

# *Target:* LYME DISEASE

Insects carrying the bacteria will be out in force this summer. Experts tell us how to detect, treat, and thwart the ticking time bomb.

BY AMY PATUREL

**W**hen 12-year-old Kaleigh Ahern was showering before school one morning, she discovered a tick on her shoulder. “She was screaming like Charles Manson was in the shower with her,” says Kaleigh’s mom, Holly Ahern, a professor of microbiology at the State University of New York’s Adirondack campus. “I came running into the bathroom and discovered the tick embedded in her skin, waving its arms and legs. I removed it and took both Kaleigh and the tick to the doctor.”

▼ **Toxic Ticks**  
The ticks that carry Lyme disease can be smaller than a pinhead. And they release numbing compounds so victims don’t know they’ve been bitten.

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The doctor sent the tick to the health department, where it was identified as a black-legged tick, known to transmit Lyme. Ahern assumed the doctor would prescribe antibiotics, given the risk of Lyme disease. Instead, he said the recommended approach was to wait and watch for a bull's-eye rash. He told her that if one appeared, or if Kaleigh developed flulike symptoms, to bring her back.

Kaleigh seemed healthy and went off to college. During her freshman year, she became an NCAA All-American swimmer. But within a week of competing in the Nationals, she became seriously ill. She suffered from overwhelming fatigue and could barely get out of bed for months. She had searing headaches, muscle pain, and brain fog. "She had episodes where she would just lie on the ground writhing in pain, and there was nothing we could do to help her," says Ahern.

The Aherns didn't connect the dots to Kaleigh's tick bite until Kaleigh's father, Kevin, a social studies teacher, attended a presentation at his school about Lyme disease. "As his colleague described her symptoms, my husband realized they were exactly like our daughter's," says Ahern. "So we took her back to the doctor and asked for her to be tested.

The results came back positive for Lyme."

After nearly a year of antibiotics, plus lifestyle changes and some naturopathic treatments, Kaleigh, now 27, has regained about 95% of her health. She still has occasional headaches and muscle pain, but she graduated from college, earned a master's degree in laboratory science, and is now studying to become a nurse practitioner so she can help other people suffering from complex diseases like Lyme.

Kaleigh's illness affected her mother's

career, too. Holly Ahern switched her focus from studying the genetics of a different bacteria to studying the bacteria responsible for Lyme. She only wishes she'd been an expert before her daughter got sick. "If I could go back in time, I would go back to the day at that doctor's office and

say we're not leaving without a prescription for antibiotics. I really believe that if Kaleigh had gotten antibiotics then, none of the rest of what happened to her would have happened."

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Caused by the bacteria *Borrelia burgdorferi*, Lyme disease is already the most frequently reported illness transmitted by insects and arthropods such as ticks in the United States, and the incidence is skyrocketing. In 2012, the Centers for Disease Control and

Even when early symptoms are treated with antibiotics, it's possible the bacteria remain dormant in the body with potential to do damage.



▲ **Life changes from Lyme:** Holly Ahern and daughter Kaleigh found career inspiration from Kaleigh's illness; Randy Gibson had to stop working because of Lyme.

Prevention reported 30,000 cases annually. In 2013, the agency revised the estimate of cases upward to more than 300,000, which would make Lyme the second most common infectious disease of any kind in the United States (chlamydia is the first).

While climate change and the resulting changes in bird migration patterns provide increasingly favorable conditions for ticks, Ahern believes there are additional reasons for the climbing rates of Lyme. Getting bitten by a tick may not be the only way the disease is transmitted. *Borrelia* and other tickborne bacteria are now in the donor blood supply. The pathogens can be passed from mother to child in utero. And some researchers suspect the bacteria can be sexually transmitted, too.

Even worse than the increasing number of cases is that many people with the disease aren't being diagnosed until they've been battling symptoms for months or even years. Misdiagnoses, especially in the early stages, are rampant because blood tests to screen for the disease are notoriously

inaccurate. "That's scary given that Lyme can be a difficult disease to treat, particularly during later stages," says Ahern. Even when early symptoms are treated with antibiotics, it's possible the Lyme bacteria remain dormant in the body with the potential to do damage.

As scientists race to learn more about the disease, doctors are manning the front lines, treating those who are already battling illness. They're hampered by blood tests that are wrong as often as they're right, symptoms that mimic so many other conditions that Lyme is often not suspected, and bacteria that can successfully hide from the drugs prescribed to eradicate them.

### LOOKING FOR LYME

A Lyme-carrying tick may be smaller than a pinhead, and it releases numbing compounds while it feeds, so many victims never realize they've been bitten. If the tick stays attached to the skin and is not removed within a day or two, it will transmit the disease. But still most people won't know they're infected. Within a month of a Lyme-carrying

FROM LEFT: COURTESY OF HOLLY AHERN; COURTESY OF RANDY GIBSON

tick bite, only 10% of infected people develop the target-shaped rash associated with the disease. Half never develop any kind of rash at all. When patients visit their doctors with common symptoms like fatigue and muscle aches, but with no rash and no idea they've been bitten by a tick, many doctors don't even think to test for *Borrelia*.

But even those savvy doctors who do suspect Lyme and order a blood test may be misled by the results. Most popular lab tests for Lyme are inaccurate about half the time in the disease's early stages because it takes weeks for the body to mount an immune response. Until then, there are no antibodies to detect. "So a negative test doesn't necessarily mean you don't have Lyme disease," says Ying Zhang, a microbiologist at Johns Hopkins University's Bloomberg School of Public Health. Without a positive blood test or the telltale bull's-eye rash, Lyme disease's myriad symptoms,

including joint and muscle pain, fatigue, heart palpitations, and memory loss, are vague and could apply to many conditions, explains Richard Horowitz, a Lyme-treating physician in Hyde Park, NY, and author of *How Can I Get Better? An Action Plan for Treating Resistant Lyme and Chronic Disease*.

Trying to diagnose Lyme disease months after a tick bite is just as confounding. Later in the infection, Lyme patients may again test negative because the antibody reaction wanes as the disease progresses. "The longer you have the infection, the harder it is to detect and the more likely doctors are to attribute symptoms to some other condition, like chronic fatigue, fibromyalgia, rheumatoid arthritis, or Alzheimer's disease," says Horowitz.

### TREATING AN ELUSIVE BACTERIA

When doctors catch and treat Lyme early, within the first few months, many

experts believe treatment is straightforward. Public health officials say a 2- to 4-week course of a single antibiotic eradicates symptoms, and relapses are uncommon. But since many people are not treated early for Lyme, studies show that 28 to 50% of patients continue to suffer from fatigue, muscle and joint pain, and "brain fog" after completing standard treatment.

The reason? *Borrelia* is no ordinary bacteria, says Ahern. In the same way a tick burrows into the skin, the corkscrew-shaped *Borrelia* worms its way into tissues that have few circulating antibodies, where it's harder for antibiotics to reach. Although *Borrelia* is bacteria and not a virus like HIV, Ahern likens it to HIV in its ability to hijack the immune system while simultaneously wreaking havoc on every major organ system.

Though public health officials continue to say that therapy with a single antibiotic drug can successfully eradicate the disease, the latest research suggests treating Lyme with only one medication—doxycycline, for example—can sometimes trigger the bacteria to mutate into a more persistent form. In a 2012 study published in *PLOS ONE*, Tulane University researchers reported that monkeys infected with Lyme and then treated with a single antibiotic still had *Borrelia* bacteria lying dormant in their systems months later.

### NEW TESTS, NEW TREATMENTS

Recognizing that current treatments are leaving many people with Lyme

suffering even decades later, doctors are trying new strategies. For instance, while antibiotics are still the frontline treatment for Lyme disease, researchers are learning they may work best in concert. Instead of giving a chronic Lyme patient a single antibiotic for 30, 60, or 90-plus days, they deploy antibiotics in pulses, to trick the persistent bacteria into thinking the chemical assault is over, and then hitting them again when they're off-guard with additional doses or different drugs.

Much of this research is still in laboratory or animal trials, and without a reliable treatment available from conventional medicine, many patients are increasingly turning to integrative treatments and complementary remedies even though there's little research to indicate these therapies may be successful.

Scientists recognize that since antibiotics are currently the only approved therapy for Lyme disease, and antibiotics are effective only during the early stages of disease, successful treatment hinges on developing a replacement for the inaccurate diagnostic tests doctors currently rely on. Right now genetic sequencing is the most promising possibility. A Lyme activist named Tammy Crawford, who founded the patient advocacy organization Focus on Lyme after her daughter's infection, was responsible for convincing researchers that the technology could be useful in diagnosing Lyme.

Crawford spent 5 years shuttling her daughter to doctors across the country.

► ***Borrelia* bacteria in the bloodstream:** The bacteria that causes Lyme is a master at hiding from the drugs prescribed to eradicate it.

KATERYNA KON/SCIENCE PHOTO LIBRARY/GETTY IMAGES





◀ **The characteristic Lyme rash** is target-shaped, but it appears on only 10% of people within a month of a tick bite.

If continued trials are successful, Crawford says the test could be available as early as 2018.

Until accurate tests and effective new treatments are widely available, advocacy groups and patients themselves are trying to raise awareness of the disease. First comes preventing Lyme infection by wearing light clothing (so ticks can be detected more easily and removed before they reach skin), using insect repellent, checking skin after being outdoors, and removing ticks quickly when found. Next is educating people to recognize the signs of Lyme disease early and go for help when current treatments have the best chance of success.

That awareness came late for Lyme sufferer Randy Gibson, 60, but it was still critically important. Gibson has been battling Lyme disease since he lay down in the grass while traveling in New York almost 30 years ago to marvel at the trees' changing leaves. "I never felt a tick bite," says the former pastor and father of three. "I just got sick." Five days after his idyll in the grass, a bull's-eye rash appeared a few inches below his right elbow. About a month later, he experienced minor muscle aches and pains followed by debilitating fatigue. Gibson lives in California, and although his primary doctor did suspect Lyme, his diagnosis was dismissed by the medical director at the facility where he worked, who—not knowing anything

about the trip to New York and the tick bite—said there was no Lyme disease in California. Gibson was told he probably had the flu, but his symptoms kept getting worse. Months later he suffered a crippling headache and went to an urgent care facility. A doctor there began caring for Gibson, and after several months began to suspect Lyme. Finally Gibson got the correct diagnosis.

But because Gibson's disease was diagnosed so late, his symptoms have persisted. In 1991, he was forced to give up his job and go on disability. Every morning he wakes up feeling exhausted, no matter how long he's slept. Once out of bed, he faces an assortment of ailments ranging from debilitating headaches and difficulty concentrating to severe muscle and joint pain. He suffers from depression, too. "I have to deal with the loss of my career as well as the loss of many things I used to enjoy but no longer have the strength and stamina to do," says Gibson, who has spent his life savings on treatments.

But this story has a happy ending—at least for the next generation. At a 2003 family reunion on the Chesapeake Bay, Gibson's family members checked each other for ticks every night. But

within a few days of returning home from their trip, Gibson's then 10-year-old son developed three bull's-eye rashes from his waist to his shoulder. When the pediatrician didn't recognize the signs of Lyme disease, Gibson was ready with the answer. He convinced the doctor to write a 2-week prescription for the antibiotic doxycycline, and Gibson's son has remained symptom-free ever since. "Luckily, we knew what to do," says Gibson. "The saving grace in all of this is that my diagnosis saved my son from long-term suffering." 🐾



## WHEN TO SUSPECT LYME

### TYPICAL EARLY SIGNS AND SYMPTOMS (ALTHOUGH SYMPTOMS CAN OCCUR AT ANY TIME)

- ▶ Fever, chills, muscle and joint pain, and other flulike symptoms
- ▶ Fatigue
- ▶ Erythema migrans (target-shaped) rash at the site of the bite
- ▶ Headache or stiff neck

### TYPICAL LATER SIGNS AND SYMPTOMS (ALTHOUGH SYMPTOMS CAN OCCUR AT ANY TIME)

- ▶ Severe headaches and neck stiffness
- ▶ Additional target-shaped rashes on other areas of the body
- ▶ Arthritis-like swelling and pain, particularly in knees and large joints
- ▶ Shooting pain, numbness or tingling in the hands, feet, or back
- ▶ Inability to control facial muscles, or facial palsy, which causes the face to droop
- ▶ Heart palpitations or an irregular heartbeat
- ▶ Dizziness
- ▶ Shortness of breath
- ▶ Nerve pain
- ▶ Problems with short-term memory

ANASTASIAKOPA/SHUTTERSTOCK