



## **The truth about Lyme disease**

Lyme disease can masquerade as MS, ALS, even dementia, and its numbers are growing. So why is Canada lagging behind in treating it?

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**In this piece from our archives, senior writer Anne Kingston examines the science and politics around Lyme and its treatment. In July 2014, she posted this [update](#).**

For decades, Gabriel Magnotta, the well-known Ontario wine-industry firebrand, went hunting with a group of friends. These expeditions took them into the wilds of almost every Canadian province. In time, three of the men would share something else: symptoms associated with “neurological” diseases—numbing of limbs, tremors, dizziness. Two were diagnosed with Parkinson’s when only in their 40s. Magnotta—co-founder with his wife, Rossana, of Vaughan, Ont.-based Magnotta Winery—was not as readily diagnosed. He began having balance problems in 2003, but test after test in Canada and the U.S. came back negative. Meanwhile, his health deteriorated: He had difficulty walking and talking, cognitive fog, double vision and intense joint aches.

In 2005, Rossana, who studied microbiology and worked as a lab technician early in her career, chanced upon a newspaper story about Lyme disease, an infection spread by ticks carrying the bacterium *Borrelia burgdorferi*. She read that the corkscrew-shaped microbe, a spirochete, can drill through tissue, then embed itself in the central nervous system, heart, brain, liver, spleen and joints, resulting in a raft of symptoms ranging from dizziness to paralysis. Lyme could explain Gabe’s symptoms, she realized, as she recalled seeing bites on his legs after hunting trips. The fact that the condition was treatable with antibiotics buoyed her: “I thought, ‘Finally this could be the answer,’ ” she says.

But getting Gabe Magnotta diagnosed and treated for Lyme would be an arduous journey, one that took the couple across continents and into an acrimonious medical debate. Lyme treatment guidelines, set by the Infectious Disease Society of America (IDSA), assert that the infection usually manifests in a bull's-eye rash and is readily diagnosed through two-tiered blood testing: the ELISA (an enzyme-linked immunosorbent assay), then Western blot. Recommended treatment is oral antibiotics over several weeks. But Magnotta never had a rash; an ELISA taken in Canada came back negative. Further testing in the U.S. and Europe in 2006, however, confirmed Lyme. In Germany, he was told he also had three co-infections, also transmitted by tick bite, and was treated with an IV antibiotic not available in IV form in Canada. The Magnottas then found an American doctor experienced in treating chronic Lyme. Treatment was aggressive because diagnosis had taken so long, Rossana says: "Gabe had 45 sessions of hyperbaric pressure, trying to get antibiotics deep into his tissue." By August 2009, he'd finished treatment and was on the mend, able to walk over a kilometre a day. Then, in December, he died suddenly of a heart attack. He was 59.

Discussing Gabe's plight, Rossana, now president and CEO of the family winery, expresses sorrow and a steely fury. "The Canadian health care system failed my husband," she says, sitting in her office surrounded by a lifetime of awards and family portraits. "He only had an infection, and the infection should have been addressed in a country like Canada. But he suffered unbelievably. And I suffered watching him." Heart failure was a known risk, given how weak his system had become, she says, adding that one neurologist wasted a year and a half investigating a "genetic condition": "He sent us down a path that cost Gabe's life."

The experience has transformed Rossana Magnotta into an activist. Last year, she founded the G. Magnotta Foundation for Vector-Borne Diseases, which is funding Canada's first facility dedicated to the research, testing and treatment of Lyme. It is slated to open in the fall of 2015 in the redeveloped Humber River Hospital. Solid, peer-reviewed research is needed, says Magnotta, who calls Canadian testing "a joke." Animals are tested more thoroughly, she learned, when her dog received a routine Western blot at the vet: "Now, I love my dog," she says, "but I love my husband a lot more. And I could not get a Western blot [for him] in this country if I cried or screamed or paid for it."

Doctors aren't to blame, she says: "They don't know what to look for." Canadian medical students are taught about tropical infections such as malaria, yet bacteria in their own backyard are ignored, she says: "We are a country of valleys and trees and forests; we need to be talking about Lyme."

Magnotta joins a rising chorus of alarm about Lyme, and other vector-borne infections, one now being debated on Parliament Hill. Green Party Leader Elizabeth May's private member's bill, C-442, which saw second reading last week, calls Lyme a "national crisis" and proposes a "made-in-Canada strategy" to deal with it. The bill has all-party support and the backing of the Canadian Medical Association. That isn't surprising. Chronic Lyme may not be a bona fide medical diagnosis, but most Canadians know someone touched by it, or have heard the harrowing stories of high-profile victims, such as writer Amy Tan and singer Kathleen Hanna. Advocacy groups, led by the [International Lyme and Associated Diseases Society](#) (ILADS) have called Lyme an unacknowledged epidemic for decades, one that leads to nerve damage, immune dysfunction, neurological deficits and miscarriage. ILADS rejects IDSA guidelines, saying a bull's-eye rash often isn't present, and clinical presentation can be blurred by co-infections, including chlamydia and babesiosis. *Borrelia burgdorferi*, they note, can lurk undetected in blood in a cystic form. All have potentially catastrophic consequences for public health. "Lyme-literate" doctors treat chronic Lyme with antibiotics over months, even years, often via IV—an approach the ISDA argues is "dangerous" and can lead to life-threatening allergies, liver damage, IV line infections and antibiotic resistance.

#### **Update via Anne Kingston: [Health Canada's new Lyme 'action plan' — you act, we'll watch](#)**

The result has been a medical standoff—and an underground Lyme treatment network that sees Canadians travelling to the U.S. and paying upward of \$50,000 for treatment. All Canadian doctors who are vocal about treating chronic Lyme have been shut down, says Jim Wilson, president of the [Canadian Lyme Foundation](#). "But you'll never find they've been shut down because of Lyme, specifically." Ernie Murakami, a physician based in Hope, B.C., who treated more than 6,000 people for Lyme directly and with other doctors, relinquished his medical licence in 2008 after what he calls "constant harassment and investigation" by the B.C. College of Physicians and Surgeons. Murakami, who now runs a foundation, lectures and directs patients to doctors willing to treat, doesn't understand the resistance: "When it comes to chronic Lyme, there is pathological denial."

The U.S., which has reported on Lyme incidence since 1991, has shown greater willingness to research and treat the disease (though doctors there have been disciplined). Seven U.S. states now permit doctors to treat Lyme with long-term antibiotics. Last year, a U.S. Centers for Disease Control and Prevention study reported that Lyme is far more prevalent than thought: 300,000 Americans are diagnosed each year—10 times higher than reported—making it a “tremendous public health problem.” The U.S. government earmarked funds in its last budget to research Lyme, with focus on “long-term complications” and developing “sensitive and more accurate” tests.

Similar urgency is not evident in Canada, where public health officials speak as if the bacteria and the vectors that spread it respect national borders. The Public Health Agency of Canada (PHAC) reports 833 cases since reporting began in 2009. CanLyme’s Wilson says incidence is “seriously under-reported,” noting his organization gets 3,000 new inquiries a year. Physician Geoffrey Taylor, the chair of PHAC’s Canadian Nosocomial Infection Surveillance Program, agrees that the rise from 128 cases in 2009 to 315 in 2012 is concerning. But he defends current protocols: “Based on what the evidence shows us, physicians in Canada are doing the best job they can,” he says. U.S. lab tests for Lyme are “invalidated,” he says, noting that “post-treatment Lyme disease syndrome,” the term given to those who experience symptoms after being treated with short-term antibiotics, requires research: “We don’t know what’s behind it,” he says. “It could be the immune system; it could be a number of factors. That’s typical when new diseases are emerging.” A PHAC spokesman likewise downplays risks of co-infections: “Although some cases have been identified in the northern U.S., the risk to Canadians is low,” says Robert Cyrenne.

A far more dire picture emerges in a 2010 policy paper from the Provincial Health Services Authority, by Brian Schmidt, its senior vice-president. The study, never released publicly but unearthed in an Access to Information search and available online, is a critical assessment that concludes Lyme diagnosis and treatment is “inadequate.” (Schmidt did not respond to interview requests.) A 2012 Health Canada bulletin also sounded the alarm, reporting that Lyme tests have “sensitivity and specificity limitations” and “should not be the primary basis for making diagnostic or treatment decisions.” It also reported 24 cases of “false negatives.”

That fact puts people with Lyme-like symptoms at real risk of misdiagnosis, says Magnotta. Lyme, dubbed “the great pretender,” mimics other conditions for which there is no known cause or cure, including fibromyalgia, multiple sclerosis, dementia, lupus, bipolar disorder and amyotrophic lateral sclerosis, or ALS. Many patients came to Murakami diagnosed with other conditions, he says, adding that 21 were in wheelchairs, which they no longer needed after treatment.

The centre funded by Magnotta’s foundation will house Canada’s first bio-repository, or human tissue bank, to test people who fit the Lyme profile. “That way, people will be able to get immediate help,” she says. Billions of health care dollars are being wasted, she believes, on revolving-door doctors’ visits and misguided treatments, tests and medication, which includes addictive painkillers, steroids, anti-depressants, sleeping pills and anti-psychotics: “My husband drained a lot of money out of health care. If we had just tested him the right way, we would have been way ahead.”

But the price isn’t only financial, evident in the dilemma faced by Arielle Arnold-Levene in November 2010: whether to follow doctors’ orders and undergo chemotherapy for a mysterious, degenerative condition, or pursue Lyme treatment in the U.S. The 24-year-old fourth-year University of Toronto history student first experienced odd symptoms that summer: She was tired and irritable; then the right side of her body went numb and her vision blurred. Up until then, she’d never been seriously ill or even taken antibiotics. Emergency room visits and neurologist consultations yielded no answers: “This was making sense to no one,” she says.

Even so, she underwent two gruelling rounds of steroids and a course of intravenous immunoglobulin. Her health declined; by the fall, one foot was paralyzed and she was experiencing electrical shocks down one side of her body, forcing her to quit as editor-in-chief of the school’s *American Studies Undergraduate Journal* and cut back on classes. A neurologist finally diagnosed her with “atypical aggressive multiple sclerosis” and told her to select an MS drug. When her symptoms worsened, Arnold-Levene was admitted to hospital for more tests, and possibly a round of chemotherapy. “They didn’t know what was happening,” she says. “They wanted to put me on drugs, but they don’t know.”

Lyme was ruled out early on after a negative ELISA. (Arnold-Levene recalled seeing a tick on her in New Hampshire in 2009.) But her father, a former university professor, continued researching Lyme, even after subsequent tests sent to a California lab came back inconclusive. Leaving the hospital was difficult, Arnold-Levene says. One infectious diseases specialist told her she could contract potentially fatal sepsis from the IV. He also warned her of unscrupulous players: “He said, ‘If they look for Lyme, they’ll find Lyme.’”

But she did leave to consult with Maureen McShane, an American doctor who lives in Montreal and practises in Plattsburgh, N.Y. McShane began treating Lyme after contracting it in the Laurentians in 2002. It took her almost a year to be diagnosed (one doctor said it was menopause), and two years to treat. Since then, she has treated more than 300 Canadians, many of whom are angry: “They’re incensed they’re paying for health care and being denied treatment,” she says.

McShane confirmed that Arnold-Levene had Lyme and co-infections, and sent her to a doctor in Washington, who put her on six months of IV antibiotics. The total treatment cost \$30,000, says Arnold-Levene, who reports she’s now in good health and completing her masters at the University of Waterloo. She thinks about what her life would be like if she’d had chemotherapy, she says: “It wouldn’t be good. I don’t think I could have recovered.” Murakami agrees: “Steroids are the worst thing to give any infection,” he says, noting the result can be a Catch-22: “People with an MS diagnosis who have Lyme will get worse, which is chalked up to natural disease progression.”

Richard Horowitz, a physician in New York’s Hudson Valley who has treated more than 12,000 people with tick-borne illness over the past 25 years, sees current foundering over Lyme as symptomatic of a deeper medical crisis: the inability to deal with chronic diseases, which account for 70 per cent of deaths, and the lion’s share of health care costs.

It's a topic Horowitz tackles in his 2013 book *Why Can't I Get Better: Solving the Mystery of Lyme & Chronic Disease*, which claims the medical system is primed to provide care for acute conditions, such as heart attack and urinary tract infections, but not complex chronic illness. He blames "Pasteur's postulate"—the "one germ, one disease" model taught in medical school. "Everyone is thinking in black and white," Horowitz says in an interview with *Maclean's*. But chronic illness is "multi-modal," he says—with overlapping and compounding bacteria, protozoa, fungi, viruses and parasites. He calls for a "paradigm shift" in the form of his proposed "16-point differential diagnostic map" that assesses various contributors to chronic illness, among them sleep disorders, autonomic nervous system dysfunction, allergies, gastrointestinal disorders and liver dysfunction. Treating Lyme is not a one-step process, Horowitz says: "Patients with toxins, and/or adrenal or nutritional insufficiencies will never get well until all of those problems are addressed, too."

Tick-borne infections are destined to affect future generations, Horowitz says, citing the arrival of *Borrelia miyamotoi*, a bacterium identified by the CDC last year that's known to cause dementia-like symptoms and fetal death. He wants to see pregnant women tested for Lyme, because it has been shown to be transmitted to a fetus. Much remains unknown about Lyme, Horowitz says, including transmission. Medical research, including a 2011 study in *Annals of Internal Medicine*, shows tick-borne infections from blood transfusions on the rise; last year, the CDC sent out an advisory calling babesia in the blood supply a "risk." Canadian Blood Services (CBS) allows people treated for Lyme to donate blood six months after exposure to tick bites, provided they "feel completely well" and are off antibiotics. Yet, people who have had malaria or have been diagnosed with MS cannot donate, and CBS asks prospective donors if they've had babesiosis, a Lyme co-infection that's difficult to detect. CBS spokesman Marc Plante says the risk of contracting Lyme through blood is only theoretical. "To date, no case of transfusion transmission of Lyme has ever been documented." Such claims do not reassure Murakami, who recently refused a blood transfusion after surgery to get his iron levels up. "I'm taking a risk of hepatitis and HIV, but also co-infections of Lyme," he says. McShane is also adamant: "Unless I was almost dead, I would not accept a blood transfusion and, even then, it would be a difficult decision," she says.

New research suggests blood may not be the only conduit. A study in the January 2014 *Journal of Investigative Medicine* found *Borrelia burgdorferi* in vaginal and seminal secretions of people diagnosed with Lyme, suggesting it could be sexually transmitted. One of the researchers, Calgary microbiologist Marianne Middelveen, began researching Lyme after being diagnosed and treated for it after decades of debilitating symptoms.

Stories of delayed diagnosis are common, says Magnotta, who expresses concern about anyone diagnosed with a “neurological” illness of unknown etiology. “A percentage, for sure, has some sort of borreliosis,” she says, noting studies have found the Lyme spirochete in the brains of Alzheimer’s patients. Magnotta recalls visiting an ALS clinic at a hospital where a doctor told her some patients had been in treatment for 25 years. She was shocked, given the average ALS lifespan is three to five years; she suggested they’d been misdiagnosed and should be tested for Lyme. “He ignored me,” she says. When she learned that two of her husband’s hunting buddies had been diagnosed with Parkinson’s, she felt a similar pang, she says: “Nothing I could say would be welcome.” Looking ahead, however, she expresses determination to confront a stealthy, pernicious foe. “I need to make sure my husband didn’t die for nothing.”