HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

Standing Committee on Health

HESA • NUMBER 030 • 2nd SESSION • 41st PARLIAMENT

EVIDENCE

Thursday, May 29, 2014

Chair

Mr. Ben Lobb

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● (0850)

[*English*]

The Chair (Mr. Ben Lobb (Huron—Bruce, CPC)): Good morning, ladies and gentlemen.

This is our first meeting on Bill C-442, and we have Ms. May here, who is ready to present. The first hour of the meeting will be allocated to her and her comments, and to questions and answers. In the second hour, we will have some additional guests.

Ms. May, you have 10 minutes or thereabouts. If you need longer, you have a bit more time.

[*Translation*]

Ms. Elizabeth May (Saanich—Gulf Islands, GP): Thank you, Mr. Chair.

It is a great honour for me to appear before you as a witness on Bill C-442, An Act respecting a National Lyme Disease Strategy.

This bill was conceived in a non-partisan perspective in order to help people everywhere in the country. I hope that in an equally non-partisan spirit, we will be able to create the strategy set out in the bill.

The bill would introduce a collaboration framework involving the federal, provincial and territorial ministers, as well as representatives from the medical community and patients' groups, in order to expedite diagnosis and treatment of the disease.

[*English*]

I think all members are now quite familiar with the fact that Lyme disease is spreading, particularly across southern Canada.

As I just mentioned in French, I have to say that this is a very non-partisan effort. I am enormously grateful to all members and all parties represented in the House for support for this bill. At the top of my list is thanks to the Minister of Health, Rona Ambrose. I know her officials will be coming in the second part of the health committee's review of the bill.

Let me just explain what it is I hope my bill will do, and then I'll talk about some of the supporters we have for this effort. The support, both politically and from the expert medical community, is quite substantial. Of course, Lyme disease patients from coast to coast have been extraordinary in their support and in reaching out with petitions, which I think many of you have tabled in the House on behalf of your constituents, in support of the bill.

As any of you will know, as members, when you set out to write a private member's bill you're very aware of the constraints: it has to fall squarely within federal jurisdiction and it should not attach itself to any measures that involve spending money.

That said, I know that the Minister of Health would like to have some amendments made. I want to get that out right away. From my point of view, the amendments that the minister or the health department officials will bring to you, certainly the ones I've been consulted about, are absolutely fine.

I tried very hard; I called this the national Lyme disease strategy. It may work better in terms of avoiding any treading on provincial jurisdictions to call it a federal framework or something like that. I'm not prescriptive about what the minister brings forward, obviously. But we do want to make sure that it doesn't tread on provincial jurisdiction. That was my intention in drafting. To any extent that I failed to do that, I want to make sure that the bill is a purely federal effort that engages the other jurisdictions in a collaboration.

So that's the first thing to set out: the effort is to make sure that the federal Minister of Health takes the lead, but the engagement is truly across provincial boundaries in a way that's respectful of jurisdictional limits.

In that vein, I'll let you know that I was amazed to discover that just recently a bill has been tabled in the province in Nova Scotia that will mirror this one. So I think that might be the beginning of what we'll see across the country as more provincial jurisdictions are aware of the spread of Lyme within their own area.

I give credit to Health Canada that since 2009 Lyme disease has been a reportable illness. That's quite a lot of progress, because there was a time, a decade or so before that, when you would be hard pressed to find a jurisdiction that thought Lyme disease was a serious problem. There are horror stories.

The first person I knew with Lyme disease was a neighbour in Nova Scotia, Brenda Sterling. She's very prominent in the movement, so I don't mind mentioning her name. But when she first contracted Lyme, she kept trying to talk to provincial authorities in Nova Scotia. They told her they didn't have Lyme disease in Nova Scotia, so therefore she couldn't have it.

Imagine the change that's occurred. As I said, there's a bill before the Nova Scotia legislature that mirrors this bill.

So what will this bill do? Under this bill, the minister will be required to convene a conference. Now, my bill says within six months. The timing around that might change in terms of government amendments. I don't think that's material as long as it's clear that it must happen. The minister will convene a conference of his or her provincial and territorial colleagues in the departments of health, as well as representatives of the medical community, as well as representatives of patients' groups, and that group will work together to develop a strategy.

There are several key elements of what's missing for the best possible approach in Canada to this illness.

One is that we lag behind the U.S. in terms of awareness for prevention—i.e., when people go out on a hike. I was talking yesterday to the cameraman from CBC who interviewed me on this. He's a volunteer Scout leader. He said it's his second job, and he loves it. He takes the kids out in the woods. They have really ramped up their own awareness for tick awareness, such as checking each other for ticks.

We want people to enjoy the outdoors. We don't want people to get phobic about going on hikes and being outdoors. But we need the awareness to tell them to tuck their pant legs into their socks, to check afterwards, to have a friend check to see if they picked up a tick, and then to know what to do if they have. Awareness and prevention are key.

The next piece, which is much more complicated, is the diagnostic piece. In the letter of support from the Canadian Medical Association, which will be tabled with you in both official languages at your next hour's hearing—I've checked that with the clerk and that appears to be fine to do—the president of the Canadian Medical Association, Louis Hugo Francescutti, had this to say:

> Diagnosis of Lyme disease can be difficult because signs and symptoms can be non-specific and found in other conditions. If Lyme disease is not recognized during the early stages, patients may suffer seriously debilitating disease that may be more difficult to treat.

We should find ways to share best practices across jurisdictional lines between members of the medical community so there is a shared understanding of best practices for diagnosis because, as the Canadian Medical Association has noted, with quick diagnosis, treatment is excellent. It's usually a course or round of antibiotics, and patients return to full health. On the other hand, as with my friend Brenda Sterling in Nova Scotia, left untreated, it's debilitating. When I met her she was already in a wheelchair, and I was shocked at the time to discover that she was in a wheelchair due to Lyme disease.

The next piece, of course, is better treatment and management, and that again can be done through sharing of best practices within members of the medical community and finding a recommended national approach that will reflect best practices for treatment of Lyme disease.

All of the materials that can be shared are described in the bill so that there's a public health aspect of this to increase the awareness to help the medical community with the treatment and management of this disease.

The bill goes on to describe the ways in which the Minister of Health will, in an ongoing fashion, share information and help the medical community and provincial and territorial colleagues to work together so that the spread of Lyme disease does not represent a significant threat of permanently debilitating illness to Canadians when it's easily treatable if properly diagnosed. Also there are ways to avoid contracting the illness by being aware of ticks and tick bites.

This is pretty straightforward. I just want to stress one thing about the illness. We know it is under-reported in Canada. How would we know this? In the United States last summer in 2013, the Centers for Disease Control and Prevention in Atlanta, Georgia, based on their understanding of the disease in the United States, increased their estimate of the prevalence of the disease tenfold from 30,000 understood cases to probably in the range of 300,000.

We can assume the same is likely the case for Canada. Since tabling my bill I've had literally hundreds of Canadians write to my office with personal stories. I've also had health professionals, both nurses and doctors, contact my office and say, “I know that in my own province of X, we have only *x* number of reported cases, but we think it's far higher.”

We are actually acting in a timely fashion. The Parliament of Canada is doing something really useful and helpful, and the Minister of Health in the lead can make a real difference in the lives of Canadians, those who are already suffering with Lyme, and those who can avoid suffering with the steps that can be taken through a federal framework.

● (0855)

I have one very last comment, Mr. Chair. This is not a case where parliamentarians should become doctors, or think we're doctors, or have the politics of the issue have any impact whatsoever on what the medical community decides around the issue. I think that's really important. In some cases in the U.S., there have been some areas where the medical community has felt that politicians went too far. I'm very grateful, again, that in Canada the established medical community and organizations are very supportive of this bill. We're not doctors. We're here to work on public policy.

With that, I open the floor to any questions anyone may have.

● (0900)

The Chair: Thank you very much.

We'll start up our rounds of questions,

First up, we have seven minutes from Ms. Davies. Go ahead.

Ms. Libby Davies (Vancouver East, NDP): Thank you very much, Mr. Chair.

Thank you, Ms. May, for coming today. I think your bill is very important. This has been a long-standing issue. I'm sure all of us at one time or another have heard from constituents who are suffering from Lyme disease. I know certainly, over the years, I've had many constituents come in and see me, and we've written letters, so I'm really glad to see that one of the key elements of your bill is the establishment of national guidelines.

What I heard over and over again was the incredible frustration and, literally, pain of people who thought they had Lyme disease, would go to a doctor or go to another medical practitioner, and couldn't get a diagnosis. It just seemed so incredible that in today's age people were not only suffering, but then they were having the additional suffering of not being able to know for sure what they really had, even though they suspected.

What I heard about repeatedly, and I'm just curious to know if this is what you heard as well and whether it's still as prevalent today, is the lack of testing. I don't know if it varies from province to province. I think that's one of the issues as well, that in some jurisdictions there is testing available and in other jurisdictions there isn't. So I wonder if you could just speak a little bit on that.

I agree obviously that prevention and education are very important, but it seems to me that the whole diagnosis and testing is just a critical step, so that we can get into a better treatment and management program, as you say. Have you any information to offer about diagnostic testing? For example, are there examples in Canada where there is good testing available? Is there a good case model that we could look at? I know we're not going to design the strategy, but I'm just curious to know. Are there some good practices going on in Canada?

Ms. Elizabeth May: Thank you.

First, I know that I should be formal and call you Ms. Davies, but Libby, I'm so grateful that one of the first letters of support was from your party, with full support for the bill. It's a long slog when you're a private member putting in a bill, hoping that it's non-partisan and that everybody will jump on board, but we all know how rare that is.

I want to say again—to the Conservative Party, to the Liberal Party, to the New Democratic Party—that I am so grateful. Thank you.

In terms of diagnostics, I'm not going to try to be a doctor about it, but there is a study that I referenced in the preamble to the bill, the Schmidt report, that was prepared at the request of the British Columbia government and published by the Provincial Health Services Authority. It talks about some of the diagnostic problems.

Part of the problem, as the letter form the Canadian Medical Association mentions, is that it looks like other things. It's quite often misdiagnosed as multiple sclerosis. This is entirely by inference, but some people have looked at the stats and said it's interesting that Canada has such a higher incidence of multiple sclerosis as compared with the U.S. We have relatively more MS than the U. S. and a lot less Lyme. The U.S. has relatively more Lyme and a lot less MS. I'm not suggesting that this is more than an interesting observation that the medical community itself should analyze, but is it possible that we've been misdiagnosing a lot of Lyme as multiple sclerosis?

For a lot of doctors, number one, when they went through medical school, Lyme was not as prevalent as it is now. They sometimes think, okay, if you don't have that classic bull's-eye rash, you don't have Lyme. Well, it turns out that, no, you can actually have been exposed to Lyme disease and never get the classic bull's-eye rash.

Some of the serological testing, the blood testing, will come back negative when in fact it's a positive. That's a problem. Even if a doctor suspects Lyme and sends the blood work away, it can come back negative and the patient can still have Lyme.

One thing I've heard is that one of the best ways to know if there is any risk that you've gotten Lyme disease is to save the tick and stuff it in a little plastic Baggie with some moist tissue so that the particular specimen is preserved. The surest way to know if you've been bitten by a tick that had the bacteria present is to have the actual tick that bit you, because they do hang on, and to get it tested. But I've talked to patients who went into doctors' office and were told “Yes: okay” before the doctors—again, because we haven't had this program of sharing best ideas—would throw it in the trash and then continue.

So your best diagnostic is often to get the tick itself analyzed. There are individual doctors who.... One of the pleas I've heard from doctors is that this is a disease where, in terms of the ability of a doctor to diagnose it in the office, sometimes the best blood work and the best additional testing will miss it. But when the patient is sitting in front of you, and you go through the checklist of symptoms, and you analyze what happened and so on, at that point you as a doctor should feel secure to say, based on the sharing of best practices, that, you know, that doctor made a diagnosis...and order a course of antibiotics.

Deciding not to do it at an early stage can lead to permanent debilitating conditions, and really, at this point, it's very, very hard to know how people are helped if it's gone to....

I should tell you that there's a fault line between the medical community and some of the Lyme disease activists. There is a community out there who could be described as Lyme disease activists. I'm not taking a position on that fault line. As I've said, I'm not a doctor. But the doctors will say “That's post-Lyme disease syndrome”, and the people who are suffering with it will say “I have chronic Lyme”. It's a very hotly contested question of what you call it at that point.

I'm not going to call it one or the other. I'm going to say that some people who have Lyme disease end up in wheelchairs for years. Whatever we call it, it would be wonderful to train some of the sharing of best practices around what to do. There are basically three different kinds of action: avoiding it through prevention; quick diagnosis when someone has first been bitten; and then that longer-term question, if somebody has been a wheelchair for years, of how you diagnose it—as Lyme or something else. That's a very hard one to diagnose.

Sorry. Did I use up all your time?

Ms. Libby Davies: It's all right.

● (0905)

The Chair: Ms. Adams, go ahead for seven minutes.

Ms. Eve Adams (Mississauga—Brampton South, CPC): Thank you.

Ms. May, thank you very much for coming before us today and for bringing forward this very important bill. It has been our pleasure to work with you. You have been nothing but accommodating and kind, and really focused on making sure we act in the best interest of Canadians across the country.

I know we've shared with you some amendments that we'd like to bring forward just to make sure that the bill and the legislation would be workable. If you would be so kind....

I know you referenced a number of them in your opening statements, but just to confirm for the record, we would refer to this as a federal framework to better respect and engage the provinces.

You also note that we would have the conference take place within six months. I would ask for some flexibility there, as we don't know the legislative calender, and perhaps make that six to twelve months. We are keen to bring this forward and to act on this; we just require some flexibility to make sure we can actually hold to our word here.

Are you comfortable with those two, for instance?

Ms. Elizabeth May: Oh, absolutely, and I want to thank you as parliamentary secretary and through you the minister. It's so nice in Parliament to have an opportunity to work in a non-partisan, collaborative fashion. I'm very grateful.

The chair and I were talking earlier; anything we could do to speed this through...because there is a time limit here. To me, it's key to see the first conference take place before the next election, if possible, for obvious reasons: people need help.

So I'm very flexible about the time, and it's easier for me to take 12 months, if we get the bill all the way through, or whatever we can do before we break for summer.

Ms. Eve Adams: We're fully agreed. Hopefully we can have all-party cooperation and push this through the legislature as quickly as possible.

Ms. Elizabeth May: But I understand that the minister might not want to have her hands tied, because the conference does involve convening with provincial and territorial authorities.

Ms. Eve Adams: Yes, this is the challenge, and we genuinely do want to respect their authority in these matters.

Ms. Davies has raised a very important point, as have you, and that is that we have all, I think, received letters from and have had discussions with constituents who have faced what they believe to be Lyme disease. The constant, recurring theme is that they go to doctor after doctor. They know something is wrong with them—they're having bouts of serious arthritic pain—and doctor after doctor is misdiagnosing it.

It is something whose consequences are very heart-wrenching to see. You can have very young people afflicted by this. It is a serious issue that I think we need to bring some national awareness to, so that people speak up and even flag for their physicians the question: do you think this might conceivably be Lyme disease, and if so, then what can we do?

It is so treatable, if caught early, and the pain that people are enduring when it's not caught is terrible.

● (0910)

Ms. Elizabeth May: If I may, I'm sure this isn't only my experience; I have talked to members of Parliament on all sides of the House who have also had constituents who have gone to the U.S. for treatment. Some very prominent doctors have become noted for their expertise in both diagnosing and treating Lyme.

It is even the case that some Canadian doctors who recognize what they have in front of them and want to treat Lyme with a course of antibiotics...and sometimes it's more than one course. Treating Lyme disease requires an expertise that unfortunately many of our constituents are finding only south of the border. That of course means that only those of significant means, or those on modest means who are prepared to sacrifice a tremendous amount, go to the U.S. for treatment.

We have a wonderful health care system in Canada, and I'm hoping that with the collaboration we're seeing around this table, the medical community, working with Health Canada and the provincial departments of health and the provincial medical officers, will be able to share the information to increase the level of awareness among doctors and also increase their willingness to use what have been found to be effective treatments in other jurisdictions.

Ms. Eve Adams: Mr. Chair, I'd like to split my time with Mr. Lizon, so could you give a one-minute heads-up before the end of my time, please?

Ms. May, would you be so kind as to let me know the types and the names of the groups you have consulted with?

Ms. Elizabeth May: One of the groups, which I hope is coming to testify later today, is the Canadian Lyme foundation. But I consulted with and am very grateful for support from the College of Family Physicians of Canada, and I will be able to share their letter once I've translated it. It will come before the end of the hearing portion of this legislation.

I also have consulted with the Canadian Medical Association, as well as with many individual doctors. I have consulted and met with a clinic that deals with Lyme disease in Vancouver. Allison Bested runs it. It's called the complex chronic diseases program at the BC Women's Hospital and Health Centre. I have met with her. Her centre was created to help patients with these complex diseases. In addition to Lyme disease, that centre deals with chronic fatigue syndrome and fibromyalgia. As you can imagine, the symptoms may look similar, but the treatments are different. It's really a complex set of issues that we have here for diagnosis.

So I've talked to everybody I can talk to who has expertise in the issue.

Ms. Eve Adams: Thank you again for working with us in such a wonderful spirit of non-partisanship on an issue of national significance. Thank you.

Ms. Elizabeth May: Thank you.

Mr. Wladyslaw Lizon (Mississauga East—Cooksville, CPC): Thank you.

The question I want to ask is this. The bill deals with the results of the bites; however, it is caused by ticks. It's not only a Canadian problem; there is a huge problem in Europe. In the past 30 years they have noticed an extreme expansion of the tick population; therefore they are working—I don't know whether you are aware of the studies that are being done there—on finding out the reasons for the growing population, because eventually it should be stopped there, before we are affected.

Of course, your bill does not address that part of the problem, but this is a huge problem, and it should be addressed first. The work is being done internationally. Do you have any suggestions on how to approach it?

Ms. Elizabeth May: Thank you. It wasn't until you drew my attention to what you had seen in Europe, the expansion of tick populations and Lyme disease there, that I started looking into what is happening in Europe.

My bill does touch on this; Bill C-442 deals in paragraph 3(b) with guidelines that also touch on prevention. Of course, that is not quite the same thing as.... A portion of prevention could be the studies that you suggest, to understand exactly why it is spreading. The current prevalent theory is that because of changing temperatures caused by the changing climate, the tick population is spreading.

But we're also seeing other evidence. There was a story in the *Times Colonist*, the newspaper that covers part of my riding, from Victoria, that there was a raptor discovered—a dead hawk—that had a number of ticks around his eyes. When they analyzed those ticks, they found that some were not deer ticks, but they were also carrying the bacteria that carries Lyme disease. This is hypothetical, so please don't take it as evidence, but there certainly is anecdotal evidence that the bacteria is spreading from deer ticks to other kinds of ticks.

So it may be on the move in other ways that scientists have not yet quite understood. We know that it's more prevalent and we know that it is spreading, and not just where it started, around Lyme, Connecticut—that's why it is called Lyme disease—but into other jurisdictions, obviously including Canada, but also Europe.

Of course, that is the challenge for the medical community. When many of our doctors went to medical school, this wasn't something that was presenting itself as a serious cause of illness.

● (0915)

The Chair: Ms. Sgro.

Hon. Judy Sgro (York West, Lib.): Thank you very much.

I'm really happy that you have picked up this initiative. I think many of us around this table have met with family members and so on over the last several years and really heightened our awareness of the issue. I'm thrilled that you have picked it up and are running with it. My applause goes to you for doing it. There are so many things that we are inundated with here in the House, and needless to say, we can't do everything. But I guess each and every one of us, in our own way, picks up an issue and runs with it. I think it's fabulous that you've done this. I applaud you for it.

What is being done elsewhere? I mean, finally this issue, through the work of many families, is getting to the forefront here. I'm thrilled that we're all going to support this and move it through as quickly as possible. What else is happening in the U.S. or in Europe concerning the recognition that this is a serious issue that needs to be dealt with? The only way we're going to deal with it is to start getting it recognized around the world, so that they're recognizing it for what it is.

So what is being done, whether in Europe or in the U.S., on this particular issue?

Ms. Elizabeth May: A lot of legislation has been happening at the state level in the United States, and there is a current bill before the U.S. Congress as well. Because Lyme disease was first spotted, as everyone knows, in Lyme, Connecticut, the legislation in Connecticut is quite advanced. In 1999 they passed a limited Lyme disease insurance bill where insurers must pay. Now, of course, they have a for-profit health care system that involves getting the insurance companies to agree to the treatments. So they passed a bill to ensure that insurers must pay for 30 days of IV antibiotic treatment or 60 days of oral antibiotics.

They also passed legislation in 2009 to protect the medical community. It permits licensed physicians, who have determined the presence in patients of signs compatible with acute infection, or of what they call late-stage, which deals with this dividing line between calling it chronic and calling it post-Lyme disease, whatever they call it, to also treat people who've been basically afflicted with something quite persistent with long-term antibiotic therapy. They are protected by law. It is extraordinary that we have legislators passing laws to say that doctors are protected if they choose to do this.

Pennsylvania, Rhode Island, and California have laws, and the U. S. piece of legislation I mentioned that's currently before the Congress there is the Lyme and Tick-borne Disease Prevention, Education, and Research Act of 2007. So that's still before their Congress.

As to the matter of what the medical community does, there's been quite a lot more progress, again, because it was more prevalent earlier in the U.S. We're catching up now, so I'm not casting blame on anyone in the Canadian medical community. But the U.S. has had a longer experience with it, so they have much more advanced prevention programs.

You approach a U.S. park, and it's just the same way as in Canada for UV awareness, and put on your sunscreen. We now have regular broadcasts on the UV index. Put on your sunscreen; it's a high UV day. When I was growing up, we never heard of such a thing, because we didn't have the same worry. The ozone layer hadn't been attacked when I was growing up. So we catch up with these things.

In the U.S. they have much better prevention signals as you go to hike in an area. Tick awareness: think about it, be careful, and check yourself after. Check your dogs after too, because that's another problem. A dog can come in the house and carry a tick in with him. So it might not even be that you've gone for a long hike; your dog might bring the tick to you.

So there's a lot more awareness programming in the U.S., and the medical community is more aware, and they do have better diagnostics in terms of the lab work that can be done. Since I'm not an expert in that field, I'm very nervous to go too far into explaining what the medical community in the States does. But they have more familiarity with it, so they've developed additional testing.

● (0920)

Hon. Judy Sgro: Over and above the medical side, from the environmental side, why do we have, clearly, an increase in the amount of ticks that are out there carrying this, whether it's in Europe or in the U.S. or Canada? Is it just the fact that it's being recognized now?

Ms. Elizabeth May: The prevalent explanation—it's one that's been around for a long time—is the whole area of vector-borne diseases. It's a disease carried by a mosquito, tick, or whatever. Due to climate change, we will be seeing a spread of vector-borne diseases. This is not news. Goodness, when I worked in the office of the federal Minister of the Environment in 1986, I can remember the scientists at Environment Canada telling us then that the climate crisis would involve the spread of vector-borne diseases; more malaria in places that didn't used to have malaria, dengue fever in places that didn't have dengue fever. We didn't talk about Lyme disease particularly, but it falls in that category.

Now, as Mr. Lizon has suggested, maybe there's something else at work, and we need more research to understand why the ticks are spreading and why the bacteria is prevalent on different species of ticks from what we had expected. Typically we thought it was deer ticks. Clearly, jurisdictions that thought there was no such thing as Lyme disease in their jurisdiction held to that fairly firmly until the evidence made it impossible to hold to that theory. Now they have—

Hon. Judy Sgro: In the time I have left, I want to turn it over to my colleague Mr. Hyer—since we're working so well together on this issue.

Ms. Elizabeth May: Thank you.

Mr. Bruce Hyer (Thunder Bay—Superior North, GP): Thank you very much.

Ms. May, I would like to give you the opportunity to tell us briefly what you think the biggest obstacles are to implementing a national strategy on Lyme disease, and what you think the biggest opportunities and needs are—all in a minute or two.

Ms. Elizabeth May: I'll be brief.

Thank you, Mr. Hyer. Speaking of cross-party cooperation, it's the first chance I get to be in the same party with somebody. It's really fun, I have to say.

The biggest barriers, I think, have been the fixed notion on the part of some that because Lyme disease wasn't prevalent 20 years ago, it's not prevalent now. I think that has largely been overcome, and again I want to give credit to the Minister of Health in 2009, who brought forward the idea of making Lyme disease a reportable illness in Canada. That was a big step, because when Health Canada says it's a reportable illness, it's very hard for anyone to say it's not real. It's a reportable illness. Health Canada recognized it in 2009. That's a big step forward.

The biggest opportunity is to convene this conference as quickly as possible. We have a moment here, and I don't want to lose that moment. We have a moment of non-partisan cooperation here in the House of Commons. We have the fact that Minister of Health Rona Ambrose is willing to move quickly on this. I don't want to speak out of turn—and the parliamentary secretary can correct me—but I have a great sense that she's personally engaged on this. We have the opportunity now to do something soon, to bring the provincial and territorial health authorities, the medical community, and the community of Lyme disease patients into the same room to share where we are on this and to figure out best practices.

As much as I've been engaged in this issue, I don't know best practices. I put this bill forward for first reading almost two years ago, and it is what it is. You have to wait until your turn comes up in the lottery. Even as much as I knew about Lyme disease before I put the bill forward for first reading, that has only confirmed for me, as I sit before you today, how much I don't know. We need to listen to the medical experts, and that's our best opportunity.

The Chair: Okay.

Mr. Wilks, go ahead for seven minutes.

Mr. David Wilks (Kootenay—Columbia, CPC): Thank you, Chair.

Thanks, Elizabeth, for being here today. I think we can call one another by our first names here.

I'll be sharing my time with Mr. Young.

I just wanted to say that I know a young man in my riding of Kootenay—Columbia, Kurtis Schwindt, and his family as well—I have no problem saying his name—who struggled with Lyme disease in his early twenties and had to go to the United States finally to resolve his issue. One of his things was that he ended up with a whole bunch of his peers saying he was just a lazy young kid, but the fact of the matter is he couldn't stay awake. That was part of the problem. He would sleep for days, just days, and they could never figure out what the problem was. Luckily he has been able to move forward. He still struggles somewhat with it.

I'm very glad to see this go forward. I am curious about something. I'll ask this and then I'll turn it over to Mr. Young. I'm wondering if you can provide some insight into the challenges that Lyme disease poses to Canadians, and how this legislation would help to address those challenges.

I know we're repeating a bit here, but I think it's important for you to get your message across.

Then I'll turn it over to Mr. Young.

● (0925)

Ms. Elizabeth May: Thank you very much, Dave. I appreciate it enormously as well as the story you shared of your young constituent. I'm looking around to see if the witness you'll hear later this morning is here yet. Nicole Bottles lives right near my riding and is an amazing young woman.

Part of the story of how it's afflicted young people is that not only is it physically debilitating if not diagnosed, but the ability to study, to have a textbook, to be in a school.... One of the symptoms that seems to occur is not only being exhausted but also having a hard time holding a thought from moment to moment. That's very difficult, because even if it's physically debilitating, young people can go to school in wheelchairs, but when you're in a wheelchair and you can't concentrate, then you're really losing your educational opportunities as well as having a lot of quality-of-life issues.

I'm sorry, Dave. I started thinking about young patients, and I lost the question you wanted me to answer.

Mr. David Wilks: You can carry on with that as well, or I can just turn it over to Mr. Young. My question was with regard to the challenges that Lyme disease poses to Canadians and how the legislation will help.

Ms. Elizabeth May: Right.

Of course the legislation will be enormously helpful. I think it was very kind of Irwin Cotler to make this point in his speech at second reading. He talked about the fact his own daughter has Lyme disease, and he said that even having the debates we're having in the House has already helped increase awareness. That's good, but I want to get the bill passed.

When we have a federal framework, we'll be identifying for all jurisdictions how to better prevent it through more awareness. We'll identify how to better diagnose it through doctor-to-doctor sharing of best practices so that when a patient shows up in a doctor's office, the doctor will be looking for symptoms and asking if this could be Lyme disease. Once a quick diagnosis is made, we'll know how to treat it and therefore have better treatment.

I didn't touch on this part of the bill, but I should mention the part about collecting information. Paragraph 3(a) of the bill calls for a surveillance program, so the data will be collected by the Public Health Agency. We'll track incidence rates and also the economic costs of Lyme disease. That's going to be very useful information to justify the programs going forward.

The Chair: Thank you.

Mr. Young.

Mr. Terence Young (Oakville, CPC): Thank you.

Congratulations, Madam May, on this initiative. I was pleased to second it in the House of Commons, subject to some amendments, which we've discussed today and previously.

When I first got involved in the subject, I was also pleased to see that our government has been active on the file since 2006. The Public Health Agency of Canada is working to support the provinces and territories. Our government's invested $4.5 million to date for research related to Lyme disease. They made it a reportable disease as well, so they're tracking it. The improved surveillance is going to be helpful. We've actively engaged with provincial and territorial partners in monitoring the spread and development of the disease.

I first became aware of the disease, and we've discussed this, when my friend Janet Mitchell, who's a former Oakville town councillor, had Lyme disease. She was misdiagnosed for years. They told her she had MS and would be in a wheelchair for life. She didn't believe them and did her own homework. She got on the Internet and she did her own research.

They gave her the ELISA test in Ontario, which is a failure for Ontario patients. It's not reliable. She and her husband went down to the States. She paid for it herself and she got the Western blot test, which proved she had Lyme disease. Then she took a nine-month course of antibiotics. The bacteria is no longer in her system; she's pursuing one other possibility.

But the ELISA test is not reliable. This is a case where the provinces have let down Canadians, the health care system, and the doctors. The neurologists were saying she couldn't have Lyme disease, we don't have Lyme disease in Canada, as if ticks don't go on deer and birds and fly across the international borders.

But it's happening now. I did some research recently, just two weeks ago. I called around the GTA to find out—I looked on the Internet—where someone can get this reliable test, this Western blot test, in Canada. There was one naturopath's office in Thornhill, Ontario. I left a message to learn more and never got a call back. I guess they're swamped with calls. Two days later they finally called back and said they were only doing it on Monday and they had to get the doctor's permission, etc. There are two offices of naturopaths in Ottawa where someone can go and get this reliable Western blot test.

That is not good health care. When you think the provinces will have to pay for a nine-month course of antibiotics, they're willing to pay that much money, but not willing to pay the money to get a reliable test where a patient might only need a 10-day course of antibiotics. It just doesn't make sense.

Could you please tell the committee what you've heard from the medical profession on your bill and if you've heard any similar comments from them?

● (0930)

Ms. Elizabeth May: Thank you so much for the question.

When you talk about the cost, not only is it the cost of treating Lyme disease, whether it's a 10-day course or a nine-month course, but add up the costs of misdiagnosis, of putting people on treatments for diseases they don't have. You're not only setting back the health of the patient who is misdiagnosed, but that's also a very significant cost to our health care system, which is why the economic costs of Lyme disease form part of the surveillance program that Bill C-442 would put in place.

I've been very gratified—and I thank you for the question, Terence—by the fact that the Canadian Medical Association is absolutely in support of the bill. The letter will be shared so you'll all have it in detail. They support the implementation of a national strategy or federal framework because they believe that we need “to address the breadth of public health and medical issues surrounding the spread of Lyme disease in Canada”. They regard it as a new infectious disease threat. They're looking at in a very holistic way, looking at the various ways in which the bill will help patients.

The College of Family Physicians of Canada likewise wants to make sure that their representative on the Public Health Agency steering committee will help develop practice guidelines on Lyme disease. This is the medical community itself saying, “It's hard to diagnose. We need practice guidelines. We want to work with you. We want to make this happen.”

As I said, there's been a barrier around it, and I think there's a substantial attitudinal change happening. People used to say, “There isn't Lyme disease in Canada”, or “There isn't Lyme disease in my province”, or “We don't get Lyme disease on Vancouver Island.” These are all things that patients have told me they've heard. Now there's such clear evidence that it's spreading and we do have this illness in all parts of southern Canada that I've heard of.

So the medical community is supportive. I know the Medical Association of Canada would have provided a witness to the hearings on Bill C-442, but just due to timing they're not able to be here in person. But they do plan to submit a brief, and I'm grateful for the chance to mention that.

The Chair: Thank you very much.

Ms. Mathyssen.

Ms. Irene Mathyssen (London—Fanshawe, NDP): Thank you, Mr. Chair. I will be sharing my time with Ms. Davies.

Thank you, Ms. May. I'm very interested in all this work you have done. I did a little background reading and you talked about there being a new awareness about the spread of the disease, yet in the bill you make mention of B.C. undertaking active testing. Is B.C. the only province that is being so active, or are other provinces beginning to understand the importance?

Ms. Elizabeth May: Thank you.

I don't want to overstate the extent of British Columbia's ability to diagnose, either. There is still a lot of patients who go to their doctors in British Columbia and, looking around the table, there are three of us from British Columbia here, and unless James or Dave want to jump in and suggest otherwise, I'm still hearing from people who've gone to a doctor who hasn't recognized it.

What is unusual is that the B.C. government, through the Provincial Health Services Authority, commissioned a major study on chronic Lyme disease in British Columbia, authored by Brian Schmidt. It's from May 2010 and is a very useful summary of the challenges of the illness and the difficulties in diagnosing it properly. The Provincial Health Officer for Public Health in British Columbia has also stated his support for this bill, because it takes a constructive approach going forward to work together to develop best practices.

Right now there are pockets across Canada. Dr. Murakami in Vancouver, for instance, is one of the people who is acknowledged as a Lyme disease expert. There is a number of doctors across Canada, but they quite often have to send the samples for testing to labs in the United States.

● (0935)

Ms. Irene Mathyssen: I was reading an article about the Rossana Magnotta foundation. Apparently, her husband suffered dreadfully for years, wasn't diagnosed until later in his life, and he actually succumbed to the ravages on his health. Have you been in touch with the foundation, and what kind of progress are they making?

Ms. Elizabeth May: Jim Wilson from the Canadian Lyme Foundation is here as well, and I know they work quite closely. They were represented at a recent Lyme disease awareness event that took place in Victoria. While very uncommon, it's not unknown for someone to die of Lyme disease, and in that case Mr. Magnotta did. He had been a very successful businessman and a very important part of the community. Tragic events like that help us focus on exactly how critical it is that we get better awareness, better prevention, treatment, and understanding of the illness.

I skipped over something Mr. Young said that I should have drawn attention to. I don't think a lot of Canadians know about the decision of Health Canada; I'm not sure when it started, but there's been almost $5 million committed to research in Lyme disease. That's really encouraging. I think with the private foundation community and the public health authorities and Health Canada working together, one of the key pieces—I obviously couldn't put it in the bill, because I can't attach any money commitments to a private member's bill—is that we really do need to do more research into what to do to assist people who, either through misdiagnosis or through failure themselves to pursue diagnosis while thinking they're tired all the time, are in wheelchairs: they really need advanced funding for research to find a way to get back to health, after having been suffering from Lyme for some time.

That's a piece where the foundation work is so critical.

Ms. Libby Davies: I'd like to come back to the question of the testing, because I think it's so critical. You said a number of times that it's hard to make a diagnosis, but I kind of wonder about that. It could be partly, as you say, lack of awareness on the part of medical practitioners, but there is a test available. We heard Mr. Young's story about its availability in very few places. It seems to me that's more the issue. Unfortunately, this is quite a familiar story that we hear.

There are incredible technologies available in Canada for health care, but it's accessibility, so I think it's linked very much to the need for national guidelines and a national treatment program. It seems so inequitable that in some places you might be able to get the test, if you know where to look, and in other places you don't have a hope in Hell, because the right one doesn't exist.

I'll put this question as well to the foundation. I think they're here on Tuesday. But I wonder if you have more information about that. It's not that the diagnosis is hard, it's that people don't have access to the testing and they're not being referred to it. Is that a more accurate description?

Ms. Elizabeth May: I think it's actually true that it is hard to diagnose, because it presents with a cluster of symptoms that can be other things.

Ms. Libby Davies: But wouldn't a physician then say, okay, you might have this; let's go test you? It could be fairly straightforward.

Ms. Elizabeth May: That's right, but as I said, some of the lab blood tests that people thought were reliable could come back negative when a person actually has Lyme disease.

One of the doctors I've spoken with, who was actually copied on a letter from the Canadian Medical Association, Dr. Edward Carmode, is very clear that we ought to be able to trust that a doctor, looking at a patient in his office, can make a clinical diagnosis for himself or herself. With the right set of indicators, they could make that diagnosis and order a course of antibiotics, particularly when it's timely and it matters to move quickly.

I'm not going to jump into this discussion and suggest what doctors should or shouldn't do. I think the medical community is going to share its best information through the process of developing this federal framework so that everybody knows the guidelines and how to move forward. No doubt we could develop better tests than what we now have.

We need to be able to be sure, as you say, that there is not this terrible inequity. If somebody is feeling ill and they don't think about Lyme disease when they go into their doctor's office, it's the luck of the draw that the doctor is going to think of it. Sometimes the patient can be carrying a Baggie with a tick in it, and it's the luck of the draw whether they get a doctor who says, “Oh, how smart of you to bring me the tick, I'll have it analyzed to see if it has the bacteria”, or he throws it in the trash and says, “I think you're fine. I think you're down with a touch of the flu and you'll be fine in a few days.”

Right now, it's extremely spotty to find a clinician who knows what to look for, to find a lab that can do the test, and to get treatment quickly. So many people have to go to the U.S., which is really a harsh indication that our.... I mean, I believe in our health care system and I think we have a wonderful health care system, but this is an area that needs a lot of improvement because of the spread of this disease.

● (0940)

The Chair: For the last few minutes, do we have Mr. Lunney, or is it Mr. Young?

Mr. Terence Young: I'd like to make a comment briefly.

Mr. James Lunney (Nanaimo—Alberni, CPC): We can split the time.

Mr. Terence Young: Thank you.

I previously mentioned my constituent Janet Mitchell, who refused to believe her doctor that she didn't have Lyme disease. But she's a critical person. She's a former councillor. She's well read. She's intelligent. She has resolve.

I guess there is a phenomenon happening that I would call “empowered” patients—patients who challenge their doctors. Most people are afraid to challenge their doctors. On the one hand, we have doctors who are waiting for guidelines and are throwing away ticks that may hold a deadly poisonous bacteria and not understanding, and then we have patients who go on the Internet and diagnose themselves and pursue treatments on their own.

I do want to get on the record that the test I mentioned, the Western blot test, is only provided in southern Ontario, to my knowledge, by a company called IGeneX, out of California. It's available through some naturopathic offices. I want to get that on the record for anybody who is reading the transcript of this hearing.

Thank you.

Dr. Lunney.

Mr. James Lunney: Thanks very much, Elizabeth, for bringing this forward to us. It's a growing problem, and a troubling one. I appreciate that you covered very well in your opening remarks about the need for prevention, for quick diagnosis, and then sharing best practices.

In terms of looking at the diagnostic tests, I've been trying to get a handle on this. We haven't had experts here to advise us. It's a little unusual to start a study without expert opinion in front of us.

But this ELISA test, this enzyme-linked immunosorbent test, is to detect antibodies. The Western blot test is also to identify antibodies reacting to certain proteins on the organism. As well, there is a polymerase chain reaction test.

It's a spirochete that we're talking about here, which causes other infections as well. This particular one is very problematic, tick-borne, but as you mentioned it also can be carried by dogs, white-footed mice, horses, and it may be that as ticks are moving around, other animals are carrying these ticks as well. We're in a farm area on the island. It may be that we have other animal vectors that we haven't been cluing in on.

I think we need to get a handle on best practices, and I appreciate that you've brought it forward for discussion. We need to find the appropriate diagnostic tests because the spirochete can be hiding in various tissues and toxins. It seems to be a bit of a masker and impairs, binding with other proteins in the tick, causing immunosuppression and delayed response. We need to get a better handle on exactly what the mechanisms are.

I hope we're all going to learn more as we work through the process and as we get the Lyme society speaking, and experts appearing before committee as we have a look at it.

Elizabeth, thank you for bringing it forward. I appreciate that we have an opportunity to learn something and to help advance the treatment of a troubling syndrome that's developing.

● (0945)

Ms. Elizabeth May: Thanks so much to you, in light of what you were just saying, and thanks to Terence for mentioning the company IGeneX. The president of the company, Nick Harris, speaking in 2006, pointed out that part of the problem, in his opinion, is that about 20% of Lyme disease patients never make the antibodies, or they're only present at very low levels. That makes it harder for testing.

Clearly, the diagnostics can be improved. Science is always moving forward. I'm not going to jump into saying which test is going to be better than another. I'll leave that to the medical community.

I just want to say that I am a bit apologetic about being your first witness. I did push back a bit, saying “You don't need to hear from me, we should only hear from experts”, but in consultations with the health committee, I was asked to come forward first. I feel as though it would have been a better hour to hear from somebody who is an expert in the field. All I am is a member of Parliament who thinks that we ought to do something.

I think the structure of this bill will bring a significant shift, federally and provincially. Territorially is not so much of a problem because, territorially, the ticks haven't spread that far. I haven't heard of a territorial case of Lyme. It's spreading very quickly in southern Canada, but we do want to make sure that we're cognizant of our role as a federation and involve federal, provincial, and territorial ministers of health in getting to the best possible federal framework to prevent, treat, diagnose, and understand this disease better. That's going to include all those very complicated issues around why it is difficult to diagnose.

Certainly, we have better treatments than we did 10 years ago. We know what to do in ways the medical community didn't know, even a decade ago. Getting the match of the patient, who needs the help, with the right treatment as quickly as possible is something we can help with by getting this bill through as quickly as possible.

The Chair: You have time for one brief comment.

Mr. James Lunney: With diagnosis, it's so important to establish what you're treating, because long-term courses of antibiotics are really problematic. The World Health Organization recently put out an alarm bell on this, that we're developing resistant organisms. We want targeted treatment that's actually effective rather than broad-spectrum treatment that is missing the mark and perhaps contributing to antibiotic resistance.

Ms. Elizabeth May: That gives me another chance to thank your side of the House, and particularly Terence, for bringing forward Bill C-17, because we shouldn't always believe what the pharmaceutical industry tells us. We should rarely believe it.

The Chair: Okay. That's great.

That concludes the first hour of our meeting. We're going to suspend for a minute to allow our guests to come up: Ms. Bottles, Ms. Powell, and Mr. Wilson.

● (Pause)

●

● (0950)

The Chair: Welcome back, ladies and gentlemen.

We're in the second hour of our meeting. We have three witnesses here.

Ms. Bottles and Mr. Wilson are each going to do a 10-minute presentation, and then we'll open it up to questions and answers again.

Mr. Wilson, you may go first, sir, for 10 minutes or thereabouts. Thank you.

Mr. Jim Wilson (President, CanLyme): Thank you, everybody. Thank you for giving the Canadian Lyme Disease Foundation this opportunity to speak before you today on this very important issue.

Thank you, Elizabeth May, for putting this important bill forward.

Bill C-442 is a very important first step toward developing a made-in-Canada solution to a very serious illness now affecting Canadians in the thousands. Lyme disease is a bacterial infection caused by a spiral-shaped organism called Borrelia, and we have many strains of Borrelia in Canada and North America. Therefore, Lyme disease is a Borreliosis.

The first case was confirmed in Canada in Ontario in 1977. Here we are in 2014, almost 40 years later, and we still do not have a good definition of what Lyme disease is. Tens of thousands of Canadians have been tested for suspected Lyme over the past decades and have been wrongly told they didn't have Lyme, based on a test that cannot look at all strains of Borrelia. Yet all research and testing has stemmed from only that one strain that is recognized in the current testing model. To date, it is that poor test that has defined what Lyme disease is.

It's been known for decades that we have multiple strains. They are not new, and more strains are still being discovered as technology improves. The Public Health Agency of Canada recently published a paper showing that we have a strain of Borrelia called miyamotoi, and we have that coast to coast. There currently is no human blood test for that particular strain of Borrelia that causes Lyme disease.

In reality, Canada has no idea how much Lyme disease is in our chronically ill population. An entire set of guidelines was created in the United States that revolved around that one strain, to the exclusion of all other strains. The U.S. guidelines were adopted overnight in Canada without any discussion except within a small group of individuals from within government and the infectious disease community, who were also in regular contact with that small group of their peers in the United States who created the now infamous guidelines.

We patients and our experts were excluded from those discussions despite our years of repeated requests to be involved. As a result, our hard questions were never considered and never heard. As a result, we have a much larger problem on our hands now.

The first Lyme society was formed in B.C. in 1989 by Diane Kindree. Another was formed the next year in 1990 in Ontario by John Scott, a researcher who has now since published many papers on Lyme disease, its genetic diversity, and how it is transplanted randomly in vast numbers by transplanting the ticks via migratory birds, both on the north-south migratory flyways and the east-west migratory flyways.

Since then, the victims of Lyme disease have been connecting with scientists and physicians around the globe, developing a great deal of expertise. We've pointed out many times since then that testing was flawed and that many Canadians were falling through the cracks—or actually, falling through the gaping holes.

It has come to our attention that there is this amendment to the wording of Bill C-442 changing the term “standard of care” to “best practices”. As soon as Lyme patients from across Canada heard that mentioned on television, we got inundated with calls and e-mails from patients. That term terrifies patients. Many years ago, without giving a fair hearing to the patients and their experts, those poorly contrived, narrowly focused guidelines were imposed and from that point forward were referred to as “best practices”.

● (0955)

People with Lyme disease became not only the victims of the disease, but they became the victims of best practices. The term best practices became the phrase most used in media and literature to simply quiet the discussion, as though some all-knowing group had everything under control. They did not, and we have a huge and growing problem in Canada and around the world. The U.S. government announced last summer that they had been underestimating the number of cases of Lyme disease: instead of 30,000 cases a year, there are 300,000 cases per year.

Patients were too lowly to be listened to, despite our warnings since the early nineties. In one letter sent to us here at CanLyme from the Public Health Agency of Canada, in response to our request to be at the table for policy and guideline discussions, we were told we were just an advocacy group, end of story.

We pointed out that we had expertise in all the necessary fields of science and medicine at our fingertips, and that we had a great deal to offer; still nothing.

We pointed out that we had a vested interest in what they were deciding, as we represent the most significant and important stakeholder—the victim—whose life is directly affected by what they decide; still nothing.

Best practices continued to be imposed upon the system, yet there was no diversity of opinion allowed in their creation. Diversity of opinion is the foundation of a healthy society.

Best practices for Lyme are currently wrong on many levels, yet any physician who dares operate outside of these best practices is immediately targeted and sanctioned. Less than 2% of all physicians are investigated because of their practices, yet almost 100% of physicians in Canada who dared use their best judgment on Lyme issues and not followed the poor best practices have been effectively shut down. The complaints in almost 100% of these cases against the doctors did not come from patients; they came from specialists who did not like their initial diagnoses being questioned. The complaints were specifically that the doctors were currently not following best practices.

Best practices currently trivialize the many symptoms caused by Lyme disease, labelling them in writing as the aches and pains of daily living.

These so-called aches and pains of daily living have been causing people to no longer be able to work or go to school. These aches and pains of daily living have been putting people in wheelchairs, continuing to confine them to bed, or, in an unknown number of cases, causing death.

These are hardly the aches and pains of daily living.

Best practices ignore the fact that thousands of Canadians have been misdiagnosed with having everything from multiple sclerosis, Alzheimer's disease, Parkinsonism, Lou Gehrig's disease, lupus, chronic fatigue syndrome, fibromyalgia, psychiatric disorders, various forms of arthritis, and many more, only to find out later it was treatable, chronic Lyme disease all along.

Best practices have allowed inadequate level-3 evidence to guide health care, when only level-1 evidence should be allowed where lives and health are at stake. Best practices have denied treatment for chronic Lyme disease because the best practice states there is no such thing as chronic Lyme disease.

Each committee member will be receiving a compilation of references to over 300 published papers that show quite convincingly that chronic, active, persistent Lyme disease, beyond short rounds of antibiotics, is very real. Best practices ignore and dismiss this body of research; no discussion allowed. Instead, they made up a name for symptoms after short-term antibiotics, calling them “post-treatment Lyme disease syndrome”, a term for which there is no research to support; no discussion allowed.

● (1000)

We haven't even identified what Lyme disease is yet, and we have not explored all the various strains of Borrelia for their response to treatment and for their broad symptomatology. Yet we have best practices in place and enforced.

Physicians refuse to diagnose and treat Lyme disease regularly by claiming they follow best practices. Tens of thousands of people who chose to ignore best practices now have their life back, including me and my daughter. My son didn't make it, though. He passed away in 2005. I contracted Lyme disease in 1991 in Dartmouth, Nova Scotia. My children contracted their infection in B.C. a decade later, along with other kids in our area, another of whom is deceased as well.

If this committee recommends the change of wording from “standard of care“ to “best practices“, we believe it must be made clear in the wording that there can be no best practices put in place without full participation and approval of the victims and their chosen experts. We cannot continue to allow the current autocratic system to further erode what should be a common-sense democratic process of evidence-based health care. That demands a diversity of opinion.

Bill C-442 is only a start, but it can be the hand that opens the door to a new era of cooperation and discussion. If we simply use the term best practices without open discussion and all-inclusiveness, then that door will quickly close again.

According to Health Canada, we have two million Canadians suffering from conditions of unknown origin, many of which, as I mentioned, are those misdiagnoses given to Lyme patients. We have no idea how many in fact have Lyme disease, but we do know that number is significant.

Those chronically ill people are also the biggest user group of our health care dollars. Many of those people have had their careers stopped short. That affects employers from coast to coast to coast. Still others will be unable to enter the workforce and will instead draw on our public disability payment systems.

There is much more needed to be done. Victims and their experts must be allowed an equal voice at all levels from this point forward.

The Chair: Excuse me, Mr. Wilson. We're quite a bit over time. Are you close to concluding?

Mr. Jim Wilson: Ten seconds.

● (1005)

The Chair: Perfect. Thank you.

Mr. Jim Wilson: CanLyme supports Bill C-442, and our preference is that the wording not be changed to reflect best practices over standard of care. The term best practices has been used far too many times to justify the wrong directions.

Besides, what purpose does the term best practices serve other than to make a claim of excellence and highest standards? History shows us the term was used to hide behind or to ignore contradictory research and opinion. Do we need that again? Ask yourself why.

Thank you.

The Chair: Thank you very much.

Next up, for ten minutes, is Ms. Bottles.

Go ahead.

Ms. Nicole Bottles (As an Individual): Thank you so much.

My name is Nicole Bottles, and I'm here with my mother and caregiver Chris Powell. l'm 21 years old and live in Victoria, B.C.

I'd like to give you a glimpse into my personal battle with Lyme disease, and also remind you that I am not alone in my struggles. My story mirrors that of so many Canadians whose progression of illness follows a similar path: a mysterious illness; multiple specialist visits; negative lab work; which culminates—possibly years later—with misdiagnosis or no answers at all. The tragedy is that the longer you leave this infection unchecked, the more dire the consequences.

I was 15 and halfway through my grade 10 year, eager to be planning my future. All that changed when, several months into a prolonged illness, I realized one day that I couldn't get out of bed, not even to attend a few hours of school. It was one of the hardest decisions I've had to make.

My symptoms began in 2006 with migraines, breathing problems, and fatigue, and gradually expanded in 2007 to migrating joint pain, dizziness, nausea, weakness, and memory and concentration issues. As my mysterious illness progressed in early 2008, I developed intense pain, swollen joints, exhaustion, severe short-term memory, and cognitive impairment. Within a few months, I was no longer able to walk, remember new things, go to school, or live in a way that could be conceived as tolerable or acceptable.

The culprit, we would later discover, was a tick the size of a poppy seed. We visited many specialists, none of whom could figure out why I went from being a healthy, active teenager to a girl barely able to walk or function.

The months that passed between the initial onset of my illness, the specialists' circuit, and my eventual American diagnosis wasted precious time and resulted in my becoming much, much sicker. At this point, I will most likely suffer permanent damage from the infection.

While doing research, my mom learned about a complex bacterial infection that could wreak havoc with every organ and body system and cause severe neurological problems. All my seemingly unconnected symptoms matched a classic manifestation of this infectious disease, which I had yet to be tested for.

I was so relieved we were on the right track, and I assumed that with a few months of antibiotics I'd be fine. We didn't know about the controversy, but we learned quickly when we brought a checklist of Lyme disease symptoms to my specialist appointments. I had three-quarters of the symptoms at that point.

We weren't prepared for the unusual response that inquiries into Lyme disease elicited. “Lyme disease is very rare” we were told by every specialist as they completely disregarded our concerns. I needed to “start living” with my disability, and essentially get on with my life, which at age 15 was unacceptable.

After months of repeatedly requesting to be tested, I was finally given the ELISA test. Like so many other Canadians, I had a negative test result, which doctors incorrectly assumed rules out Lyme disease, despite my classic clinical symptoms. We weren't aware of the 2005 NIH study at Johns Hopkins University, which showed that the test is less accurate than a coin toss. More sensitive serological testing available from U.S. laboratories like IGeneX later revealed that in fact I did have Lyme disease.

With no diagnosis in Canada, and my health rapidly deteriorating, my family made the difficult decision to seek the help of Lyme-literate experts in the United States, as thousands of other Canadians do. We lived in Connecticut for 10 months of intensive treatment. It was a choice that saved my life and started me back on the road to health.

Four leading experts clinically diagnosed me with Lyme disease and two co-infections. Almost six years of antibiotic and natural therapy are slowly helping me to regain my well-being. I no longer experience seizures and blackouts, and my pain, overall cognitive ability, and abdominal issues have improved.

In spite of my illness, I graduated from high school in 2010. I love teaching knitting classes at my local library; I practice yoga, I sing in two choirs, and I try to “fill the unforgiving minute with sixty seconds' worth of distance run”, as Rudyard Kipling wrote. I've come a long way but realize that I still have a long journey ahead of me.

● (1010)

Over the course of the past five years, I've seen three infectious disease doctors in Victoria. Each stated categorically that I do not have Lyme disease, based solely on the flawed negative ELISA test. They did not take into consideration the 85 years of collective experience from the four U.S. physicians I've seen, who've treated thousands of patients with Lyme disease. One of the ID doctors admitted they had never seen a case of Lyme disease in their 10 years of practice.

The *Canadian Adverse Reaction Newsletter* in October of 2012 stated that: “Serological test results are supplemental to the clinical diagnosis of Lyme disease and should not be the primary basis for making diagnostic or treatment decisions.” Additionally, the article stated emphatically that Lyme disease test kits are not designed to screen patients or to establish a clinical diagnosis.

Another example of the need for doctor education can be seen in the results of Dr. Bonnie Henry et al from the BCCDC survey of over 1,600 doctors in British Columbia: 63% of the physicians did not know that the “bull's-eye rash” was diagnostic of Lyme disease. The gulf between the medical literature and patients' experiences in their doctors' offices has a far-reaching impact.

The most heartbreaking part of our collective story is the unnecessary suffering. Lyme disease is easily cured in its early stages with $100 worth of antibiotics. Instead, like so many Canadians, l've spent the past six years battling this illness and the medical establishment, while my family has accumulated well over $100,000 in medical bills not covered. Our family home was sold, bank accounts and life savings drained. My father is 67 and is unable to retire due to the financial burden.

A 2006 study from the CDC found that the annual burden of disease, the BOD, when Lyme was treated early in the course of infection, was under $1,500 for only one year. If the illness was left untreated, developing into a chronic infection like I have, the burden of disease jumped to $16,000 per year, every year. The cost of being misdiagnosed is astronomical for our health care system. The cost to patients could be their lives.

There are two standards of care for the treatment of Lyme disease. Patients are abandoned in our current system, because Canada follows the IDSA guidelines that limit our ability to access care beyond 30 days, as stated in the treatment guidelines. The polarity between the IDSA and the International Lyme and Associated Diseases Society, that advocates patients be treated until their symptoms resolve, suggest that the two standards of care need to be re-evaluated.

Lyme disease is a global issue. We need a made-in-Canada framework, such as the regionally specific strategies adopted by Germany and Scotland. The Schmidt report, commissioned by the B. C. PHSA in 2011, investigated the challenges faced by Canadian Lyme patients and outlined a bold action plan. Tragically, none of the eight recommendations have been implemented, but could serve as a blueprint for the constructive change the national framework envisions.

After decades of denial and suffering, and a crippling deficit of knowledge, our country's ability and willingness to fight the Lyme epidemic is at a turning point. Ahead, the changing climate and human encroachment on wildlife habitat will lead to an explosion in tick population. The national Lyme disease strategy, if successfully executed, will set about reconciling the two standards of care into a workable set of guidelines, transforming a toxic situation into a constructive environment for patient care.

When I first became ill, I made a promise to myself that I would do everything in my power to ensure that others would not have to endure life in Canada as a Lyme-leper . l'm asking you to do the same.

Thank you so much.

The Chair: Thank you very much.

We'll go into our rounds of questions now.

First for seven minutes, Ms. Davies. Go ahead.

Ms. Libby Davies: Thank you very much, Chairperson.

To both of the witnesses, Mr. Wilson and Ms. Bottles, thank you so much for coming. I'm sure it's not easy to come before a parliamentary committee and literally bare your life to us and put it on the table. I really want to say thank you for sharing your own experience, because I think it does help us understand what you're facing.

We have a brief opportunity here; we have this meeting today, and then there's another meeting on Tuesday, where we'll go through the bill clause-by-clause to look at amendments. There's a brief window here to get it right. I'm sure you're hoping that we do get it right, and the information you've provided us is invaluable.

I have lots of questions, and I'm sure we won't necessarily get to all of them.

First of all, Mr. Wilson, you spent a lot of time talking about the amendments. I'm sure you've read the bill. The bill as it is now, in paragraph 3(b), says:

> the establishment of guidelines regarding the prevention, identification, treatment and management of Lyme disease, including a recommended national standard of care that reflects current best practices for the treatment of Lyme disease;

You suggested that there will be a government amendment. We didn't hear them from Ms. Adams earlier, so maybe others are coming, but you're suggesting that this paragraph is going to be changed to talk only about best practices.

Are you happy with the way it's written now? It still does say “reflects current best practices”, but you're telling us that really doesn't fit the bill.

● (1015)

Mr. Jim Wilson: Right. Current best practices are a real sore point with us and patients, because the term best practices implies they were derived and developed with an all-inclusive, diverse opinion, where input came from all directions. The current best practices have been developed by very few people.

Ms. Libby Davies: Are you okay with the way paragraph 3(b) is written? Or do you think that this is going to create a problem? It does say “reflects current best practices”. It does talk about a national standard of care.

Mr. Jim Wilson: My understanding is that it was going to be amended to just reflect best practices.

Ms. Libby Davies: But are you okay with the way it's written now?

Mr. Jim Wilson: We would prefer that the term best practices not be used, or, if it is going to be used, it cannot be used in the framework of “current” best practices, because the current best practices are terrible.

Ms. Libby Davies: Okay. Well, that's helpful, because we will be getting to amendments.

Based on what you've said, Ms. Bottles, which has been very helpful, is the whole question of testing. Both of you spoke about this.

I find it so surprising that you had to go so far to get the test you needed to get a proper diagnosis. Is it that the test that you did finally get, and the treatment you got in the U.S.—I think you said you had to live in the U.S. over 10 months—was not available to you in Canada?

Ms. Nicole Bottles: The test has to be ordered through a physician. The laboratory is in the States. If you went to your GP or an infectious disease doctor, they would tell you outright that this test is from an unaccredited lab, that the results therefore cannot be trusted. I've taken that test to many doctors and heard the same thing.

Ms. Libby Davies: So when you did get the tests done, and you got the diagnosis in the United States—I think you mentioned from four physicians—when you came back to Canada it wasn't recognized here, is that it? So as far as the Canadian system is concerned, you're not seen as someone who's suffering from Lyme disease, is that correct?

Ms. Nicole Bottles: That is correct. They are positive that I do not have Lyme disease.

Ms. Christine Powell (As an Individual): They don't know what she has, but they're positive that she doesn't have Lyme.

Ms. Libby Davies: That's really quite incredible.

Mr. Jim Wilson: Could I add a little bit to that?

Ms. Libby Davies: Yes, please.

Mr. Jim Wilson: We hear that from doctors and from people from coast to coast, that IGeneX can't be trusted; they're offering positive results just for a fee; they're a for-profit lab; therefore, they're not to be trusted.

I don't think Canadians in general understand the testing process currently in practice in Canada. Our Canadian labs don't develop their own ELISA test and Western blots. They buy pre-manufactured kits. These pre-manufactured kits are from corporations who are for-profit corporations in the United States and in Europe.

Now, we approached one of those corporations in writing and asked them specifically why their test only incorporates Borrelia burgdorferi strain B31 as the foundation of the test. Why aren't they incorporating more strains to reflect what's out there in nature? They told us in writing that they are dictated to by the United States Centers for Disease Control as to what they can include in their testing in order to be licensed to sell to governments.

● (1020)

Ms. Libby Davies: Can I just ask you one other quick question so we can get it on the record?

Are there any other amendments to the bill that you would like to see? This is our opportunity to hear from you about what they are so that we can consider them. You've looked at the bill. We've talked about that paragraph 3(b). I understand what you're saying. Is there anything else in here that you think...?

I mean, when a bill is drafted, the sponsor has the best intentions, but I can tell you that when we all do our bills, there are often things that are consequential that you didn't know at the beginning. Is there anything else that you think needs to be modified or improved?

Mr. Jim Wilson: I think if we clarify the patient's role in and around what will be called best practices, the patients and their experts, then I think it's a very good bill.

Ms. Libby Davies: Thank you.

Mr. Jim Wilson: I just also wanted to point out that when I asked that company why they did not incorporate that, they told me that... because the United States Centers for Disease Control, but they also said in writing to me that if we want broader testing, they suggest we contact IGeneX , a lab in northern California.

Now, the word across Canada is this is an unaccredited for-profit lab. That is wrong. They are a fully accredited, certified, proficiency-tested laboratory, run by Ph.D. microbiologists. They use multiple strains in their Western blot, unlike Canada. That is why they're having much more success. They also are the only lab we're aware of in North America that is using strain 297, which is a human-derived strain out of the cerebral spinal fluid of a woman with Lyme disease. All other strains used in tests in North America are tick-derived. We think, from a microbiological perspective, that has considerable significance.

I just thought I would put that in.

Ms. Libby Davies: Thank you.

The Chair: Thank you.

Ms. Adams, seven minutes.

Ms. Eve Adams: Thank you very much. I'll be splitting my time with Mr. Lunney.

I'd like to thank all three of you for coming forward.

Mr. Wilson, you certainly have vast knowledge on this issue.

Ms. Bottles, your extraordinary experience, with the support of your mother and your family—you're very good people. I feel terrible for what you've been experiencing. I want to commend you for sticking with school and graduating. Hearty congratulations on that front. I know just from how well spoken and how poised you are, and what an outstanding advocate you are on this front, that you are really going to do great things. So congratulations on that.

I'd like to focus a little bit on your journey, Ms. Bottles. You contracted the disease. What were those first days like? How long until you finally went to the doctor? Just if folks are looking up the record and are trying to self-identify here, what were the symptoms you felt in those first days? How long until you finally went to the doctor? What were you presenting with?

Ms. Nicole Bottles: It was a progression of a thousand knives. One day it was “I'm a little bit more tired”. The next day maybe a particular joint was hurting. It wasn't like one cataclysmic event.

To be honest, I've had health problems since early childhood, so I think I've possibly been sick for most of my life. But I guess I realized I was having quite severe breathing challenges, which is associated with Babecia, in addition to Lyme disease. Babecia is a co-infection. I don't know if you've gotten there yet.

I sort of developed a flu-like illness and bronchitis and pneumonia in 2008. That's when I never got better. That's the story we hear so often: someone got a weird summertime flu or a flu-like illness and then they just never recovered. They had another unrelated health problem and they never got better.

● (1025)

Ms. Eve Adams: Thank you. I certainly don't mean to pry.

Ms. Nicole Bottles: Not at all.

Ms. Eve Adams: I do want to thank you for sharing your health experiences. I know it's particularly trying.

You then went to the United States. You saw the physicians who diagnosed you with Lyme disease and then you had the treatment there in Connecticut for 10 months, I think you said.

How did you find that treatment? How quickly were you recovering?

Ms. Nicole Bottles: I have a lot of short-term memory problems, so I actually don't remember anything that's happened after June of 2008. If I could pass that question on to the lovely lady on my left, that would be great.

Ms. Eve Adams: Of course. I don't mean to put you on the spot.

Ms. Christine Powell: When we went to Connecticut, Nicole doesn't remember going there. She doesn't remember living there. She doesn't remember her doctors. If you put into a room those four doctors who were in Seattle, San Francisco, Connecticut, and New York state, she would never recognize them, and she has met them multiple times. That's how severe her short-term memory loss is.

If you asked her what year it was right now, she wouldn't have a clue.

Ms. Eve Adams: That is truly tragic.

Ms. Christine Powell: In terms of the onset of symptoms, it started off slowly but then the symptoms multiplied in 2008. She went from sort of having these flu-like symptoms in February of 2008 to a wheelchair by April. I could see that the medical profession was not going to get to the bottom of it, and I lived in the States for 22 years—I am Canadian, but I lived there for 22 years—and I just said we need to do something else. I actually thought she was going to die. That's how sick she was. She's still in treatment. I want you to know that she still is being treated. She's had a PICC line.

So it's not like she lived 10 months in Connecticut and, wow, all hell broke loose and she's fantastic. That was just the start of her being brought back to life, shall we say.

Ms. Eve Adams: Thank you for sharing your story. I can see by the anguish on your face just how stressful it is to relive watching your daughter suffer, so thank you very much for coming forward to share this.

Mr. Lunney.

Mr. James Lunney: Could you give me an indication, Mr. Chair, of how much time I have to work with?

The Chair: You have two minutes and 30 seconds.

Mr. James Lunney: Mrs. Powell or Nicole, could you give us an indication of what does treatment currently looks like? Are we talking about antibiotics, long-term antibiotics? What does treatment look like?

Ms. Christine Powell: Yes, we're definitely talking about long-term antibiotics, IV antibiotics in Nicole's case, and oral antibiotics. She has managed to survive that, shall we say. She did have an episode of pancreatitis in 2012, but that resolved in three days. Yes, it's a health risk, definitely, antibiotics; I completely agree. During her lifetime before she became ill with Lyme disease, she hardly ever had antibiotics.

It wouldn't be a choice that I would want for anyone, but I think without question it saved her life.

Mr. James Lunney: Thank you for that.

Mr. Wilson, did I understand you correctly that you contracted Lyme in Dartmouth, and your son caught it in—

Mr. Jim Wilson: My daughter and my son caught it within a year of each other in British Columbia. I contracted mine in Dartmouth, Nova Scotia.

I was sick for years before they finally figured it out. It required lengthy treatment for me to get my life back, but I was to the point where I could hardly walk. I choked on my food. I drooled when I talked. My mind had completely left me. I got in my car to go somewhere one day and my wife found me sitting out there half an hour later. I had no idea I had to put the key in the ignition.

I was 38 years old and I figured that was it, my life was over. My legs were rubber. I wasn't stable on my feet.

Mr. James Lunney: In terms of your recovery, are you still undergoing any kind of treatment?

Mr. Jim Wilson: No, I'm not.

Mr. James Lunney: So you sound like you've fully recovered.

Mr. Jim Wilson: I've recovered 90%. I still have some issues, but they're minor compared with what I was living like.

Mr. James Lunney: You had a very disappointing experience with the use of the term best practices. I understand that fully. We are quite aware of other examples where experts have not been up to dealing with emerging diseases, with different concepts. We're stuck in old models, and apparently we don't know everything yet, so we ought to remain open to examining issues. I understand your frustration.

But we're going to have to call it something. Standards of care can be just as bad, if they won't change, as best practices.

● (1030)

Mr. Jim Wilson: Absolutely—so long as it's understood it's collaborative and the patient does have input.

Mr. James Lunney: I certainly understand why you'd get an allergic reaction to that term, but we're hoping we can help you get back there, because we really do need best practices—that actually work.

Mr. Jim Wilson: True. I agree.

The Chair: Thank you very much.

Ms. Sgro.

Hon. Judy Sgro: Thank you so much.

Ms. Bottles, I recall meeting with you some time ago and your mom and others, and I never did forget that meeting. I think you know we're all tremendously sympathetic and we really welcome this opportunity put forward by Ms. May to do whatever we can to move this issue forward.

It doesn't make sense that you have to be here championing this issue, either one of you, for what you've gone through, but no one's going to question why God puts us where we are. There will be a special in heaven for all of you for the work you're doing on behalf of thousands of other people.

May I start with Mr. Wilson? Is there any connection at all to the horrific thing that you and your family have had to endure between your son, your daughter, and yourself? Have they been able to find anything in your past, or hereditary conditions, or anything? I'm sure they look for ways to blame it on many other things. How is it?

Mr. Jim Wilson: There hasn't been anything that they've been able to relate genetically. There is some suspicion that there is a genetic tendency in people who experience this chronic form of Lyme that is more difficult to treat. But such a huge percentage of the population carries that gene, what do you do with that information?

So we find that the most significant thing is the fact that we have a lot of Lyme out there and there are different strains. My sickness did not look like my daughter's, and my son's did not look like my daughter's or mine. Is that strain-related? Is that individualized to the individual? Is it dependent upon where in the body the organism has taken up its primary residence? Those are all things we don't know. There's so much about this organism that we don't know. We know nothing about these newly discovered ones.

I brought this little vial here just to give an example. Up until just recently, Borrelia bacteria were thought not to be passed from the mother tick to the egg. So these tiny little speck-like larvae you didn't have to worry about; it was the next-larger size, the nymph, which is easier to see.

But in this new Borrelia, Borrelia miyamotoi, the mother tick is able to pass this transovarially to the egg, and if she's infected and the eggs are infected, those larvae are hatched infected. In here, there are 65 little specks. These are the larval ticks that could be infected. If you look at them, you'll see that not only are they the size of a period at the end of a sentence, but they're almost see-through, transparent. They're flesh-coloured. So if they're on you, the chance of ever seeing one of these is very slim. So that's extremely worrisome.

Are there other Borrelia out there that we have not known about, or haven't properly investigated, that may also be passed transovarially? There's just so much we don't know. We don't know how Borrelia miyamotoi responds to antibiotics. No tests have ever been done. We don't know how severe the symptoms can become from Borrelia miyamotoi.

We also don't look at Borrelia hermsii, Borrelia bissettii, Borrelia curtainback, Borrelia californiensis, carolinensis. We have lots of Borrelia. Decades of focusing on Borrelia burgdorferi, strain B31, that's used in the test.... I want to point out that this is a laboratory strain. It's a non-wild strain. If we're going to be doing proper human diagnostics, we've got to be using today's best technology to measure what they're running into in the wild, not a cloned replica in the laboratory, because it's been washed out.

There's a lot that needs to be done. A lot of this we have been stating for years, not on our own but with the backing of our experts on four different continents. We collaborate with experts and all kinds of fields of science. We're also working with the G. Magnotta Foundation, a newly formed foundation in Toronto, to begin to do the first human tissue study program, where we're going to use today's most advanced DNA technology to start looking in the tissues of these patient groups with MS and Parkinsonism and Lou Gehrig's and Alzheimer's and chronic fatigue syndrome and fibromyalgia.

But we can't do it alone. This is an enormous undertaking. We have developed protocols. We've worked with scientists on those four continents who have helped us put this whole protocol together. It's going through the process right now. But we cannot do this alone. We're going to need the assistance and the collaboration of governments for this. It has to be done. We're talking about a huge number of people and an incredible financial hit to the Canadian economy. That's already under way. We just have no way of measuring it at this point.

● (1035)

I think if we use today's next-generation sequencing technology we will begin to understand that. I can use an analogy that one of the Genome Canada-funded scientists gave to me to explain what they are capable of doing. He said that right now the Western blot is like using a magnet to go over a haystack looking for the needle. There are a lot of variables in there as to whether you are going to find that needle or not. But using new next-generation sequencing, not only are you going to immediately find the needle but you are going to be able to identify every piece of straw in the haystack and every living organism on every piece of straw in the haystack.

Now, that's powerful technology, and that's what we need to be using to move these health issues forward. Nobody is satisfied with Lyme disease; and the argument isn't just whether we should have long-term antibiotics or not, because we know, too, that's not the answer in some cases. It is certainly beneficial to the majority who suffer from this chronic disease after the short-term treatment process, but there are others who still for some reason are struggling with the treatment and not responding. So there is a lot we need to do.

Currently there has been an avoidance of looking in the human, and we've got to get back to that, because that was the foundation of science. We've got to allow the other foundation of science, out of medicine and health care, to be put back in the system, which is allowing that doctor with that patient to use that physician's best judgment and not be overshadowed with this threat that currently the doctors are under. We have probably heard that 100 times a year from patients getting it related to them by their physician: “No, no, I'm not diagnosing Lyme; I'm sorry, you will have to go south of the border or somewhere else. I'm not touching that. I have a licence, and I have children.” Those are the comments we get.

So I think we can really improve things and move things forward better if we work collaboratively. We have a great deal to offer in that regard.

The Chair: Thanks very much.

I just want to mention as well in regard to amendments that my clerk has advised me that we are going to need them in by Monday at noon if they are going to be ready for Tuesday. I just put that out there now and if anybody needs any clarification we can provide it.

Mr. Lizon, seven minutes.

Mr. Wladyslaw Lizon: Thank you, Mr. Chair. I will share my time with Terence Young.

I'm a little bit confused here, because I don't think we have enough knowledge. I'm not a medical expert, and therefore in regard to all the information we've been given it would be nice to hear from the medical professionals and scientists about actually where they are currently.

I understand that we hear your side of the story and you are on the receiving side of the line. But there is the other side, and I don't know whether we should assume that there is a group of doctors who don't want to work in good faith or if there is something that has not been developed.

I just checked what is happening and recommended in Germany, for example. The Robert Koch Institute as a diagnosis recommends two stages. First, they do an ELISA test before they recommend to do the Western blot. Therefore it would be nice to hear from our scientists what is available, where they stand, and how they collaborate with scientists around the world, because this is probably not working in bad faith but we are probably not there yet where we can provide easy testing to the patients.

I understand your frustration, but the question I have is this: if you had a knowledge of how to prevent it, would it prevent your disease or your kids' disease?

● (1040)

Mr. Jim Wilson: What was the question again?

Mr. Wladyslaw Lizon: If you were aware of the tick bites and paid attention, would it prevent your disease?

Mr. Jim Wilson: Do you mean, if I knew I had a tick attachment, what would I do at that point?

Mr. Wladyslaw Lizon: That's correct.

Mr. Jim Wilson: I would insist on antibiotics before they identify the tick, before they have the tick tested, or certainly before an ELISA is run, because the human does not build antibodies to this bacteria until four to six weeks after infection. By that time, the disease is disseminated into your system.

Mr. Wladyslaw Lizon: Well, let me tell you something. I travel to Europe quite often, and if you go there you can see—especially in the summer on TV—ads very often, many times a day, saying that if you have a tick and it is identified, go to a doctor; don't try to remove it yourself. You are given antibiotics whether you like it or not; that is the procedure. Also, if you decide to remove it yourself, they show you how to do it properly, because you can leave part of it in your body, wherever the bite is, and the removal of it is ineffective.

This is happening there. I don't know why it shouldn't be happening here. That is where I was coming from.

Had you known, would this have helped you and your children—or you, Nicole?

Ms. Nicole Bottles: Absolutely. I wish I had listened when we did a little research about Lyme disease a while ago and I met a deer in the forest. My mother said, “Oh, you could contract Lyme disease”, and the end of the argument was “But it's treatable with antibiotics”, and I wasn't concerned.

Of course I wish I had known that something so small could have such an impact.

Mr. Jim Wilson: The point also is that most people whom we hear from do not know they have had a tick attachment; they are completely unaware that they have encountered a tick.

If you look at the biology of the tick and what they're capable of, you learn that if a tiny little nymph tick crawls on you—they are already only the size of a poppy seed, and as you see, the larvae are much smaller than that—the first thing they do when they find a place to feed on you is inoculate you with a freezing, and so you don't know they're there. The next thing they do, once they stick their nose parts in and find a blood source, is secrete a bonding cement, and so they're not brushed off easily. Then they sit there and feed, and they can feed for days unnoticed, because quite often they're heading to private areas, under hair or in areas you're just not looking at, such as behind the knee. Most people don't recognize it.

The ELISA is not a good first test, especially if we're only going to use an ELISA that is still just looking for Borrelia burgdorferi strain B31. If we're going to stay on that strategy, then we have to devise better ELISAs, because the one we have currently is missing most cases.

● (1045)

The Chair: Thanks very much.

Unfortunately, we've come to the end of our two hours. This will conclude our first meeting on Bill C-442. I look forward to seeing everybody else here on Tuesday.

Thank you again to our guests for taking the time to be here and for providing your information.

Thank you. This meeting is adjourned.

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