

Critics call for rewrite of ‘regressive’ Lyme Disease national framework

As Canada’s May deadline nears to create a Federal Framework on Lyme Disease, advocates are calling for drastic changes to a ‘status quo’ document.

NEWS | SAMANTHA WRIGHT ALLEN

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Sue Faber, left, and Jennifer Kravis have both been diagnosed with Lyme Disease. The two mothers came to Ottawa Wednesday to try to meet with Health Minister Jane Philpott to give feedback on a national framework for the disease they say doesn't go far enough. *Lobby Monitor photo by Samantha Wright Allen*

Sue Faber stood before Parliament Hill Wednesday holding two binders stuffed with some 2,000 letters as Jennifer Kravis, tears in her eyes, echoed the sentiment written by so many on the impact of Lyme Disease and the lack of treatment in Canada.

Both mothers have been diagnosed with the infectious illness, as were their children. With Kravis, the tick-borne disease caused sudden, debilitating symptoms.

“It has changed my whole life... There are no doctors that can help you. It’s a life-changing, debilitating illness that robs people of jobs, robs parents of their ability to care for their children,” said Kravis, voice shaking, recounting how she’s sought treatment in the United States and spent \$200,000 seeking care.

The former lawyer said she had her career cut short 11 years ago. It took six years for the “mystery illness” to have a name, an experience echoed by many who are misdiagnosed. An early diagnosis and immediate antibiotic treatment can make all the difference - a key reason advocates are pushing for more education among the public and medical community.

“To receive such poor care, so little care in your own country is what makes it one of the hardest things,” said Kravis, who travelled with Faber from the Greater Toronto Area just weeks before the May deadline for government to present its final national framework on the disease.

The draft form, released earlier this year, has been panned by the two women and other advocates, including Green Party leader Elizabeth May, who introduced the private member’s bill that became law in 2014. The day before Kravis and Faber came to Ottawa, May arranged a press conference calling for more input on the framework she called unacceptable.

“The tragedy of Lyme is if [it’s] diagnosed quickly... that person can be restored to complete health,” said May, who pointed to a warming climate for the increasing prevalence of the infected ticks.

The illness is caused by the bacterium *Borrelia burgdorferi*, which is tick-borne and transferred through bites. Symptoms include fatigue, muscle and joint pain and paralysis and untreated symptoms can last for months to years.

In 2015, Canada had more than 900 reported cases of Lyme Disease, according to Public Health Agency of Canada data. That’s up from 144 cases in 2009, when the country first started tracking the disease. United States estimates put its annual numbers at 300,000 diagnosed, according to the draft document.

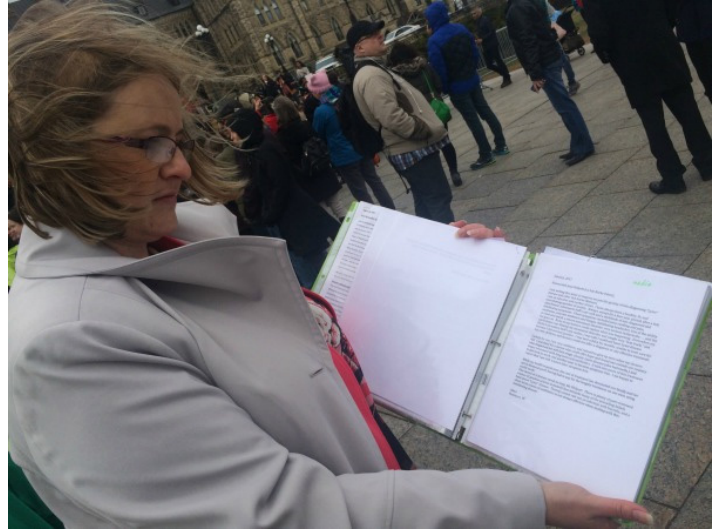
Kravis and Faber said they came to Ottawa hoping to speak with parliamentarians, show the letters and speak of a petition that has garnered 38,000 signatures. By Wednesday they had set up about 10 meetings with MPs but had yet to hear back from Health Minister Jane Philpott, who they hoped to hand the letters.

“We aren’t a FedEx service. We’re not just here to drop off letters,” said Faber, who has read through each submission and highlighted key passages she hopes to share with the ministers. “We want patients to be engaged in the process.”

Philpott’s office said government recognized the impact of the disease and did not say if she would have time to meet with the two women.

“Minister Philpott has met with members of a number of Lyme organizations previously and will continue to listen to their concerns,” said Andrew MacKendrick, Philpott’s press secretary by email. “The Public Health Agency of Canada will carefully be considering these concerns and perspectives as we move forward to finalize the framework.”

The director of the Canadian Lyme Science Alliance



said the framework doesn’t include the last decade of research on the disease.

“As a medical researcher in the field of Lyme Disease biology I am concerned by the lack of scientific rigour, collaboration and leadership that is demonstrated in this document,” said Melanie Wills, adding it should have a clear understanding of the disease, “unbiased scientific evaluation,” and tangible deliverables.

“The framework fails drastically in all of these areas. It reads as a vague and unquestioning endorsement of the status quo rather than a road map to a brighter future,” she said, calling it “regressive.”

Lyme Disease is fastest growing infectious disease in Canada, said May, and any framework must include language affirming that any Canadian with Lyme Disease has right to treatment.

“We need to have the tools to address this,” said May, pointing to prevention and awareness and surveillance as both uncontroversial approaches everyone agrees on.

“Where the problem lies is how do you create the kind of awareness within the medical community...

How do we create the response that becomes immediate, could it be Lyme?”

Where the controversy also comes in is in what some term “Chronic Lyme Disease” symptoms persist when conventional antibiotic treatments don’t work.

“Research continues into the causes of these persistent symptoms and methods of treatment since there is no definitive evidence that continuing symptoms represent an ongoing infection,” said the draft framework, noting a need for “ongoing dialogue” to “build consensus on the prevention and control of Lyme Disease.”

May said fixating on terminology is the wrong approach when country should be focusing on the “health emergency.”

“The framework language needs to dispense with... the dogma around the notion that there is a big open question about whether people can have symptoms,” she said of post- or chronic Lyme Disease. “Whatever we want to label [it], we need to face the reality that people who have had LD, and particularly where it’s not properly diagnosed, not treated early - have a lifetime of disability. We need to find and focus research and find ways to assist those people whatever you want to describe the condition they are dealing with.”

There also is disagreement on current testing methods, which Health Canada has said laboratory diagnostic guidelines “meet current international standards.”



“This draft framework tells me as a doctor treating Lyme disease that i should follow outdated guidelines that haven’t been revised in over 20 years,” said Dr. Liz Zubek, a B.C. family physician who specializes in treatment of the disease, at Tuesday’s press conference.

Zubek said Canadian tests identify the disease about 40 per cent of the time, but better tests used in some European countries can detect the disease 84 per cent of the time.

The framework acknowledges “limitations” in available lab tests, but doesn’t say there are other proven methods for Canadian doctors.

“New methods should be evaluated, and any that prove to outperform current methods will be incorporated into updated guidelines for laboratories and clinicians,” the draft reads.

Conservative Senator Kelvin Ogilvie said Canada has to find a method to diagnose the complex disease correctly and immediately.

“A country that is capable of developing a treatment for Ebola disease a world away certainly has the capacity to identify and develop appropriate diagnostic testing for a disease that exists in our country and a treatment thereof,” said Ogilvie, who chaired the health committee that reviewed the bill.

May pointed to his presence alongside NDP MP Tracey Ramsey and Liberal Francesco Sorbara Tuesday to stress the framework is a non-partisan issue.

A consistent critique among advocates standing beside May was that government failed to consult beyond the public forum held last May.

“It was almost as if it had already been written,” said Faber, who was diagnosed in 2016, and founded LymeHope with Kravis with the goal of giving voice to those affected by the disease.

“It was almost like the conference never happened,” added Kravis, who was one of about 100 who shared their experience with the disease at the 2016 public forum - a requirement of Bill 442, the Federal Framework on Lyme Disease Act

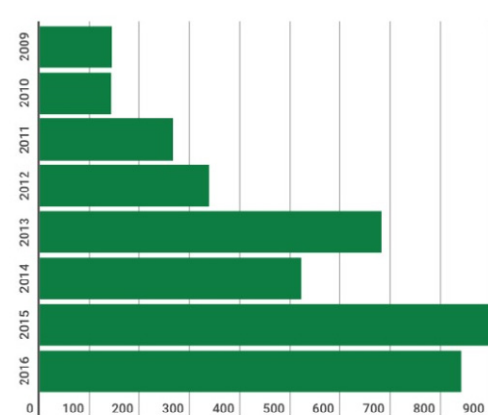
Rossana Magnotta, director with the Canadian Lyme Disease Foundation, said the correct course of action adopting more input, even if it means delaying the framework

“The legislation embodied openness. It did not state that a conference would be held and collaboration would stop,” said Magnotta, adding the draft “met none of the requirements” outlined in the bill.

Ramsey said some of her constituents called the approach a “betrayal.”

“When we are able to see pets in our country that are treated and have pathway to health around Lyme Disease when people in our country don’t, something is seriously broken,” she said.

Lyme Disease in Canada



Source: Public Health Agency of Canada *2016 numbers are preliminary data. Graph via infogram

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