medical

In September 2004 I consulted many different specialists. All their diagnostic tests were inconclusive. One rheumatologist agreed that "something is going on here," but he couldn't pinpoint its cause. None of these doctors ever mentioned the possibility that I had contracted Lyme disease.

Most painful to me was the fact that family members were dismissive of my crippling symptoms thanks to the myriad consultations and tests I underwent that did not produce definitive results. They too attributed my illness to anxiety and told me After all the blood work returned with negative results, the doctor, to my consternation, derisively branded my symptoms as "anxiety." I was certain that my declining condition had an underlying medical source.

From the beginning of this journey, I talked to Hashem constantly because I could not focus on davening from a siddur, and I asked for a miracle.

to pull myself together and go on with my life. I felt abandoned, isolated, and so very ill. Years later, my family's attitude would shift to compassion as they attempted to comprehend the significant challenges I face, but back then their attitude compounded my considerable physical pain.

From the beginning of this personal journey, I talked to Hashem constantly because I could not focus on davening from a siddur, and I asked for a miracle. I petitioned Him to send someone to help me decipher the cause of my suffering as I couldn't fend for myself anymore. Finally Hashem heeded my pleas. Auspiciously, about a year after the onset of my devastating symptoms, an old friend, Goldie,\* called me to inquire about shidduch information for her daughter.

After hearing my despairing narrative, she asserted, "You do not have anxiety. There is something medical going on. You just haven't been to the right shaliach." She immediately took me under her wing and orchestrated my medical care. In June 2004, after accompanying me to several doctors to rule out other diseases, she escorted me to a Lyme-literate medical doctor (LLMD) who drew new blood samples. These tests finally revealed the source of my multisystemic symptoms. I had a "striking case of Lyme," the physician said, brandishing the sheaf of papers that contained the results.

I shared these findings with other physicians, who all concurred with the Lyme diagnosis. I was euphoric as my condition now had a name and could be cured. A year later, blood tests taken by a different doctor further disclosed that in addition to Lyme disease I also

suffered from other tick-borne diseases termed co-infections. Unfortunately, years have passed since my diagnosis and I am still symptomatic, which makes me a sufferer of "chronic Lyme disease."

I have since learned that there is significant controversy over Lyme disease treatment. As a chronic Lyme patient, I seek to debunk the misconception that Lyme is "easy to diagnose and easy to treat," words of the established Infectious Disease Society of America (IDSA) guidelines that discredit the existence of chronic Lyme disease. I am currently being treated by an LLMD who believes that there are chronic "stealth" infections in my body that need to be treated with antibiotics.

While there are those fortunate Lyme patients who do recover completely with long-term antibiotics, I can attest that chronic Lyme disease is real and that there is no absolute cure for many of its long-term victims. It has baldly robbed me and other Lyme-disease patients of the vigorous life we once enjoyed. These days, I am preoccupied with the management of my disease in my ongoing battle to retrieve my health, or at least regain a higher level of functionality.

I clearly believe that my fate is in the Hands of Hashem, Who masterminds the epic scope of the universe, and I am cognizant that Hashem in His mercy can reverse this harsh decree.

Despite the suffering of Lyme, there is a silver lining in the cloud of this disease. As I reached out to patients who preceded me in undergoing treatment for Lyme, newly diagnosed patients now reach out to me for advice, referrals and support.

Unfortunately, the number of Lyme-disease patients is burgeoning. Along with other chronic Lyme-disease patients in the frum community who are advocating for ourselves, I focus on educating others. We campaign to promote awareness by disseminating the information that a deer tick bite can destroy lives. Lyme disease strikes anyone and does not discriminate between young and old, rich and poor, man and woman.

My experience illustrates

\*All names, including that of the author, have been changed to protect privacy.

## **Ticks**

## What they are and how to avoid them

Deer ticks cannot jump or fly, and do not drop from above onto a passing animal. Potential hosts — which include all wild birds and mammals, domestic animals, and humans — acquire ticks only by direct contact with them.

In tick-infested areas, the best precaution against Lyme disease is to avoid contact with soil, leaf litter, and vegetation to the greatest extent. However, if you garden, hike, camp, hunt, work outdoors, or otherwise spend time in the woods, brush, or overgrown fields, you should use a **combination of precautions** to dramatically reduce your risk of getting Lyme disease:

**Then,** when you spend time outdoors, make these easy precautions part of your routine:

- Wear enclosed shoes and light-colored clothing with a tight weave so you can spot ticks easily.
- Scan clothes and any exposed skin frequently for ticks while you are outdoors.
- Stay on cleared, well-traveled trails.
- Use insect repellant containing DEET (diethyl-meta-toluamide) on your skin or clothes if you intend to go off trail or into overgrown areas.
- Avoid sitting directly on the ground or on stone walls, which are havens for ticks and their hosts.
- Keep long hair tied back, especially when gardening.
- Do a final, full-body tick check at the end of the day. Also check children and pets.

that when one gives of oneself to another, Hashem repays in kind. Some years had elapsed since my diagnosis, and Goldie's daughter was still not married. In gratitude for this dear friend's monumental efforts on my behalf, I wished to play a role in finding her bashert. And so I did. Through a series of astounding events of hashgachah pratis, I was a key player in facilitating her daughter's shidduch. Thus Divine Providence granted us the pleasure of assisting each other.

Throughout the tribulations of wrestling with chronic Lyme disease, I have learned to embrace each good moment and celebrate each good day. When I see the radiant smiles of my grandchildren and feel their trusting hands in mine, I know that despite the trials of chronic suffering, life is well worth living.

However, the summer months are upon us again, and deer ticks abound in the countryside or in any rural setting where so many of our community members vacation. I therefore urge people to be vigilant about the risks of contracting Lyme disease since the deer ticks that carry Lyme disease are very widespread and harbor many lethal infections.

I didn't foresee that I would contract chronic Lyme disease. I urge you to do all you can to protect yourself from it. And if you know anyone who can benefit from my experience, I can be reached through this magazine, whose editors know me well and can vouch for the truth of this story.

**Editor's Note:** This is an account of one person's unique experience with a severe challenge. All medical information is specific to this one case and in no way reflects the general progress of this disease.