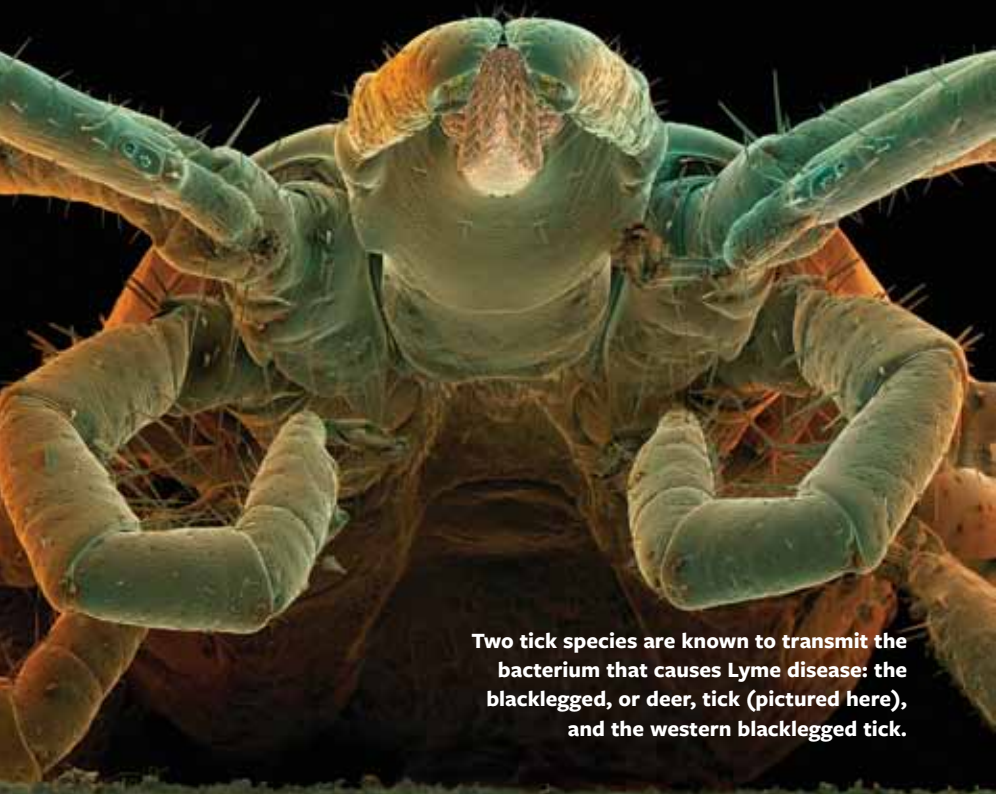


UNDER THE SKIN



Two tick species are known to transmit the bacterium that causes Lyme disease: the blacklegged, or deer, tick (pictured here), and the western blacklegged tick.

NEARLY EVERYTHING ABOUT LYME DISEASE IN CANADA IS CONTESTED. FRUSTRATED AND CONFUSED, SUFFERERS JUST WANT THE NIGHTMARE TO BE OVER.

BY LIA GRAINGER

Cathy Kirkland* first noticed it in the summer of 2003: a large red inflammation spreading outward from her left ankle in a horrible bull's-eye pattern. She was only 16 at the time, an athletic teenager with an insatiable love of nature. "My life revolved around the outdoors," says Kirkland, now 23. She'd taken a summer job as a junior forest ranger in southern Alberta's Crowsnest Pass, near the American border, but it wasn't until she returned to her home near Legal, Alta., that the rash appeared. "I thought it was simply a bad bug bite."

In the months that followed, Kirkland's leg and foot became so swollen, she couldn't wear a shoe. The skin was red and hot to the touch. She visited a hospital: Doctors told her to purchase an over-the-counter cream. She did. The cream did nothing. The swelling eventually receded. Life went on.

But after a few months, Kirkland noticed her body becoming weak: "It felt as if my mind wanted to be active,

(OPPOSITE) DAVID SCHARF/GETTY; (TARGETS) ISTOCKPHOTO

* Name has been changed to protect privacy.

but my body just wouldn't let me." A family doctor referred her to multiple specialists. Eventually, she was diagnosed with blood clots and was put on medication. But her fatigue worsened and she was forced to cut back on sports and other physical activity.

"Doctors had no answers, and I was bumped from one hospital to the next," says Kirkland. Several physicians thought her symptoms pointed to multiple sclerosis (MS) and treated her for that. "To be told you might have MS at 17 is like a death sentence," she says. "I lived in hospitals and on medication. My life turned into nothing."

When the steroids Kirkland was prescribed for MS had no effect, her family's online research led them to suspect that she had Lyme disease. "We mentioned to a neurologist that my symptoms were similar, and she looked at us and laughed," says Kirkland. "She assured us that we don't have Lyme disease in Canada."

Named after the Connecticut town where it was first diagnosed, Lyme disease is caused by the bite of a tick infected with the bacteria *Borrelia burgdorferi*. It is the most common vector-borne disease (a disease transmitted by an organism such as a mosquito or tick) in the United States, with over 28,921 confirmed American cases in 2008. Yet in Canada, public-health officials claim that cases hover around 20 to 60 a year. It's a figure that doesn't sit well with the myriad Lyme disease support and advocacy groups that have sprung up across the country in recent years. Members of these groups

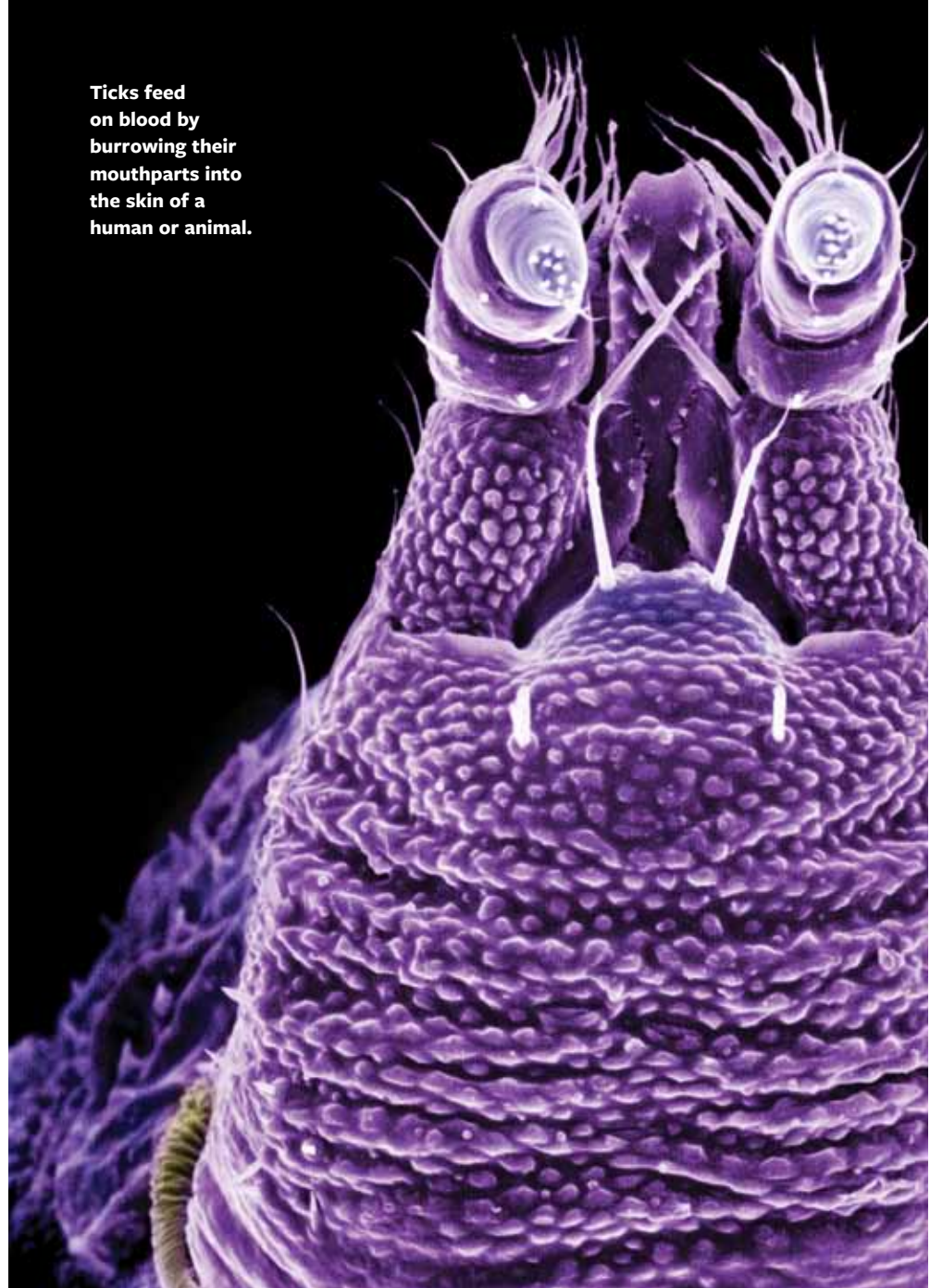
question the reliability of statistics that seem to imply that ticks stop at the border. They claim Lyme disease in Canada is a silent epidemic.

"I think in ten or 15 years, when the tests improve and there's better medical knowledge, the health authorities will look back on this period in time and be shocked," says Gwen Barlee, a British Columbia Lyme disease advocate and former patient. "I think Lyme disease is going to be far more widespread than doctors anticipate or acknowledge, and they're going to have a real medical problem on their hands."

From prevalence and research to diagnosis and treatment, nearly everything about Lyme disease in Canada is contested. Aside from the cause of the disease, there are only a few basic facts on which most doctors, researchers, advocacy groups and patients can agree: Early symptoms tend to include fatigue, fever, chills, headache, muscle and joint pain, swollen lymph nodes and "erythema migrans"—a rash at the site of the bite that can appear in the form of a bull's eye.

If diagnosed early, Lyme disease can usually be treated with a single course of antibiotics lasting from two to four weeks. But if it goes undetected, Lyme disease can lead to arthritic symptoms, heart palpitations, multiple skin rashes, extreme fatigue and central and peripheral nervous-system disorders. Untreated patients in later stages can become severely incapacitated. And because the symptoms so closely

Ticks feed on blood by burrowing their mouthparts into the skin of a human or animal.



VEER

MANY CANADIAN PATIENTS SEND THEIR BLOOD TO AMERICAN LABORATORIES AT THEIR OWN EXPENSE. THE RESULTS OFTEN COME BACK POSITIVE WHERE OTHER BLOOD TESTS HAVE NOT.

mimic other conditions—multiple sclerosis, Parkinson’s, arthritis and Crohn’s disease, to name only a few—patients are often misdiagnosed and receive unnecessary treatment and even surgery.

Yet early diagnosis is nearly impossible, according to Jim Wilson, founder of the Canadian Lyme Disease Foundation (CanLyme). “The first problem is the ELISA test [enzyme-linked immunosorbent assay],” he says, referring to the primary blood serum test recommended by the Canadian Public Health Laboratory Network to identify Lyme disease. The problem, he explains, is ELISA’s accuracy: Researchers complain it often produces a falsely positive result. Chronic sufferers, on the other hand, claim it often turns up false negatives for them. “Everyone knows ELISA is a joke,” says Wilson.

Another problem is the prevalence of the rash, or erythema migrans. The Public Health Agency of Canada says that 70 to 80 percent of those infected get it. However, statistics from some U.S. state health departments, including Connecticut’s, found the rash to be present in only 35 to 59 percent of Lyme patients.

Wilson, who founded CanLyme after battling the disease in the 1990s and experiencing years of misdiagnosis, says Lyme should be diagnosed by looking at “global symptoms”—a combination of neurological, cardiological and fatigue problems. He would also like doctors to let go of the idea that the illness can only be contracted in certain areas of the country. He mentions a 2009 paper titled “The Emergence of Lyme Disease in Canada,” in which leading Lyme disease experts predict climate change will accelerate

the spread of infected ticks. The study also notes there are tick populations in Nova Scotia, New Brunswick, Manitoba and Quebec—not just in Ontario, as previously thought. But perhaps most startling is the discovery that ticks can be carried and spread by migratory birds. “It means you can get it anywhere in Canada,” says Wilson.

However, Nicholas Ogden, a researcher at the Public Health Agency of Canada and lead author of the 2009 paper, says that while there are more ticks in Canada than in previous years, this doesn’t necessarily translate into a huge increase in Lyme disease. “It’s easier for the tick to become established than the *Borrelia burgdorferi* bacteria,” explains Ogden. “It can take years for the infection prevalence to rise.” He maintains that the percentage of the tick population carrying Lyme is still much higher in the United States. “We certainly aren’t seeing the risk that exists somewhere such as Rhode Island,” says Ogden.

Like most Canadian Lyme disease researchers, Ogden is reluctant to comment on the work of organizations such as CanLyme. “I think they raise positive and negative issues,” he says. “They provide basic messages about protection, but some of the information they put out there is not correct.”

People often come to CanLyme sure they have Lyme disease, but unable to get a positive diagnosis. Jim Wilson’s advice? Head south. “The testing methods of some of these U.S.

labs are much better,” says Wilson. He refers to privately run testing facilities—the most popular is IGeneX—that specialize in diagnosing tick-borne illnesses. IGeneX runs four separate tests for Lyme, including a DNA test that is not used in the Canadian testing protocol. Many Canadian patients send their blood to these laboratories at their own expense, and the results often come back positive where other blood tests have not. Ogden believes much of the Canadian controversy surrounding the disease is rooted in these American testing facilities. He argues that urging patients to send their blood to the States in search of a positive diagnosis spreads doubt about Canadian tests. “A few of those people probably have Lyme disease,” says Ogden, “but some of them likely don’t, and they’re being sent down the wrong path.”

Muhammad Morshed, a clinical microbiologist at the BC Centre for Disease Control, contributed to the Canadian diagnostic guidelines. “Our tests are safe and quality assured,” he says. He joins Ogden in warning against testing at private laboratories and points out that Canada’s two-tiered testing method—an ELISA test followed by a second test, called a “Western blot”—is also the protocol recommended by the Centers for Disease Control in the United States.

A 1997 study on the effectiveness of this two-tiered system suggests it will correctly identify those who are actually infected with Lyme disease 75 to 93 percent of the time. However, about



An infected tick transmits the *Borrelia burgdorferi* bacterium via its saliva.

55 percent of healthy individuals will also test positive using this method.

Morshed admits it is an imperfect system. “There are a lot of scientists working on finding a better test,” he says, adding that current research suggests a future test might be able to better identify cell-surface proteins to deliver more accurate results. “But test development takes time. Like all aspects of this disease, its diagnosis is complicated.”

In the meantime, can Lyme sufferers afford to wait? “The reality is that while they work to come up with a better test, there is a ton of collateral damage,” says Wilson. “The evidence is there already, if they look.”

Cathy Kirkland wasn’t diagnosed with Lyme disease until she’d been sick for 2½ years. She’d pleaded with doctors to test for it, but no one felt it was merited. Needing a clinical diagnosis, her family decided to seek out the help of a Lyme-literate doctor (LLMD)—a physician who believes in the prevalence of Lyme disease and the need for treatment with powerful drugs over the course of several months or years.

Kirkland’s family contacted Dr. Ernie Murakami, one of the most well-known and controversial LLMDs in Canada. He diagnosed her with chronic Lyme disease—a term used by LLMDs to denote a persistent *Borrelia burgdorferi* infection—even though the test the family had paid IGeneX \$800 for had come back indeterminate.

“I do remember questioning

whether this was an American corporation looking to make money from their patients,” says Kirkland of the test. “I began to realize health care is an industry like any other. It made me less receptive.” Still, she was willing to try anything that would make her well, and so in July 2006 she began Murakami’s recommended treatment of long-term antibiotics.

Not every Canadian patient is able to find a physician as sympathetic as Murakami. Shannon Goertzen, 38, of Richmond, B.C., has been fighting Canadian doctors for the past four years to get long-term antibiotic treatment for the chronic Lyme disease she says she and her two sons, Taylor, 18, and Parker, 11, suffer from.

They’ve been diagnosed by Dr. Steven Harris, an LLMD in Redwood City, Calif., who has treated over 3,000 patients for the disease. Despite Harris’s diagnosis, Goertzen says physicians at the B.C. hospital where she and her sons are being treated have been very reluctant to treat her younger son, who now uses a wheelchair. “I’ve heard doctors say to Parker flat out, ‘Lyme is a serious disease, you have a life-threatening infection, but I’m not willing to risk my licence to treat you,’” says Goertzen.

And while Parker’s pediatrician and neurologist acknowledge his improvement on the oral antibiotics he’s been taking, Goertzen says, they refuse to continue to prescribe them, despite Harris’s recommendations. At Goertzen’s request, Parker’s pediatrician asked eight other doctors if they

would write the prescription, but all declined. After much searching, Goertzen has finally located a Canadian doctor who is willing to follow Harris's recommendations for her personal prescriptions, but only if she promises to conceal his identity.

Doctors publicly treating Lyme disease with long-term antibiotics have good reason to fear for their licences. Murakami retired in 2008 after the College of Physicians and Surgeons of British Columbia repeatedly challenged his diagnosis and treatment methods of the disease. Two years later, Dr. Jozef Krop, an LLMD in Ontario, also chose to retire instead of continuing to deal with what he describes as persistent hassling from the College of Physicians and Surgeons of Ontario over his treatment methods of Lyme and other controversial diseases.

Those doing the reporting and investigating of LLMDs cite concerns about the misuse of antibiotics, and point to the complete absence of peer-reviewed literature that proves long-term antibiotic treatment for Lyme disease works. And the risks associated with antibiotic overuse are well-documented: It can lead to serious and possibly fatal blood infec-

tions, adverse drug reactions and the creation of antibiotic-resistant bacteria (superbugs) that could seriously harm the general population.

But, for the small number of LLMDs operating in North America, the perceived benefits of long-term treatment outweigh the risks. "Once you know what's going on, it's hard to ignore it," says Dr. Maureen McShane.

An American LLMD, McShane practises in Plattsburgh, N.Y., where she is licensed, but she lives in Montreal. After becoming infected with Lyme disease in 2002, McShane personally witnessed the inability of doctors in Canada and the United States to recognize and treat the condition. Though her practice is south of the border, roughly 80 percent of her patients are Canadian.

"By the time they come to me, they're about 100 percent sure they've got it, and when I listen to their stories, I know they have it," says McShane, who bases her patients' diagnoses primarily on clinical symptoms. She says many of her patients have visited dozens of doctors before seeking her out.

Jennifer Sierzant, 44, of LaSalle, Que., is one of McShane's Canadian patients. "Do I have Lyme? She diagnosed me with it," says Sierzant of McShane's verdict. "I had to go with that because I was sick and I had to try something. But I always wanted to see something for Lyme like a pregnancy test: You're either pregnant or you're not."

Sierzant has her doubts about the disease's prevalence. "I think a lot of



DOCTORS PUBLICLY TREATING LYME DISEASE WITH LONG-TERM ANTIBIOTICS DO SO AT THE RISK OF LOSING THEIR LICENCES.

people probably don't have Lyme disease and are being told they do," she says. "They say they have it because they don't want to accept another diagnosis."

Cathy Kirkland also grew to have doubts about the disease and its treatment methods. In the summer and fall of 2006 she took several different antibiotics prescribed by Murakami and experienced immense improvement. "It was as if I'd missed out on three years of my life and finally had it back. It was amazing."

Thanks to her turnaround, she was able to begin her bachelor's degree in environmental science at the University of Lethbridge. By that time she had researched the mechanisms of the drugs she was taking and began to question their value. "I realized long-term antibiotics could do more bad than good," says Kirkland. With the help of a naturopathic doctor, Kirkland weaned herself off the medication without the disease returning.

Today, she works as a municipal-planning intern in Alberta's Wetaskiwin County.

Reflecting on her experience, Kirkland sees the Lyme disease debate in Canada as a double-edged sword: "On the one hand, we've put a lot of trust in our doctors. We need to question what we're being told and take responsibility for our own health. On the other hand, doctors *should* be trusted—they've studied the body more than anyone. But everyone is human, everyone makes mistakes."

"Ultimately, I don't know if I ever had the disease," says Kirkland. "Dr. Murakami said I did."

One thing seems clear: There is a dire need in Canada for more research into the illness. At the moment, only \$820,000 over five years has been specifically allotted to the disease by the federal government—to study the tick. Until we know more about Lyme, patients such as Kirkland will remain in the dark about the nature of their illness. ■



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