

Ticking Lyme bomb

Increased awareness of Lyme disease among health professionals will help alleviate some of the suffering associated with the illness.

BY DANIEL PUNCH

In tears, Sue Faber pleaded with her doctor to give her one more chance.

“Please,” she implored during a July 2015 appointment. “Is there anything else you can think of that might be wrong with me?”

For 14 years, Faber, a Burlington RN with expertise in both emergency and community case management, had struggled with mysterious and debilitating symptoms. She had seen half-a-dozen specialists who put her through every test imaginable. Each one came back negative.

In 2015, she was juggling a part-time job, a master’s degree program, and three frequently sick young children. She was desperate for answers.

Reluctantly, her doctor agreed to order one more round of blood work. She handed Faber the requisition form, then immediately took it back. We may as well add Lyme disease, she said, since there was so much hype in the media.

Faber admits she didn’t know much about Lyme disease at the time, and doesn’t remember learning about it in nursing school. She didn’t realize it then, but her doctor’s last-second decision was a breakthrough in her long journey toward a diagnosis. It would eventually lead to treatment that relieved her symptoms, but not before she spent thousands of dollars and felt she was failed by the Canadian health-care system. It would also thrust her and her

family into a heated controversy about the nature and transmission of Lyme disease, and inspire her to rally together other nurses to advocate for Lyme sufferers.

The arrival of warmer weather in Canada didn’t always trigger media hype about Lyme disease, an infection reported to be caused by the *Borrelia burgdorferi* bacteria, typically transmitted to humans via tick bites. Until the 1990s, Lake Erie’s Long Point Provincial Park was the only area in the country with ticks carrying the bacteria. But rates of Lyme infection have risen dramatically in recent years – from 143 in 2010 to nearly 1,000 in 2016, according to the Government of Canada – and infected ticks have spread across the country.

Public health authorities are now warning Canadians to be on the lookout for signs of a tick bite, including a round, red “bullseye” rash. A resulting Lyme infection could come with symptoms like extreme fatigue, fever, headache, heart problems, and issues with short-term memory. As Lyme becomes more prevalent in Canada, patients and health professionals are questioning whether education and awareness about the disease have kept pace. Many Canadian health-care providers have little or no experience with patients who have Lyme disease, and the two-stage blood test commonly used to diagnose it has been criticized as inadequate by sufferers of the illness, as well as some specialists.

Faber doesn’t recall ever having a tick bite or bullseye rash, so it was surprising when her blood test came back positive for Lyme disease. Her doctor was also surprised, telling her it was almost surely a false positive. But when Faber began researching the disease, it all finally added up. The crushing fatigue that made her collapse after coming home from work, the pain that migrated all over her body, and the “brain fog” that sometimes made it tough to remember her kids’ birthdays – these were all common symptoms.

Faber says she spent the next few months dealing with skepticism and outright dismissal from the Canadian health-care system. On the advice of other Lyme sufferers, she paid to see an American doctor who sent her blood to Germany for testing that came back positive. Unfortunately, the Canadian medical community disagreed. She was referred to an infectious disease specialist who confidently told her she did not have Lyme disease and recommended she try yoga and meditation to help alleviate her symptoms.

Faber continued advocating and eventually a diagnosis of late-stage chronic Lyme disease was confirmed by her Canadian infectious disease doctor. She began antibiotic treatment in January 2016, and her symptoms eased almost immediately. She felt hope for the first time in years that she would get better.

Unfortunately, that hope was short-lived. Within six weeks of her treatment ending, the



Sue Faber (left) and Catherine Kinsella pour over research materials to support their ongoing work on Lyme disease.

“

We *listen* to our patients, we *advocate* for our patients, and we *care* for our patients. I believe we, collectively, can be a **BEACON OF HOPE** for Lyme sufferers, and we can also be a **VOICE FOR CHANGE**.

– SUE FABER

”



Sue Faber (left) has been back and forth to Ottawa to push for change with LymeHope co-founder Jennifer Kravis.

symptoms returned. She went back to her Canadian infectious disease specialist hoping for another course of antibiotics. Instead, she was told she was cured, the treatment was over, and her symptoms were no longer caused by Lyme.

Frustrated, Faber chose to pay for additional antibiotic treatment in the U.S. She has been taking antibiotics on and off since April 2016, and says her symptoms have improved to the point where she can function and work part-time as an RN care co-ordinator. Though she feels better, she is dismayed by how Canadian doctors refused to accept she could have Lyme disease, then refused to believe her symptoms could be ongoing.

Faber had stumbled upon one of the most hotly debated questions in health care: whether Lyme disease can be a chronic illness.

On one side are organizations like the Infectious Disease Society of America (IDSA), which publishes popular guidelines for treating Lyme. IDSA recommends a single course of antibiotics, saying it will cure more than 95 per cent of patients. While IDSA acknowledges that some patients will have lingering symptoms after treatment, it says there is no biological evidence to prove the existence of chronic Lyme disease and advises against ongoing antibiotic treatment.

On the other side are a growing number of health professionals, patient advocates, and

groups like the International Lyme and Associated Diseases Society (ILADS) that recognize chronic Lyme disease. According to ILADS, 40 per cent of Lyme patients end up with long-term symptoms. Its guidelines recommend that health professionals use their clinical judgment and provide longer-term antibiotics if needed.

Caught up in the “Lyme wars” are people like Faber and fellow RN Catherine Kinsella.

In the summer of 2013, after her own rocky road finally led to a diagnosis, Kinsella was prescribed antibiotics to treat the Lyme disease that – on top of the typical flu-like symptoms – caused neurological symptoms associated with bell’s palsy, a condition in which the muscles on one side of your face become weak or paralyzed.

Kinsella suspects she contracted Lyme while hiking at a provincial park near Kingston in the spring of 2013, ten days before she got sick. Warning signs were posted on the trail, so she checked for a tick bite after the hike. She didn’t find anything. Even as a nurse, she says Lyme disease wasn’t on her radar back then. She wonders if her disease trajectory may have been different if she had more education about it.

Her symptoms improved with treatment, and she was able to return to work part-time after months on sick leave. But they returned shortly after finishing her course of antibiotics. In a follow-up appointment, Kinsella’s infectious disease doctor told her

the symptoms could linger for up to a year, but she was no longer infected with Lyme disease and the treatment was adequate.

“And that was the end of that. Here I was going downhill without a doctor,” she recalls.

Fortunately, she wasn’t alone. She found strength at Lyme disease support meetings in the Hamilton area, where she lives and works as a research assistant. The meetings were full of people with similar chronic symptoms, many of whom were never officially diagnosed. She was struck by the trouble everyone seemed to have accessing health services in Canada. “I think we’re decades behind in our knowledge about this disease,” Kinsella says.

Determined to get better, she found a new doctor who continued her treatment, and she eventually felt like herself again. She was also determined to raise awareness about Lyme disease and promote new research so others wouldn’t have to struggle as she did.

That passion led her to meet Faber on Facebook in 2016. The pair bonded over their shared desire to research Lyme disease and advocate for better care. “I knew I had to use my experiences and my expertise as a nurse... to help others,” Faber recalls.

By that time, Faber had three more reasons to take up this fight: her kids. While researching her own illness in November 2015, she read about studies indicating that untreated pregnant women could pass the *Borrelia burgdorferi* bacteria to their children, causing them various physical and cognitive

symptoms. Could this be why her daughters were often so sick?

Like chronic Lyme disease, congenital transmission is not widely accepted in the medical community. Faber was unable to find a doctor in Canada who would test her kids because they'd never had a tick bite. Again, she paid out-of-pocket in the U.S., and all three of her daughters, aged 7, 13 and 15, tested positive for Lyme disease antibodies.

Out of options in Canada, Faber paid for treatment for her two (symptomatic) daughters from a pediatrician in Connecticut.

She says they both improved significantly within a month of starting treatment, but it didn't come cheap. Between her treatment and her daughters', the family has spent more than \$40,000. Faber recognizes she is lucky to have had the option to pay out-of-pocket. Not every family can afford that kind of care. Knowing this strengthened her resolve to do whatever she can to improve Lyme care for all Canadians.

In January 2017, Faber met with then federal health minister Jane Philpott to share her family's story. Inspired by that meeting, she started the "[Lyme letters](#)" campaign, reaching out on social media to encourage people from across the country to send her their stories about Lyme disease and their struggles with diagnosis and care. Letter after letter came to her doorstep, and her inbox flooded with emails. Within a few months, she amassed 2,700 personal stories. It was around this time she teamed up with retired lawyer Jennifer Kravis to create [LymeHope](#), a not-for-profit organization dedicated to education and outreach on Lyme and related diseases.

In February, as the letters continued to pour in, the federal government released a draft

framework for a new Lyme disease strategy. Though it included a significant investment in research, Faber and Kravis were disheartened that none of the issues and concerns they had heard from Canadian Lyme sufferers were addressed, including inadequate testing, alternate modes of transmission, and persistence of infection. In response, LymeHope launched a petition that same month on which they've since received nearly 60,000 signatures to get these issues on the government's agenda. Many people also shared their personal experiences in the comments section of the online petition, allowing Faber to amass more than 14,000 Canadian Lyme stories.

In the spring of 2017, Faber and Kravis went back and forth to Ottawa three times with binders full of these personal stories. They shared them in meetings with MPs and were invited to speak as witnesses at the Parliamentary Standing Committee on Health. Around that time, Faber and Kinsella also met two RNAO colleagues who suggested the association could help get the message out: CEO Doris Grinspun and Halton chapter executive member Opal Robinson. Grinspun encouraged them to write a resolution about Lyme disease for the next annual general meeting (AGM) and Robinson invited Faber to share her story at the chapter's November meeting.

Nurses at that meeting were alarmed by the challenges Faber faced accessing health services for her family, and decided to take action. They voted to support a resolution on Lyme disease, seeking to raise awareness and amplify the voice of patients. "We wanted to bear witness to the suffering of these patients...and bring their story to the rest of

RNAO," says chapter president Louela Manankil-Rankin.

In the weeks that followed, Faber, Kinsella and Manankil-Rankin co-authored a resolution that urges RNAO to "...advocate, at all levels of government, for Lyme disease prevention programs and the rights of all patients with symptoms consistent with Lyme and/or co-infections to receive evidence-based, patient-centred care for both acute and multi-systemic chronic presentations of the disease in Canada; emphasizing health-care provider education that acknowledges alternate modes of transmission, persistence of infection, and integration of a collaborative clinical model inclusive of ILADS guidelines in the treatment of this illness."

The resolution was carried on April 20. "I'm so proud to be part of a profession that supported me and lifted me up," Faber says, noting that several colleagues at the AGM approached her with hugs and thanks for bringing the resolution forward.

Both Faber and Kinsella will continue to work on Lyme disease research. Faber also meets regularly with government and public health officials, and attended a roundtable discussion on Lyme disease with federal MPs in May. Both nurses say they are hopeful a shift in policy is on the horizon.

If things are going to get better for Canadians with Lyme disease, Faber says nurses will be a critical part of the solution. "We listen to our patients, we advocate for our patients, and we care for our patients. I believe we, collectively, can be a beacon of hope for Lyme sufferers, and we can also be a voice for change." **RN**

DANIEL PUNCH, FORMER STAFF WRITER FOR RNAO, DOES FREELANCE WRITING IN THE U.K.



Consultation representatives at RNAO's 2018 AGM vote in favour of the resolution about Lyme disease.