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Paradise LOST

THE PREVALENCE OF LYME DISEASE HAS FOREVER CHANGED ONCE CAREFREE SUMMMERS. BUT HOPE—IN THE FORM OF PROPER TESTING AND EVEN A VACCINE—IS ON THE HORIZON.

By Marcia DeSanctis

One morning I rose from bed and was slammed with a level of nausea I had experienced only once before: the time I joined my son on the Gravitron ride at a country fair. But I had only been sleeping, not airborne in a metal saucer. I arrived at the emergency room at New Milford Hospital in Connecticut convinced I was having a stroke until the resident there asked me, "Is there any chance you have Lyme? Sometimes it causes vertigo." I had Lyme all right, and I was lucky to have landed in the care of a physician who was switched on to the many fickle faces of a disease that seems to have co-opted our headspace and, sadly, our summers.

Button up, everyone. Just when we want to kick back and show some skin, ticks are foremost on the brain. It's hard to believe that hiking New England's leafy trails or letting the Labradoodle onto the duvet can be treacherous these days. Though the Zika virus has us on high alert, we know that **Lyme disease** is



already galloping through our sun-dappled communities. "Is it the tick bite or is it exhaustion?" is topic A over gin-and-tonics from Martha's Vineyard to Mount Desert Island. The omnipresence of Real Housewife Yolanda Foster and her children Bella and Anwar Hadid has also shone the spotlight on a disease that has changed how we interact with nature, entertain, raise our kids, and treat our pets.

A prevention strategy is not really optional anymore, because the stakes are

too high. "You always have to do the simple protective things," says Tim Lepore, medical director of Nantucket Cottage Hospital. An estimated half of the island's ticks are believed to be infected with *Borrelia burgdorferi*, which causes Lyme disease, but in 35 years no one in Lepore's family has been afflicted. "Avoid moist, brushy areas, use repellent, wear light-colored clothing, and tuck your pants into your socks. Most of all, check yourself and your kids," he says. "Ticks are small, but they're not invisible."

When my children were young I scanned them with unabated paranoia. Once I scraped what was certainly a tiny bloodsucking Lucifer from my son's shoulder, put it in a baby food jar, and

brought it to the doctor. “This is a leaf,” he said wearily. I’ve since learned that ticks wiggle as they bore their fangs into you, and they’re easy to spot. But on myself I’m delinquent, which may be why I’ve gotten Lyme disease three times. During the most recent bout, last summer, I got very sick. “This is what it’s like to be 90,” I thought. I moved as if walking through syrup. I had the notorious brain fog, a vague and disputed manifestation of the disease and one of the most confounding aspects of an illness that, especially if diagnosed too late, can mimic many other afflictions, among them lupus, rheumatoid arthritis, Parkinson’s, and ALS, and for which there is still no human vaccine or reliable test. The controversy played out on season six of *The Real Housewives of Beverly Hills*, but it’s also a big issue for researchers, physicians, activists, naturopaths, and your next door neighbor.

The tests sanctioned by the Centers for Disease Control—ELISA and Western Blot—look only for antibodies and are notorious for giving both false positives and false negatives. “We’re looking for the bug in blood, and that has been the holy grail of Lyme disease research,” says Paul Fiedler, a pathologist with the Western Connecticut Medical Group and the director of the group’s Lyme registry, which collects blood from patients with the goal of isolating either the organism or its DNA. In April, I became the 393rd member of the study, in the hope that my three Lyme infections might have some upside.

The need for a foolproof test is urgent. Tick-borne illnesses (including babesiosis, ehrlichiosis, bartonella, and the deadly Powassan virus) are ravaging the Northeast and the Midwest, but Lyme disease is in all 50 states. The CDC estimates that there were more than 300,000 cases in 2014, but most people believe the number to be far greater.

“It’s a very complicated and confusing disease,” says artist Ally Hilfiger, daughter of designer Tommy Hilfiger. “A lot of people get bitten by a tick, get a positive

test result, go on antibiotics, and—bam—are better in 30 days. For those who don’t, it’s completely crippling and it steals your life.” At age 18, Hilfiger crash-landed at Silver Hill, in the middle of a mental breakdown, and soon was diagnosed with Lyme. At seven she was bitten by a tick, and then 11 years of clinical limbo, because of repeated false negative test results, clouded what should have been an idyllic childhood in Greenwich, with pain, fatigue, and illness. She documents the years of uncertainty and her recovery in her new memoir, *Bite Me: How Lyme Disease Stole My Childhood, Made Me Crazy, and Almost Killed Me*.

It’s hard to think of raising a kid who plays hide-and-seek in the brush and leaps into mounds of autumn leaves nowadays. “The tick explosion at a personal level has affected what I do with my family,” says David Rattray, a 13th-generation Long Islander and editor of the *East Hampton Star*. He was diagnosed with another tick-borne illness, alpha-gal syndrome, that lurks in eastern Long Island and causes an acute allergy to red meat. “Growing up, I would picnic in Montauk in these grassy places with my father and grandfather. That would be inconceivable today.”

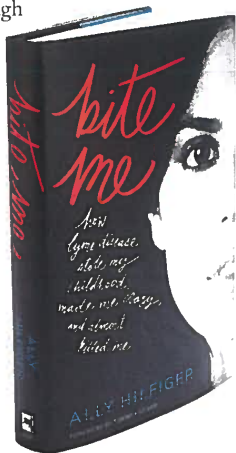
When you’ve had it three times, the potential for residual symptoms messes with your head. The question always haunts: Is it arthritis, early dementia,

exhaustion from life in 2016—or Lyme? At Columbia University, the Global Lyme Alliance is funding research on chronic pain after antibiotic treatment for the disease, and scientists have already determined that the brain may function differently in some patients following the illness.

There are other signs of progress. A canine vaccine developed at Virginia Commonwealth University is being retrofitted for humans and may be ready for clinical trials in about a year. Global Lyme Alliance’s chief science officer, Harriet Kotsoris, predicts that a point-of-service test, similar to a pregnancy test, will be available in two to five years, provided there’s proper funding.

On the human level, the situation calls for both common sense and desperate measures. More and more communities are culling their deer populations; on Monhegan Island, Maine, this approach virtually eradicated the disease. For those of us who live and thrive in the outdoors, we know the risks and act accordingly. Novelist Ann Leary, an avid horsewoman, routinely encounters ticks when riding and is diligent about prevention, checking and removing them immediately. “Also, take a shower and put your clothes in the wash right away,” she says. For Hilfiger it starts with beachwear and an organic repellent by Tick Tock Naturals. “Spray your pets and your kids and yourself,” she says. “Spray, spray, spray.”

Ticks may outnumber us, but I’m not about to live in a cement block. We hardy souls who shovel snow all winter have earned a little splendor in the grass. «



TICKED OFF
Ally Hilfiger writes about living with Lyme disease in her new memoir.

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HOW TO PROTECT YOUR PROPERTY—AND YOURSELF—FROM TICKS.

Turns out the best thing you can do to avoid ticks is clean up the lawn. Landscape designer Liz Kay recommends keeping grass short, shrubs pruned, and wood piled neat and dry. Remove deer-attracting plants like hydrangea and tulip (boxwood, lavender, and pachysandra are okay). The surest way to keep ticks away, according to entomologist Kirby Stafford, is to spray your land with a synthetic pyrethroid insecticide, which offers 95 to 100 percent control, depending on coverage.