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Official Report of Debates (Hansard)

Monday 1 June 2015

Journal des débats (Hansard)

Lundi 1^{er} juin 2015

**Standing Committee on
Social Policy**

Provincial Framework
and Action Plan concerning
Vector-Borne and Zoonotic
Diseases Act, 2015

**Comité permanent de
la politique sociale**

Loi de 2015 sur le cadre
et le plan d'action provinciaux
concernant les maladies
zoonotiques et à transmission
vectorielle

Chair: Peter Tabuns
Clerk: Valerie Quioc Lim

Président : Peter Tabuns
Greffière : Valerie Quioc Lim

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LEGISLATIVE ASSEMBLY OF ONTARIO

**STANDING COMMITTEE ON
SOCIAL POLICY**

Monday 1 June 2015

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**COMITÉ PERMANENT DE
LA POLITIQUE SOCIALE**Lundi 1^{er} juin 2015

The committee met at 1400 in room 151.

PROVINCIAL FRAMEWORK
AND ACTION PLAN CONCERNING
VECTOR-BORNE AND ZOONOTIC
DISEASES ACT, 2015

LOI DE 2015 SUR LE CADRE
ET LE PLAN D'ACTION PROVINCIAUX
CONCERNANT LES MALADIES
ZOONOTIQUES ET À TRANSMISSION
VECTORIELLE

Consideration of the following bill:

Bill 27, An Act to require a provincial framework and action plan concerning vector-borne and zoonotic diseases / Projet de loi 27, Loi exigeant un cadre et un plan d'action provinciaux concernant les maladies zoonotiques et à transmission vectorielle.

The Chair (Mr. Peter Tabuns): Good afternoon, everyone. We're here for public hearings on and clause-by-clause consideration of Bill 27, An Act to require a provincial framework and action plan concerning vector-borne and zoonotic diseases. Please note that copies of all written submissions received to date are distributed to the committee today.

Each presenter will have up to five minutes for their presentation and up to nine minutes for questions from committee members, which will be divided equally among the three parties; the first rotation will be with the official opposition. For those who are presenting, about 15 seconds before you're due to wrap up, I'll ask you to wrap up, we'll end and we'll go on to the next piece.

ONTARIO LYME ALLIANCE

The Chair (Mr. Peter Tabuns): Our first presentation: Kim Kerr. Ms. Kerr, if you'd have a seat and introduce yourself for Hansard.

Ms. Kim Kerr: Hi. My name is Kim Kerr. It was missed on the sheet that I am a member of the Ontario Lyme Alliance.

After 10 long years of fighting Lyme disease, I'm here today as a recovered Lyme disease patient, a patient advocate and a Lyme educator. The Canadian medical system and its current Lyme disease guidelines failed me, as it does so many Lyme patients in Ontario. We are abandoned and left to fend for ourselves.

I recognize that Bill 27 was written to bring positive change for Lyme disease patients. But without the inclusion of informed patients, scientists and medical experts, this legislation will result in no more than the status quo, preventing the progressive change so desperately needed for Lyme patients and our society. All the same testing and treatment guidelines for Lyme disease will continue to be used. None of the current evidence-based science which reflects a very different approach to Lyme disease will be adopted.

Equal participation by representatives of patient groups, along with international Lyme disease medical experts, is essential. It will ensure the framework and action plan on vector-borne and zoonotic diseases will begin to resolve the issues relating to Lyme disease and other tick-borne infections.

Our current Lyme disease testing is recognized as being unreliable. To quote from the Public Health Agency of Canada's website, "All lab tests have a margin of error which is why Lyme disease should be diagnosed by a doctor clinically first and foremost."

However, this being said, infectious disease doctors still refuse referrals from GPs without a positive Canadian test result. We have many examples of this in writing. For years, unknown numbers of Lyme patients have gone undiagnosed because of this flawed Canadian testing.

Early diagnosis and treatment, with the appropriate antibiotic protocol, can stop Lyme disease in its tracks. Left untreated or inappropriately treated, the outcome can be deadly. Lyme disease progressively spreads throughout the body, affecting joints, organs, tissues, the central nervous system and the brain, leaving nothing untouched.

Misdiagnosis is common for Lyme patients. They are incorrectly told they don't have Lyme disease, but instead are labelled with a multitude of other diseases, such as fibromyalgia, MS, Parkinson's, and the list goes on.

When I suspected I had Lyme disease, even though the Canadian tests and doctors said I didn't, I ordered and paid for an alternate Lyme test done by a very reputable California lab. This test came back positive for Lyme disease, but even with that positive result, there were no medical professionals willing to see me or who had the expertise to treat what had now become late-stage Lyme. With the lack of proper medical care here in Ontario, I became critically ill. I, as many other Lyme patients, was on my own.

Although I was terrified to leave the Canadian medical system and enter a foreign system, it was the best decision I could make to pursue treatment by an American doctor who had the experience and expertise needed for treating late-stage Lyme. She saved my life using a much different set of treatment guidelines. The disturbing thought is that this same life-saving treatment is not even an option here in Ontario.

Due to the out-of-pocket expenses of travel, consultation fees and prescriptions, American treatment is not an alternative for many Canadians. For those who can't afford it, their lives are taken from them. Our medical system fails the Lyme patient, resulting in chronic illness, unemployment, disability, family breakdown and financial ruin.

This is an all-too-common Lyme patient story. This cycle of devastation can be stopped by updating the medical guidelines for Lyme disease using current, science-based research, and ensuring that best practices for testing and treatment approaches are used. We, the patients, our advocates and science experts need to be equal partners in the process of Bill 27 to ensure this happens.

I'm a proud Canadian, knowing that throughout the world we are seen as leaders in so many areas of medicine, but at the same time, I am angered at the failure to help Lyme patients.

Every Ontarian is equally at risk. Our numbers are rapidly increasing as the number of infected ticks being found in our province climbs, placing a health crisis at our doorstep. This can only be stopped with changes to our Lyme treatment guidelines—

The Chair (Mr. Peter Tabuns): Could you please wrap up?

Ms. Kim Kerr: —that will provide appropriate testing and treatment options.

In your recommendations for Bill 27, please consider the need for patients' and Lyme experts' representation in the process of setting the provincial framework and action plan. This is—

The Chair (Mr. Peter Tabuns): Thank you. I'm afraid you've run out of time. We go to the opposition. First question: Mr. Barrett.

Mr. Toby Barrett: I'm sorry there isn't a lot of time for deputations. Thank you, Kim. You made mention that none of the current evidence-based, science-based research is being applied. There is one attempt, through this legislation, to essentially enable or empower the Ontario government to focus more on research, to find out some of the answers.

I'm a firm believer in neutral, objective research. Presently, there is no legislation to do that. This is one step. It doesn't come up with the solution. But as we wade through this, hopefully it's a good exercise to try and get around so much of the conflicting medical and scientific views.

Mainstream medicine in Ontario, I think you've suggested, is kind of caught one way. Maybe they didn't study this in medical school a number of years ago.

Ms. Kim Kerr: No, they did not.

Mr. Toby Barrett: It was the nature of emerging infectious diseases.

On the other hand, on the Internet—and in my riding, we've been dealing with this for about 20 years now. There is a lot of stuff on the Internet that suggests some dubious approaches as well. Hence, we have government for a reason.

In your limited time, any further suggestions? What should government be doing?

Ms. Kim Kerr: The government needs, most importantly, to use Lyme-literate doctors who have the expertise in treating and seeing patients successfully recover from the disease. We've got to bring in the experts who are first-hand. They have the experience, and they've seen the results. It's so very important to make sure they're included in the process.

Mr. Toby Barrett: Diagnosis and treatment, and management after that.

Ms. Kim Kerr: That's correct.

Mr. Toby Barrett: Okay. I don't have any further—

The Chair (Mr. Peter Tabuns): Thank you, Mr. Barrett. We'll go to the third party: Mr. Mantha.

Mr. Michael Mantha: Hi.

Ms. Kim Kerr: Hi.

Mr. Michael Mantha: I've got a very important question. Did you take the challenge?

Ms. Kim Kerr: Yes, I did.

Mr. Michael Mantha: Good. I hope everybody in this room took the challenge. That's the Lyme challenge.

I just want to start out by saying hello to Paige Spencer. To the committee: She's at home, unfortunately. She would have wished to be here today. She's a wonderful 21-year-old young woman with Lyme disease who has been misdiagnosed for 14 years. She has got a written submission. Please take the time to look at it.

Is there anything in your comments that you didn't get a chance to share?

Ms. Kim Kerr: No, it was actually timed just about right. I have one more sentence, just saying—

Mr. Michael Mantha: Finish that sentence.

Ms. Kim Kerr: You caught me off guard, there.

All I was saying was that we need to work together, setting the provincial framework in action together. This is the one essential step to ensure that the greatly needed change for Lyme disease patients and society will take place. It's not just us.

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Mr. Michael Mantha: I've got one follow-up question: Why was your testing that was done here in Canada negative, and found to be positive when you went to the US?

Ms. Kim Kerr: They have a slightly different test. The biggest challenge with Canadian testing is that there are over 100 different strains of the bacteria that cause Lyme disease. Our test tests for one strain only. When you go down to the States, their testing is broader, and therefore they catch more cases.

We also have a two-tier system; although you test positive on your first test, being the ELISA test, we then run a second test to confirm, being the Western blot. The challenge, of course, is that the first test is so faulty that it's almost impossible to get a positive test on that first one, the ELISA.

Mr. Michael Mantha: Why is our first testing so faulty?

Ms. Kim Kerr: It's something that has been set by the Public Health Agency of Canada. It's something that needs to be reviewed, and we need to look at the best practices out there to make sure that Lyme disease is caught early.

If you catch Lyme disease early and identify it, it's \$50 of antibiotics. You're fixed, and you're better. If you don't catch it, and it goes through your body, you are in a lifetime of chronic disease, draining our health care, draining your personal finances and relationships. The aftermath is just devastating.

We need to identify and get the testing right so that we are treated and we are taken care of. End of story.

Mr. Michael Mantha: And that antibiotic—is there one specified, or are there various ones?

Ms. Kim Kerr: It varies. Truthfully, I don't want to get into a lot about treatment; I am not a doctor.

The Chair (Mr. Peter Tabuns): You need to start wrapping up, I'm afraid.

Ms. Kim Kerr: Yes. I'm not a doctor. There are more people coming following me who have far more expertise in that area.

Mr. Michael Mantha: So your suggestion is to bring stakeholders together, get to the answer and start really looking at educating Ontarians in regard to Lyme disease? That's what you're saying?

Ms. Kim Kerr: And prevention efforts. You're right.

The Chair (Mr. Peter Tabuns): We go to the government. Mrs. Mangat? No? Mrs. Martins.

Mrs. Cristina Martins: First of all, I just wanted to thank you, Ms. Kerr, for taking the time to come here today to speak to the committee. I wanted to thank you for all the work that you've done, even when you were suffering with Lyme disease, to go around the province and be at various events to raise awareness for Lyme patients. I wanted to thank you for that, for being a strong advocate for other Lyme patients.

I guess the question I have is—I think you touched on this a little bit—in terms of the importance of educating Ontarians on the dangers of vector-borne diseases such as Lyme disease, and why it's important that they understand what the risks are of developing these diseases in contact with ticks and mosquitoes.

Ms. Kim Kerr: I'm dealing with it, but I look at our young people of Canada; they're outside. We're an outside country. We love the outdoors. When we're outside, we need to know what to watch for as far as ticks and tick bites. If you get one, take immediate action. Educate them, so we don't have these chronic cases that destroy lives. We've got a great people in this country.

Let's protect them, educate them and teach them the steps to prevent a chronic disease that is preventable.

Mrs. Cristina Martins: I know that provincially we're partnering with the Public Health Agency of Canada in terms of trying to raise that awareness, as well. I'm the mom of two young boys, and last week I got an email from the school secretary with a letter from public health that actually alerted the parents on Lyme disease, how to be careful, and also on West Nile virus and buckets of water. So there is a little bit of awareness being spread out there, and education in terms of being aware of these diseases.

I guess in terms of the passage of this particular bill, if you could just speak to why it would be important to you and other Lyme patients with whom you've connected, and what their response is to this.

Ms. Kim Kerr: I think the big thing that is so encouraging is that when I started this struggle, nobody even knew about Lyme disease. I'd say, "I had Lyme disease," and they'd look at me like, "Is that a drink problem?" They weren't sure.

To see this bill go forward, that we're going to take a look and try to figure out how to tackle this problem to prevent future suffering and future chronic cases, is a huge step forward that needs to be taken for the people of Ontario. Nobody is excluded. The ticks are being found everywhere, including in the city, on dogs. It's not a rural problem.

The Chair (Mr. Peter Tabuns): You need to start wrapping up, I'm afraid.

Ms. Kim Kerr: It's important. It's for everyone.

Mrs. Cristina Martins: I just wanted to say once again thank you so much, and thank you for being such a strong advocate.

Ms. Kim Kerr: Thank you.

The Chair (Mr. Peter Tabuns): Thank you, Ms. Kerr.

Ms. Kim Kerr: Thank you for your time. I really appreciate it.

CANADIAN LYME DISEASE FOUNDATION

The Chair (Mr. Peter Tabuns): Our next presenter is Jim Wilson, president of the Canadian Lyme Disease Foundation. Mr. Wilson, you're coming to us by teleconference?

Mr. Jim Wilson: Yes. Thank you for allowing CanLyme to discuss our concerns on Bill 27 as they relate to Lyme disease, the fastest-growing zoonotic disease in the globe.

First, who are Canadian Lyme disease patients? Well, look to your left and to your right. Lyme disease patients in Canada can be all of us: politicians, children, the elderly, PhD scientists, professors, engineers, lawyers, physicians, outdoor workers, pharmaceutical employees, chief executive officers, firefighters, police, armed forces personnel, and mothers and fathers at home. Collectively, we are an intelligent group, immensely capable of weighing the medical evidence used to direct our health care,

yet we have been ignored in provincial legislation for decades. It is the provinces who drive health care delivery, and it is in provincial legislation that the patients need to be stated as partners, not just commenters on policy that was developed without them, as has been the situation for decades.

Two years ago, the United States government admitted a huge mistake. There were not 30,000 yearly cases of Lyme disease; there were 300,000 cases per year, severalfold that of AIDS and West Nile combined. The clear message on the Lyme file was and is to this day that it was terribly mismanaged. Canada has a serious, similar problem, spanning decades. We patients were sounding alarms for three decades but were ignored. The present testing protocol used in Ontario will be a false negative every time if that person has one of the many strains of Lyme bacteria that are not able to be picked up by the current testing model. Currently, a review is under way of that poor testing and treatment policy by the very same people who wrote it, including those Canadians. Alarmingly, they have stated publicly they see very little change.

Last week, doctors and nurse practitioners were given a lecture by Niagara region public health officials on ticks and Lyme disease. What was being taught was to prescribe one single dose of doxycycline antibiotic for a black-legged tick bite if given within 72 hours of the bite, which is three days. Animal model studies, on the other hand, have shown us that when this treatment is initiated within the first day, there is a one in four failure rate. That could be your child. After 24 hours, only one of two had success—a 50% failure rate—and the treatment was totally ineffective after 48 hours. Doctors in Ontario are not given this information and are being directed to partake in a horrible experiment that will cause harm.

Scientists are also alarmed at this single-dose treatment because it will drive antibiotic resistance horribly. Resistance is largely a phenomenon of insufficient antibiotic that will not kill bacteria. We carry many organisms that will learn from this small taste of antibiotic, passing it on to their offspring. We cannot overstate the seriousness of this policy. Had we been involved, a very broad discussion of the science and consequences would have transpired prior to implementing such a dangerous treatment protocol.

There is nothing to fear and only good to gain in having patients equally represented at the table. We come with a great deal of expertise and professionalism. Every policy developed affects all of us and our surging health care expenditures, which are drawn from our tax dollars. Ontario can lead the nation by legally requiring patients and their experts to be brought in as equal partners. This will come; why not now?

Bill 27 needs amendment to perhaps narrow the scope of the diseases covered and to include patients in the wording, or it should not pass. Thank you.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Wilson. We go now to the third party for the first round of questions. I'll tell you when you're running out of time. Mr. Mantha.

Mr. Michael Mantha: Mr. Wilson, did you take the challenge?

Mr. Jim Wilson: I did, yes.

Mr. Michael Mantha: Fantastic. Congratulations.

I'm just reading off Mrs. Paige Spencer's letter that she gave to the committee, a written submission. It says that while she was labelled with depression, anxiety, PTSD, psychosis, chronic fatigue, IBS, a variety of fibromyalgia, not including a plethora of doctors telling her problems that she had psychologically, many stating that she had physical problems, "but I was either going crazy" or she was a pretty girl looking for attention.

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Is this a common theme that you see amongst Lyme patients who are dealing with their doctors?

Mr. Jim Wilson: Absolutely, and it's coast to coast and it is continuous and increasing.

Mr. Michael Mantha: Why do you believe that happens? Why is it that doctors look at individuals in this scope?

Mr. Jim Wilson: There's a lot of misinformation that is in the medical literature that needs to be corrected. Doctors are often functioning on short tidbits of information because they have a 15-minute window within the appointment to draw some conclusions. So they need much better information, and we certainly have to start providing that within the physician-patient relationship. There's got to be more open discussion.

When patients come into the doctor's office and those types of diagnoses are thrown out there, there's got to be more vigorous discussion going on about how those diagnoses were arrived at and what other diagnoses overlap, the symptomatology. I think that's where we're not looking at Lyme disease. Lyme disease, for many of these diagnoses that are given, should be absolutely at the very top of the list when doing the differential diagnostic workup. Unfortunately, it's often not even on the list.

Mr. Michael Mantha: I think I'm being stared at by the Chair saying that I have about 30 seconds.

In your comments, you talked about narrowing the scope of this bill. What is it that you were looking at narrowing?

Mr. Jim Wilson: I think zoonotic diseases, the way it's worded—that is vast. That covers everything. I think it may be more effective if it could be focused down to tick-borne diseases, perhaps, and then also by amending and adding the specific wording to—

The Chair (Mr. Peter Tabuns): I'm afraid you're going to have to wrap up.

Mr. Jim Wilson: —include the patients, their advocates and the science experts as equal partners.

Mr. Michael Mantha: Thank you very much, Mr. Wilson.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Wilson. We now go to the government. Mr. Anderson.

Mr. Granville Anderson: Thank you, Mr. Wilson, and thank you for your presentation. Your organization has done a great degree of work in supporting those suffering from Lyme disease by helping to bring

awareness of the disease to the medical community. How will this bill help your organization further its goal?

Mr. Jim Wilson: I don't think it will, unless it's amended to specifically name the patients and their experts and advocates as recognized equal partners in the health care process. If it's left as it is, it's really just more of the same. When I say the patients have the expertise, I seriously mean that. We're working with scientists on four different continents. We have microbiologists and physicians and other scientific experts with Lyme disease right now in Canada who cannot get treatment in Canada. So we have got to be taken seriously or this bill is not going to have the impact that we would like it to have.

Mr. Granville Anderson: Mr. Wilson, Mr. Mantha and yourself spoke earlier about narrowing the scope. I'm not sure you're aware that our government has proposed an amendment to do just that. Could you elaborate some more on what narrowing the scope would mean towards people suffering from Lyme disease?

Mr. Jim Wilson: I think the bill is going to have more effect if it's not so broad, because zoonotic disease is just a huge, huge, huge aspect of infection. By narrowing it down to tick-borne disease, at the least the focus can be on certainly what we represent.

Often Lyme disease is accompanied by other tick-borne diseases, and that can confound the diagnosis and the treatment. Also, some of these tick-borne infections are stand-alone infections. They don't come with Lyme; they are their own disease. They, too, have serious consequences for the individuals.

I think by narrowing the focus of the bill towards tick-borne disease, that will give the bill greater strength, from our perspective, so long as the patients and whatnot are named in there.

The Chair (Mr. Peter Tabuns): If you could wrap up, Mr. Anderson.

Mr. Granville Anderson: Thank you, Mr. Wilson. I found this to be very enlightening. I'm sure, as the debate continues, we'll hear further on this matter. Thanks very much again.

Mr. Jim Wilson: Thank you.

The Chair (Mr. Peter Tabuns): To the opposition, Mr. Barrett.

Mr. Toby Barrett: Thank you, Mr. Wilson. You indicated that Lyme is the fastest-growing zoonotic disease on the globe. About this time last year—in fact, every year about this time, Public Health Ontario releases their report, and they give a rundown on identified cases of various vector-borne diseases, for example.

With respect to Lyme, they included the probable cases, and the number they came up with is 185. There are actually more cases of malaria in Ontario than Lyme; there are 220. I see here there are actually more cases of West Nile, which is quite a ruckus, certainly down in my riding. I'm down along Lake Erie: Long Point, Turkey Point. West Nile comes in at 239 cases. They've identified Lyme, including probable cases, as 185—less than the others. There's no yellow fever in Ontario, for example. That's something that I find odd.

I know in the legislation we are asking to beef up surveillance. You made mention that there are officially 30,000 cases in the US. Now they're looking at 300,000 cases. I just wondered if you had a comment on this. This is what we're getting from the Ontario government.

Mr. Jim Wilson: I commented before that, unfortunately, because of the education given to physicians on all matters Lyme disease, most cases are completely missed, not even considered as a probability. That number they're giving you does not reflect the reality at all. In fact, you could easily multiply that number tenfold.

Mr. Toby Barrett: Yes, I wondered. Now, they do say they've included probable cases.

As far as narrowing the scope of the legislation, later today we will be discussing amendments. There is a government amendment to eliminate the word "zoonotic" and to focus just on vector-borne—not strictly tick. Vector-borne would include mosquitos as well, again, with respect to West Nile. It looks like that will be going forward. As the person who originally drafted this legislation, I would agree with that. The original goal of this legislation was to—

The Chair (Mr. Peter Tabuns): Mr. Barrett, if you could wrap up.

Mr. Toby Barrett: Very simply, 10,000 people died of Ebola last year. We will be deleting Ebola from this legislation if that amendment goes through.

The Chair (Mr. Peter Tabuns): Mr. Wilson, thank you for your time.

ONTARIO LYME ALLIANCE/ HAMILTON LYME SUPPORT GROUP

The Chair (Mr. Peter Tabuns): We go on to the next presenter: Jeanne Pacey. As you've seen, you have up to five minutes to speak, and there will be three minutes of questions from each party. I'll give you notice when you're getting to the end of your time. If you'd identify yourself for Hansard.

Ms. Jeanne Pacey: My name is Jeanne Pacey. I formerly worked in community development and downtown redevelopment for the city of Hamilton and the city of Brantford. However, I was forced to stop working because I became so sick in 2006. Doctors in Ontario told me I was probably suffering from fibromyalgia, chronic fatigue syndrome or complex post-traumatic stress disorder, none of which actually fit my symptoms.

I had been bitten in 1997 in Algonquin park—no bull's-eye rash, but I did have symptoms. I saw many specialists and many visits to the ER. All doctors who saw me wanted to pigeonhole me into a diagnosis that didn't quite fit.

In 2005, I was hiking in the Royal Botanical Gardens in Burlington, and I was bitten several times by many poppy seed bugs which I scratched off my leg. The symptoms continued.

In 2006, I was hiking in Hamilton conservation area off Mohawk Road in Hamilton, and I was bitten again; however, this time the tick crawled under my skin and

was there for a few days. After I discovered it, I dug it out. It was still alive. I did have a rash. It looked like I had an allergic reaction. My family doctor did not know what to do or what it was. No treatment was given. So I kept searching for a diagnosis. Meanwhile, I was becoming more and more debilitated.

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Finally, in 2011, a naturopath suggested I pay for an American Lyme disease test, because he said the Canadian test, which I had three times—negative—was less reliable.

My test result was CDC-positive from the USA, which would have qualified me for treatment had I been a US citizen. I was so relieved because I presumed my doctors would treat me, and I would soon recover. Instead, I was shocked to discover that the Ontario health care system was going to deny me the treatment that I desperately needed.

You should know that I would not be here today if I had not resorted to paying—and remortgaging my home, as a single parent with two children—for treatment in the United States.

The members of my Lyme disease support group all have similar stories about how their physicians never diagnosed them with Lyme disease. Hundreds of patients in Ontario have never received an early diagnosis, and so they did not get antibiotic treatment right after their tick bite, which is the only way to prevent this illness. These patients go untreated, develop complex symptoms of late-stage Lyme and are soon unable to attend work or school. They use up a huge amount of Ontario's health care resources, as they are sent wandering the medical system, being referred from doctor to doctor, undergoing test after test and never finding an accurate Lyme diagnosis.

Why is this happening? Well, Canada has adopted the American guidelines for Lyme disease published by the Infectious Diseases Society of America, also known as the IDSA. Those guidelines restrict doctors to prescribing antibiotics for no longer than 28 days. The guidelines also deny the existence of late-stage disease, so I would not have received treatment.

We should be developing our own set of Lyme guidelines or adopting an alternative set of guidelines that are available and which were used in my treatment. The other Lyme guidelines are authored by another group of physicians in the United States, and they do consider recent scientific studies. These doctors found that the patients responded much better when they extended the length of antibiotic treatment and used a variety of antibiotics. This group is called the ILADS. There are a growing number of physicians who choose to follow their Lyme treatment guidelines and who received certification to do so.

Ontarians who have late-stage Lyme disease are forced to go to the United States to receive treatment from one of these doctors but have to pay out of their own pocket. Many patients cannot afford to go for out-of-country treatment, and they suffer terribly. I see them

regularly. The restrictions placed upon our physicians prevent the Ontario physicians from using the alternate guidelines.

I speak for patients when I say that the development of an action plan and strategy for Lyme disease must include representation by patient groups who are knowledgeable and experienced in supporting patients with late-stage Lyme. International experts who research Lyme disease and physicians who have been trained to appropriately treat Lyme disease must be included in the consultation process.

Thank you.

The Chair (Mr. Peter Tabuns): Thank you. We'll go to the first questions, then. Mr. Dhillon.

Mr. Vic Dhillon: Thank you very much for your presentation. Our government is proposing developing a provincial Lyme disease action plan, which will include a review and update of existing public awareness, education materials, guidance documents and tick surveillance protocols. As part of the action plan, Public Health Ontario will be reviewing and updating Ontario's 2012 technical report on Lyme disease prevention and control. We will be engaging with stakeholders to promote close alignment with Lyme initiatives at federal, provincial, and local levels. Your organization has supported this action plan and other Lyme disease initiatives.

The first question: How will this bill help advance the goals of Lyme patients and advocates like your organization?

Ms. Jeanne Pacey: I think, first of all, awareness: A lot of doctors are calling me in Ontario, asking for the public health alert showing that the ELISA test isn't positive. It's providing them with the sense that they can start to treat a little bit. A lot of our doctors don't know that there is alternative training. We have a doctor who was infected with Lyme disease who taught at McMaster medical school. He sees the same doctor that I do, because he said it's not taught.

We need to start talking. We need anything that advances the awareness to all of the stakeholders. There are so many pieces to this puzzle. There is the public health; there is our doctors.

Our support groups are run by volunteers like myself who are still in treatment and still sick. We're the ones who are helping those patients who have been lost in the system, who are suicidal, who are devastated because they passed it on through birth to their children, and we have an entire family that's sick. They're coming to me. I don't get paid for that. I sit and do that out of the fact that I couldn't live with myself if these people didn't get help.

There needs to be a support system. ODSP does not recognize—we have families who have spent everything and need treatment, and they can't even qualify for Ontario disability. I was one of those. I'm a municipal product. I took half a pension because I was misdiagnosed and not working, and no long-term disability for over seven years. As a single parent with two children in post-secondary, that was tough. I lived on less than \$12,000 a year.

Mr. Vic Dhillon: My next question is, what's the value of developing standardized education materials on vector-borne diseases such as Lyme for health care providers and members of the public?

Ms. Jeanne Pacey: It's twofold: Doctors need to understand that it's not a classic bull's eye. They need to understand that it's clinical, but if they are not trained, how can they help their patients? Their hands are tied.

There are a lot of rumours that go on in the medical community that Lyme doesn't exist. I've had an infectious disease doctor tell me not to come to his office because—

The Chair (Mr. Peter Tabuns): I'm afraid you're going to have to wrap up.

Ms. Jeanne Pacey: Sorry. The public schools: I can't tell you the number of children who are picking ticks off. The teachers don't know what to do with them. The parents aren't being notified, and then they can't get antibiotics right away.

The Chair (Mr. Peter Tabuns): Thank you, Ms. Pacey. We'll go to the next questioner. Mr. Barrett.

Mr. Toby Barrett: Thank you very much for the work that the Hamilton support group does. As you know, a number of people from my area and south of Hamilton are helped by you. There are many others as well who go to Buffalo and elsewhere.

You talk about denying treatment and forcing people to go to the US, and it doesn't seem to be covered by OHIP. It doesn't even seem to be helped, say, through ODSP or other programs. We had a situation, maybe 25 years ago, where many people were going to the United States for alcohol and drug treatment—to Buffalo. I was involved in the field at the time. OHIP was paying for it; it was a given. They tightened up on that. They beefed up treatment programs in Ontario to accommodate that; the money drain, I think, was one reason. Again, how do we get around that?

Ms. Jeanne Pacey: We have no legislation. A doctor can't even make a referral to the US because it's just not even—Lyme doesn't exist. Had I not had another Lyme patient guide me—and I had to drive to Vaughan for my first support group.

I'll tell you, it was very difficult when you're feeling chronic pain, when you get lost driving because of the neurological aspect. I would not be here today. I would have either committed suicide or I would have been bedridden. I would probably be in an old-age home. It was very difficult. I am so grateful that I sought treatment. I'm here today. I'm functional. I'm back in the system. I'm not taxing our health care.

To have people be able to see that while we train our doctors, we need to be able to pay for them to go into the US for Lyme disease—we need better testing. We need better awareness in our schools. We need to catch it earlier so we're not at a late stage. We don't need people to get to where I was. We need to solve it at the beginning. But in the meantime, we have a lot of people who are like me: a lot of people who have been missed; a lot of children. That's our next generation. We have a

responsibility to make sure that our school system, our teachers, our conservation authorities, are all on the same page and we're not giving misinformation, because even if you go from support group to support group you're going to get different information. We need to unify that. We need to all be on the same page.

The Chair (Mr. Peter Tabuns): You have about 20 seconds.

Mr. Toby Barrett: As far as the personal cost, the cost to society, I think you made reference that it impacted your employment. The legislation is designed to try and capture the dollar figure on this. We certainly did that with SARS. That was, I think worldwide, a \$40-billion cost.

The Chair (Mr. Peter Tabuns): I'm sorry to say, Mr. Barrett, you've come to the end of your time.

Mr. Toby Barrett: Yes, I'm done.

The Chair (Mr. Peter Tabuns): We'll go to Mr. Mantha of the third party.

Mr. Michael Mantha: Did you do the challenge?

Ms. Jeanne Pacey: We did.

Mr. Michael Mantha: We did. I know we did.

A quick question for you: your doctor's visit.

Ms. Jeanne Pacey: Yes.

Mr. Michael Mantha: Why are the doctors—to my understanding, they're acknowledging it's Lyme but refusing to treat you for Lyme.

Ms. Jeanne Pacey: It's twofold: a GP who did not recognize all the symptoms of the third bite and the GPs that I saw in 1977. Had I been treated then, and then treated again on the two other bites, I wouldn't have lost employment. I might have been off sick a couple of weeks or a week maybe, but I wouldn't have lost employment. I would have had a full retirement pension from retiring this year. I worked 35 years for the municipality.

I'm sorry. I'm nervous and I lost my train. The second part of your question?

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Mr. Michael Mantha: Why are doctors—

Ms. Jeanne Pacey: Why are doctors—the second part was an infectious disease doctor. I saw five who would not see me. My doctor said she couldn't find any referral. She was afraid. She didn't understand the combination treatment. She didn't understand that plaquenil needed to be used with another antibiotic and what it did. I understand she just wanted to cover her backside by having an infectious disease.

My infectious disease doctor would keep me in his office for three hours and we would fight over whether or not he was going to co-sign my US prescriptions. I said to him, "Do no harm. If you don't sign these, I'm getting sicker." He said, "I'll follow you for a year," and I gradually got better. I had to fight with him at the one-year mark and say, "You need to co-sign my prescriptions." He said, "I don't believe you have Lyme. It doesn't exist. You don't have Bartonella. You don't have Babesia. You just need to start exercising more." We fought again, and then he said, on one visit, "Don't come

back. I feel you should be doing a full-time job." And I said to him, "Are you 100% positive that I don't have that bacteria?" Of course, the answer was no, he wasn't, but in his view, he was an internist and an infectious disease doctor and that we would see that I would become ill as time went on. I haven't.

I found alternative sources, I paid for my US prescriptions and I counsel Lyme patients and families for treatment because no one deserves to walk the journey that I've walked, or many others before me.

Mr. Michael Mantha: Do you have anything else you want to share with the committee?

Ms. Jeanne Pacey: Every Ontarian deserves treatment. We have a social responsibility to ensure our medical system and our departments are working together. If not, they don't deserve their job. There is a responsibility with each one of us here and every department. Any department that starts to refuse to meet and move forward, then maybe they need to go find another job.

Mr. Michael Mantha: Thank you.

The Chair (Mr. Peter Tabuns): Ms. Pacey, thank you very much.

LYME ONTARIO

The Chair (Mr. Peter Tabuns): Our next presenter is John Scott with Lyme Ontario. We have you by phone. Mr. Scott, you have up to five minutes to speak, and then we'll go three minutes to each party for questions. Please proceed.

Mr. John Scott: My name is John Scott. I'm a tick researcher. I have identified thousands of ticks that were collected from birds and mammals across Canada. Over the past 25 years, I have conducted tick and Lyme disease research and have published 21 peer-reviewed scientific articles.

The blacklegged tick—Ixodes scapularis, indigenous east of the Rocky Mountains—is the primary vector of the Lyme disease bacteria Borrelia burgdorferi. One of our latest articles revealed that migratory songbirds widely disperse Lyme disease vector ticks nationwide. Our study also found that 35% of the Ixodes scapularis nymphs are infected with Borrelia burgdorferi, and therefore a person does not have to frequent an endemic area to contract Lyme disease.

Our research also shows that migratory songbirds transport ticks into Ontario from as far south as Brazil. Some of these ticks are infected with a wide array of tick-borne pathogens. Not only are veterinarians finding Lyme disease; they are also seeing anaplasmosis and ehrlichiosis in companion animals. However, physicians in Ontario are ignoring this transporter movement of ticks on migratory birds and, likewise, the infections pathogens they carry. Migratory songbirds, which are heavily infested with ticks, can start a new tick population in a new location. At least 30 endemic areas have been detected across Ontario.

Over the years, I have studied several Lyme disease endemic areas. Despite our published research to show

the presence of Borrelia burgdorferi in these tick populations, warning signs are lacking in key areas. The Ministry of Natural Resources has done a poor job of erecting highly visible signs. For years, the park guides have not addressed the presence of Borrelia burgdorferi-infected ticks in their parks. Consequently, unsuspecting hikers and campers are bitten and contract Lyme disease in their parks. The local medical officer of health is responsible for ensuring that warning signs are erected. Failure to monitor these warning signs and make sure they are clearly visible is a violation of the Ontario Health Protection and Promotion Act.

Both my wife and I have persistent Lyme disease, so we live with debilitating aches and pains and fatigue every day—a journey through hell. We test negative with the Public Health Ontario laboratory; however, we are culture-positive and PCR positive through other reputable laboratories. As well, we are serologically positive through two US labs.

Like many Ontario Lyme disease patients, we have found that provincial testing is not reliable. Over the years we have found that the allopathic medical community is ill-informed about Lyme disease. Frankly, health care professionals live in a sea of ignorance about Lyme disease and associated tick-borne diseases. This vacuum in itself has been a horrendous hurdle and very draining. We have found that most doctors do everything possible to discount or dismiss Lyme disease. They get paid regardless. Hospital visits are no exception to this situation. Nothing changes. Families are destroyed.

We have a health care calamity in Ontario. There must be a paradigm shift in the diagnosis and treatment of Lyme disease in this province.

First and foremost, we need physician protection when they prescribe long-term antimicrobial treatment for Lyme. At least 13 US states have such legislation. The College of Physicians and Surgeons of Ontario is harassing and victimizing any physician who prescribes long-term antimicrobials for Lyme disease. Consequently clinicians are scared stiff that their regulatory college will come after them if they prescribe extended treatment. Naturally, they are afraid that they will be forced to give up their medical licence. Obviously, they steer away from Lyme disease and tick-transmitted diseases.

Ontario patients are in limbo and must—

The Chair (Mr. Peter Tabuns): Mr. Scott, if you could start wrapping up, please?

Mr. John Scott: Yes. I have two more minutes, and what I'd like to say is very important. I'd like to finish.

The Chair (Mr. Peter Tabuns): No, you have 10 seconds.

Mr. John Scott: They have to drag themselves across the border, all at their own expense, when our taxes pay for the OHIP system. This medical dilemma is unconscionable.

The Chair (Mr. Peter Tabuns): Mr. Scott, I'm afraid you're out of time on this. I'm going to turn you over to Mr. Barrett, who has the first round of questions.

Mr. Toby Barrett: I'll keep my comments brief, Mr. Scott. I appreciate your work on ticks. I have a farm. This

past weekend, for example, I picked up four ticks. I usually kill them. The last one I didn't kill, so I brought it to the committee today, if anyone wants to take a look at it. This is a dog tick; it's not the Lyme tick, but I know farmers in my area—one farmer had 200 ticks on him one day.

Mr. John Scott: Oh, boy.

Mr. Toby Barrett: You talk about the sea of ignorance with health care professionals. I'm tearing down a barn with a number of Amish fellows, and this was new information to them. A lot of this is new information to an awful lot of people.

Mr. John Scott: Yes.

Mr. Toby Barrett: This legislation does not provide physician protection. I'll turn it back over to you to finish your conclusion.

Mr. John Scott: You mean I can finish what I was saying?

Mr. Toby Barrett: Yes, please. Yes.

Mr. John Scott: The provincial public health technical report is full of erroneous information. There are at least 35 points that need to be deleted or revamped. In fact, it needs to be completely overhauled. For example, the statement, "To date, there is no convincing biologic evidence for the existence of" systemic "chronic B. burgdorferi infection among patients after receipt of recommended treatment regimens" for Lyme disease. This statement is completely false. I have compiled a list of 320 peer-reviewed scientific articles showing the persistence of B. burgdorferi in mammalian hosts, including humans, after conventional short-term antimicrobial treatment.

This technical report also states that a patient must live in or visit an endemic area to be identified as a confirmed or probable Lyme disease case. Based on our findings, this requirement is unnecessary and should be removed.

In order to have proper care for Ontario patients, we need evidence-based, patient-centred Lyme disease guidelines—such guidelines that combine medical evidence, patient values and clinical expertise. Patients must have input in their medical care, trustworthy policies, guidelines and research requiring the participation of patients. Without a seat at the table, patients' concerns fall on deaf ears.

I'm finished.

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The Chair (Mr. Peter Tabuns): Thank you very much. We'll go to Mr. Mantha, then, the third party.

Mr. Michael Mantha: Good afternoon, Mr. Scott.

Mr. John Scott: Good afternoon.

Mr. Michael Mantha: Did you take the Lyme challenge this month?

Mr. John Scott: The Lyme challenge? I have it all the time, so I have it every day.

Mr. Michael Mantha: We had a wonderful event here at Queen's Park to raise awareness of Lyme disease and the importance of getting a strategy for not only Ontarians, but setting the path forward for Canadians so that we could start treating Lyme disease patients and

their basic nightmare that they're going through each and every day.

My question to you is, there are many research kits that have been put out to the general public in order for them to amass ticks from their area, to have them sent in for testing. It has come to my attention—and I'm wondering if it has come to your attention—that some of these kits aren't being sent in and are basically not being tested, or they're being told, "Well, there are no ticks in your area normally," so they're just being told, "No." Is that an experience that you're having?

Mr. John Scott: Basically, I'm doing research. I get ticks from bird-banders and wildlife rehabilitators across Canada. I maybe get the odd one from patients.

I feel that these ticks off of people should be sent directly to Public Health Ontario and then dealt with, depending on the identification of the tick.

Personally, myself, I'm not involved in what you're talking about. What I do is identify the ticks and if they're a tick that is known to be a Lyme disease vector, then I send it for testing at a research lab in the United States.

Mr. Michael Mantha: According to the information that you have amassed, coming from the research field, there are ticks in southern Ontario, there are ticks in eastern Ontario, there are ticks in northern Ontario, there are ticks in western Ontario, and there are ticks across Canada.

Mr. John Scott: Yes.

Mr. Michael Mantha: Is that what your findings are?

Mr. John Scott: Oh, yes. I've identified 35 species of ticks that have been collected off of birds and mammals across Canada.

Mr. Michael Mantha: The repercussions to the doctors that you alluded to in your comments—I was wondering if you could add to those comments in regard to the concerns that doctors have with providing treatment to patients.

Mr. John Scott: We have encountered many physicians, not only on individual consultations but in the hospital, and basically, you mention Lyme disease and they move away from it. They'll do everything to move on to something else.

The Chair (Mr. Peter Tabuns): Mr. Scott, I'm sorry to say that we've run out of time with this questioner.

Mr. John Scott: Okay.

The Chair (Mr. Peter Tabuns): We're going to go to the government: Ms. Mangat.

Mrs. Amrit Mangat: Thank you, Mr. Scott, for your presentation. I really appreciate the work you have done as a research scientist.

Mr. John Scott: Thanks very much. Do I hang up now?

Mrs. Amrit Mangat: Yes.

Mr. John Scott: Oh, okay.

Interjection: No, no, no. Don't hang up.

Mrs. Amrit Mangat: No, no, no. I'm still asking you a question, and you're—

Interjection: He hung up.

Mrs. Amrit Mangat: Oh, my gosh.

Interjection: No, he's still there. I can get him back on the line.

The Chair (Mr. Peter Tabuns): Okay.

Mrs. Amrit Mangat: That would be nice.

Interjection: John? John? Just hold on a second. John, don't hang up. Pick it up again. They still want to talk.

Interjections.

Mr. John Scott: Oh, hello?

Mrs. Amrit Mangat: Hello.

The Chair (Mr. Peter Tabuns): Hello, Mr. Scott.

Mr. John Scott: Oh, I hung up. I guess I shouldn't have.

Mrs. Amrit Mangat: No, no, no. Nice to hear you back.

Your research has gone a long way to filling gaps in our knowledge about this disease. Your work was the first to identify raptor birds with Lyme disease and Lyme-disease-carrying ticks. My question is, can you tell us about your current research and how it is going to help prevent and treat Lyme disease?

Mr. John Scott: I don't think it's going to prevent it, because this problem is established in nature. The ticks are there. We're not going to control them.

I see it as an alarming thing, because I see quite an increase in eastern Ontario in particular. I'm also seeing some troubling spots in northwestern Ontario.

I know that it can't be stopped, and I know we can't stop the infections. But we have to come at this from the medical standpoint—to me, protecting the physicians from being harassed by the college so they'll get with it and start handling this problem professionally.

I mentioned 13 states in the United States that have physician protection. I think this is the only way to break down the door in terms of getting treatment for patients. It has to be set up so that the physicians can't be afraid to treat long-term if they need to treat long-term. They need that protection. I know if you go to the College of Physicians and Surgeons today, they'll tell you they don't harass physicians, but I have proof otherwise.

The Chair (Mr. Peter Tabuns): Ms. Mangat, if you could just wrap up.

Mrs. Amrit Mangat: How will Bill 27 help eliminate knowledge gaps and clear up misconceptions about vector-borne diseases?

The Chair (Mr. Peter Tabuns): I'm sorry to say that you brought it to the limit right there.

Mr. Scott, thank you very much for your contribution today.

Mr. John Scott: Okay, you're quite welcome. Can I hang up now?

The Chair (Mr. Peter Tabuns): Yes, you can, safely.

Mr. John Scott: Thanks. Bye now.

The Chair (Mr. Peter Tabuns): Goodbye.

G. MAGNOTTA FOUNDATION
FOR VECTOR-BORNE DISEASES

The Chair (Mr. Peter Tabuns): Our next presenter: Rossana Magnotta. I apologize if I've mispronounced it.

Ms. Rossana Di Zio Magnotta: No, you did a good job.

The Chair (Mr. Peter Tabuns): Good. Well, if you would introduce yourself for Hansard. As you've seen, you have five minutes. There will be three minutes for each party, and I'll give you a note when you're getting close to the end.

Ms. Rossana Di Zio Magnotta: I will try to keep to the agenda here.

Good afternoon. I would like to thank the committee for allowing me to present at these important hearings today. The challenge of being one of the last speakers is that we will try not to be repetitive, but if I mention certain things that have been said, I wish that they will be just a gentle reminder.

Bill 27 should not pass into law as written. It is far too broad, in that zoonotic diseases are vast in numbers. Also, Bill 27 represents the status quo of excluding the patient and their experts as stated partners in the process of setting a framework to develop a provincial strategy for zoonotic diseases.

I am the president and founder of the G. Magnotta Foundation for Vector-Borne Diseases, based here in Ontario. We recognized early on that there is a lack of human tissue study being undertaken using today's advanced technology.

There has been a great deal of important research done in Canada on ticks, but we urgently need parallel human studies done to determine the prevalence of tick-borne and other vector-borne diseases within the large and growing chronically ill population of Canada.

Ontario has a huge economic and social burden resulting from chronic illnesses of unknown origin. These illnesses have been defined by symptoms alone, and much money has been spent trying to develop medications to manage those symptoms.

Medical bureaucrats have allowed our current poor test to define the disease instead of allowing the infection to define the disease. We need to acknowledge the number of strains and new ones being found and then design a test that will do a better job in detecting all the strains that people are encountering both locally and through travel. Lyme groups like CanLyme and other similar organizations around the world have been trying to introduce better science to medical bureaucrats.

Examples of these chronic conditions of unknown origin are multiple sclerosis, Alzheimer's disease, chronic fatigue syndrome, fibromyalgia, Parkinsonism, lupus, various forms of arthritis and heart disease, bowel disorders, psychiatric disorders and many others. The cost to society and health care budgets is enormous in that it has been shown that the chronically ill population are one of the largest user groups of the health care system.

Many people who were eventually diagnosed with Lyme disease were initially labelled with one or more of those many other illnesses. Those individuals only recovered their quality of life as a result of treating Lyme disease effectively.

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What this has shown us is that a percentage of this chronically ill population have in fact an undiagnosed tick-borne disease, such as Lyme disease. The current status quo position on this is that chronic active Lyme disease does not exist, so there is no incentive to even look. This is a very disturbing situation for all of us and is not supported by the science. In fact, quite the opposite is the case.

Technology has advanced dramatically in the past decade, increasing our ability to extract DNA of microorganisms from tissues and fluids like never before.

We at the G. Magnotta Foundation have been working with scientists in Canada and around the world, developing proper tissue recovery, handling and storage protocols so that human tissue studies can be done. As a result, we have a great deal of knowledge and expertise to aid in developing a provincial strategy.

If the patient organizations were more acknowledged in this process as equal partners, it would greatly reduce the time required to receive good results. These good results will help reduce the ever-increasing chronically ill population, which will in turn improve the quality of life for these patients.

This problem is seriously affecting our health care system, taxpayer-funded disability payment system, and the workforce. And it's destroying families, because thousands of cases are falling through the cracks. My husband, Gabe, was one of them.

Patients, their advocates and their experts must be represented and named as a group in legislation—

The Chair (Mr. Peter Tabuns): You're going to have to wrap up.

Ms. Rossana Di Zio Magnotta: I'm at the end—that will require government and medical authorities to work with us as equal partners in this process. Thank you very much.

The Chair (Mr. Peter Tabuns): Thank you very much. The first question: Mr. Mantha.

Mr. Michael Mantha: Thanks for coming, Rossana. Nice to see you again.

Ms. Rossana Di Zio Magnotta: Good to see you.

Mr. Michael Mantha: I just wanted to read out something to you from the consultation process of Mr. Barrett's bill. It says, "For the purpose of developing and administering the provincial framework and action plan, the minister shall consult with any other affected ministries, the agency, boards of health, the Public Health Agency of Canada, the federal government or any other persons or entities that the minister considers appropriate in the circumstances."

We're going to be talking about clause-by-clause later. There's a word that's going to be changed in there, which is going to be proposed by the sitting government, which is to change "shall" to "may."

Ms. Rossana Di Zio Magnotta: To "make"?

Mr. Michael Mantha: To "may." You talked a little bit earlier in regard to not having the proper individuals

coming to bring some testimony in regard to this bill. I want you to elaborate on that.

Ms. Rossana Di Zio Magnotta: The question again?

Mr. Michael Mantha: Who is not coming? Who is not included in this particular bill?

Ms. Rossana Di Zio Magnotta: I think that it would be more valuable, that there would be greater assurance to the taxpayers of Ontario, or Ontarians, knowing that groups like CanLyme, and even the G. Magnotta Foundation—there are lots of Lyme groups that can really add value to the conversations that the provincial government is going to be involved with. It would be a greater assurance to know that they're named in this, so that it's not broad. Make it more exact. We would rather see our names being mentioned, rather than "we shall" or "we will" or "we won't." It would make us feel a lot better if we knew we were at the table. We're doing a lot of work in this area; there should be no reason why we shouldn't. Even with the G. Magnotta Foundation, we've just got to the first level of ethics approval for the research protocol. We've got a lot of work to do here. It has been very, very challenging. Wouldn't it be nice if Ontario could lead the way here, if Ontario could be part of this? Because what we're missing is really understanding what the relevance is, what the prevalence of Lyme disease is in Ontario, and what the percentage of misdiagnosis is that has been going on in other diseases. No one can answer that question. We should be able to answer that question effectively and honestly, but we can't.

Mr. Michael Mantha: Just one last question: Did you take the challenge?

Ms. Rossana Di Zio Magnotta: Yes, of course I did.

Mr. Michael Mantha: Good. On the other question, I don't want to speak for Mr. Barrett, but I can almost assure you, on my behalf—and I know I won't be speaking on his behalf—that we will certainly make sure you are part of these discussions. I think it's very important to bring in everybody, and I mean everybody—patients, veterinarians, everybody—

The Chair (Mr. Peter Tabuns): Time to wrap up, Mr. Mantha.

Mr. Michael Mantha: —into the process. And there's nothing wrong with being repetitive.

Ms. Rossana Di Zio Magnotta: Good.

The Chair (Mr. Peter Tabuns): Okay. Thank you very much. We go to the government: Ms. Albanese?

Mrs. Laura Albanese: Thank you for being here, Rossana. It's great that you could appear before this committee today.

As you mentioned, I know you have a personal and devastating connection to this disease, but I just wanted to say how inspiring all the work you have done so far has been to all of us. I know you're doing a lot to combat this illness despite the loss that you've had.

I know that in your foundation, the primary focus is also to establish Canada's first research centre. I'm wondering if you could speak to us a little more about how your organization plans to address vector-borne illness in our province.

Ms. Rossana Di Zio Magnotta: We said “vector-borne” because vector-borne is a huge area of science, but we’re focusing on Lyme disease first. I’m hoping that this research facility will last for generations to come. That’s why it’s got vector-borne written on the same title.

I’m working closely with Humber River, the new hospital that’s being built at 401 and Keele. They’re opening in the fall of this year. I’ve been working with their key executives for a while. It was a hospital that I worked at for a long time because my background was in microbiology. I worked in the medical field before I got into my business that I have right now.

I envision it as doing the research that will go on and on and on for many, many decades. That will be the first step. If you ask me how I’d like to see it, I’d like to see it as not only a research centre, but eventually being a treatment centre and a testing centre. Obviously, with research, we’re going to develop better testing, whether it’s with next-generation DNA sequencing or with genomics. But there will be some sort of testing protocol that will end up at the end of this research protocol.

At that point, we will have a better test. Because it’s a community hospital, we’re going to see those patients coming in right from the street level, and then eventually, being a treatment centre, like they’re doing in Europe or in the US, you come in, get tested, and if you’re positive, you’re treated. You are treated as an in-patient if you’re really, really sick or you’re treated as an out-patient if that’s more appropriate for the doctors.

I know it’s an incredible vision and it’s very exciting and it may be a dream at this point, but that’s where I see it going. That’s what I’m hoping will happen. I really believe, deep down, that if there is the will from the people and the will from the government—

Mr. Peter Tabuns: Time to wrap up.

Ms. Rossana Di Zio Magnotta: With money, anything can be done.

Mr. Peter Tabuns: Okay. Thank you very much.

Mrs. Laura Albanese: Thank you very much.

The Chair (Mr. Peter Tabuns): Mr. Barrett.

Mr. Toby Barrett: Thank you for the comments about the legislation being broad. There are amendments that we’ll be discussing later this afternoon that will narrow it down. Again, with legislation—this isn’t a Lyme bill, for example; it’s not just one disease. If we were doing this seven years ago, it would be West Nile. Now I travel around with a tick. Seven years ago, I had a dead crow in the trunk of my car. That’s what everyone was talking about in my riding, and concern with mosquitoes. We still have to be concerned with mosquitoes.

But things will be deleted. This was developed a year ago. I think even a year ago CNN was dominated by Ebola, not Lyme. People were talking to me about Ebola. It’s hard to pick diseases or decide which ones you’re going to work on and not others. That will be covered in deliberations later this afternoon.

It doesn’t mention patients. I wrote it. I guess I made the assumption our medical system is there for patients. I know when my uncle was a hospital administrator, he

would explain to me that the only purpose for that hospital was for the patients. With respect to doctors, the only reason we have doctors is to deal with patients. Now, if they have other priorities, if they’re not listening to their patients, I think we have a pretty serious problem there. I’m hearing suggestions of that with respect to the medical community in the province of Ontario. There are pretty serious allegations. Any comments on that?

Ms. Rossana Di Zio Magnotta: Yes. Actually, I think it has to start right from the education point when these doctors are coming out of school. The college needs to be much more comprehensive in training and teaching them more about vector-borne diseases or Lyme disease.

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There is no point in just talking about exotic diseases to these new doctors. You may get thalassemia—not thalassemia; you may be getting West Nile or you might be getting all kinds of exotic diseases in Canada, but we’re missing the one that’s here already. We are a country of valleys and trees and forests. We have a great environment for ticks to grow in, so why are we not focusing on what we have in our backyards?

These doctors need to be trained on it. If you look at their curriculum, there’s very little dedicated to that. We need to teach them a little bit more about what they’re going to be seeing in the real world.

The Chair (Mr. Peter Tabuns): You’re going to have to wrap up.

Ms. Rossana Di Zio Magnotta: Just one other thing: There’s not that much Ebola in Canada, but there’s tons of Lyme disease and we will show it to you.

The Chair (Mr. Peter Tabuns): I’m sorry to say you’re out of time.

Ms. Rossana Di Zio Magnotta: Okay.

The Chair (Mr. Peter Tabuns): Thank you for your presentation.

Ms. Rossana Di Zio Magnotta: It’s too bad. I love to talk.

Laughter.

The Chair (Mr. Peter Tabuns): It’s something that we all share in this room.

ONTARIO FIGHTS LYME

The Chair (Mr. Peter Tabuns): I’m going to the next presenter, Ontario Fights Lyme: Myrna Lee and Alicia DeCou.

Ms. Myrna Lee: Alicia’s not here.

The Chair (Mr. Peter Tabuns): Okay.

Myrna, you’ve seen how we’ve carried things forward. If you’ll introduce yourself for Hansard, we’ll start your five minutes.

Ms. Myrna Lee: I sure will. Hi. I’m Myrna Lee, communication director for the Canadian Lyme Disease Foundation and founder of Ontario Fights Lyme. I’d like to thank the hearing committee and organizers for providing me with an opportunity to meet some of the MPPs I’ve been stalking for the last few years and for allowing

me to advocate on behalf of Lyme disease sufferers across the country, my daughter, Alicia DeCou, included.

I'd also like to thank the many MPPs who have kept this issue alive in the House with motions, petitions and this bill: Mr. Toby Barrett, Mr. Mantha, and particularly Randy Hillier, my own MPP, whose dogged determination has served our cause well. The voters of Ontario are grateful and won't forget your support for this issue.

By now, you've heard the pros and cons of Bill 27 from my colleagues, but Parliament already has the authority to correct the most egregious errors in the testing, diagnosing and treatment of Lyme disease. So today, I'm here to ask you to influence the Minister of Health to please convey to the medical authorities what our government has seen fit to put in control of our destinies.

Please stop using the CPSO to further the unfathomable aims of the anti-Lyme lobby. Across Canada, the average of doctors investigated by the various colleges of physicians and surgeons is 2%. The average of doctors who are investigated who treat Lyme disease based on best practices and outside IDSA guidelines is 100%. Consequently, we have one medical doctor in Canada brave enough to continue to treat Lyme disease despite investigation and censure by the CPSO. In the words of the Lyme Action Group in their 2008 petition, "ensure that Ontario physicians are free to treat Lyme patients using internationally accepted protocols, without interference by the CPSO."

Please don't tell us we're crazy. We may be, but we are also physically sick. Unless you are our psychiatrist, please treat our physical illness, and the mental illness will probably be taken care of.

Please don't give us anti-depressants. We know that it will shut us up, especially if you give us the increasingly high doses that you tend to do, but it will not kill *B. burgdorferi*. If we seem depressed, it's because you keep calling us crazy when we are really sick.

You can recommend yoga to us as treatment and we will do it until we discover our yin yang, but it will not kill *B. burgdorferi*.

Tell your infectious disease doctors that the Western blot test that they studied in school back in the day is not the same as the version of the test that is used in Canada today. Some Lyme species-specific bands have been removed from the test. Canadians are paying private labs in the US that have returned those bands to the test in order to get an accurate test. Please refer to my handout for some elaboration of this situation.

Please don't tell people who have been bitten to look for the bull's-eye rash. There's good scientific evidence that at least 50% of people don't get any rash, and there are at least two other rashes that occur as regularly as the bull's eye.

Please get yourself educated by Lyme-literate practitioners and updated on science-based treatment regimes. Lyme disease is complicated. Lyme disease sufferers are dying. Please help us.

The Chair (Mr. Peter Tabuns): Thank you. Our first question goes to the Liberals. Ms. Martins?

Mrs. Cristina Martins: Thank you very much for coming in today and presenting. I just wanted to let you know that our government is committed to protecting the people of Ontario from Lyme disease. Actually, it was in the fall of 2014 that Ontario partnered with the Public Health Agency of Canada on a two-year plan, a Lyme disease pilot project, which is aimed to really enhance Lyme-disease-related resources available, educating people on what the disease is all about. We hope that this will also include a review and update some of these public policies that we have in place and public awareness materials that we have.

I guess my question is, how do you think this bill will support the surveillance plans that are already in place?

Ms. Myrna Lee: I'm not really sure that Bill 27 will do that. I'm kind of depending on the MPPs who have been working on it and the advocates who have been working behind it to ensure that the bill that gets passed will be effective. I think I'm with them in saying that unless we have patient advocates, Lyme-literate doctors and scientists who have actually been researching in the field as part of that bill, I'm not sure that it will make any really effective changes as it stands.

Mrs. Cristina Martins: Okay. And I guess the other thing—I'm sure that you're aware that the government is proposing to actually amend the scope of this particular bill so that we will only really be looking at the vector-borne diseases. I believe that's how it's planning to go. Do you see any risk of developing a single action plan to combat all zoonotic diseases instead of a unique, tailored plan that will specifically target the vector-borne diseases such as Lyme disease?

Ms. Myrna Lee: I think that narrowing the scope will make the bill more effective.

Mrs. Cristina Martins: Thank you.

The Chair (Mr. Peter Tabuns): Okay. Thank you very much. Mr. Barrett?

Mr. Toby Barrett: Sometimes I don't have my hopes up as well, but I have a feeling this legislation may pass, maybe within a day or so, and it becomes enshrined in law. Our laws do provide direction. Now, it is difficult. My assumption is the physicians are a fairly strong lobby group. They do seem to dominate our system of health, or illness, if you will. The focus actually seems to be more on illness than health.

But this legislation essentially is coming from people, people I've talked to. As I said, it's not strictly a Lyme bill; it is very comprehensive. Our Minister of Health was probably getting more interview requests and questions in the House on Ebola than he was Lyme in the past year while this legislation was being debated here. It did receive all-party support.

I think the timing is very good. We have a Minister of Health who is not only a physician; he's also trained in public health and in infectious diseases. It's very hard to find a physician in Ontario trained in infectious diseases, unless they were trained in Jamaica. My physician was trained in Jamaica. I worked in the tropics and I could come home with various diseases. He was the only one who could diagnose.

So I think things are coming together. I'm feeling very positive. Again, I'd like to think that legislation does have an impact. That's really the only tool we have. The other tool is regulation. We don't get to vote on regulation, but that's where groups like yours can come in. I wanted to comment on that. The timing may be right.

Ms. Myrna Lee: I hope so. My experience and the experience of most Lyme patients, at least the ones who have contacted me, have been very, very poor with infectious disease doctors. My daughter was dying when I took her to the infectious disease clinic in Ottawa and that doctor told me he was 100% sure she did not have Lyme disease.

Since then, we have gone to a Lyme-literate doctor. It has been two years, but my daughter has finally gained back almost all of the 25 pounds that she lost, and she is looking forward to a future now, a future where she can actually work again, rather than living her life in pain in a wheelchair.

The Chair (Mr. Peter Tabuns): Mr. Barrett, you need to wrap up.

Mr. Toby Barrett: I'll leave it at that, I think.

Ms. Myrna Lee: Thank you.

The Chair (Mr. Peter Tabuns): Okay. Thank you. Mr. Mantha.

Mr. Michael Mantha: Ms. Lee, is there anything that you didn't cover which you'd like to share with the committee right now?

Ms. Myrna Lee: No. I think if it wasn't covered by me, it was covered by others here.

Mr. Michael Mantha: Sometimes we find that repeating things sink into one's mind. If there is a message that you would like to repeat today, what would that message be?

Ms. Myrna Lee: I think that we just have to really look and work with Lyme-literate people in order to get Lyme-literate change. We just always seem to be running into a huge wall of lack of knowledge and lack of research.

Research is another thing. I tell people who are contacting me all the time that we don't know the answers to most of the questions that we ask. What's the best treatment? We don't know. How likely is it that I'm going to get Lyme disease in this area? We don't know. Knowledge is going to be our strength moving forward with Lyme disease.

Mr. Michael Mantha: Where do we find those Lyme-literate people?

Ms. Myrna Lee: Right now, they're few and far between, because basically there's no incentive for a doctor to become Lyme-literate. As I said, we do have one Lyme-literate doctor in Ottawa. She is extremely well educated. She has worked with the University of Ottawa. In a minute, she would close her practice and start teaching doctors on Lyme literacy. She has said that she would.

Mr. Michael Mantha: One last question, Myrna: Did you take the challenge?

Ms. Myrna Lee: I'm glad you asked that. I have not, but I will be taking it at the Ride for Lyme rally in

Ottawa on June 18, when the two riders who are coming across Canada hit Ottawa. We're going to be at city hall whenever they arrive. I'll be taking the challenge, probably with—we hope—Elizabeth May, who has gotten Bill C-442 passed for us.

Mr. Michael Mantha: Good for you.

Ms. Myrna Lee: Thank you.

The Chair (Mr. Peter Tabuns): Okay. Thank you very much.

Colleagues, our next two presenters are not yet available. I'm going to suggest that we recess for five minutes and return at 3:30. Because we'll be doing clause-by-clause at 4 o'clock, if you have amendments that you wanted to bring forward, if you can bring them forward soon so we can circulate them, that would be appreciated. Thank you.

Recessed until 3:30.

The committee recessed from 1523 to 1530.

The Chair (Mr. Peter Tabuns): The committee is back in session.

DR. TED CORMODE

The Chair (Mr. Peter Tabuns): We have the next presentation, by Mr. Ted Cormode, who is on the line. Mr. Cormode, you have up to five minutes to speak, and there will be three minutes of questions from each party. I'll give you a little reminder when you're coming to the end of your time. Please proceed and introduce yourself for Hansard.

Dr. Ted Cormode: Yes. Thank you for the opportunity to speak to your committee. I'm a retired pediatrician who had a consulting practice for 40 years in Ontario, during which I was a coroner for seven years and a member of the paediatric death review committee of the Office of the Chief Coroner of Ontario for 14 years.

Since my daughter's diagnosis with Lyme disease two years ago, I have read widely in an attempt to become informed about Lyme disease and its current controversies. The more I read, the more frustrated I became with the conflicting diagnosis and treatment recommendations. Then I read an interview with Dr. David Patrick, a professor of public health at the University of British Columbia, published in the Canadian Medical Association Journal in December 2014. The article was entitled "Lyme Law Uses 'Junk Science,' Says Expert." "Lyme Law" was in reference to the federal government's passage of Bill C-442, An Act respecting a National Lyme Disease Strategy.

In that interview, he referred to the issue of "duelling guidelines," that is, to the disagreements in diagnosis, treatment and investigations between the Infectious Diseases Society of America and the International Lyme and Associated Diseases Society. Both societies have headquarters in the USA; both have highly qualified experts. Here's the challenge: Both published evidence-based guidelines and policy statements that contradict each other. How can this be?

Dr. Pat Croskerry, professor at the department of emergency medicine at Dalhousie University in Halifax, published his research in clinical cognition and diagnostic care. He reports that “the majority of diagnostic failures, probably over 75%, can be attributed to physician thinking failure”—in other words, to cognitive bias.

Dr. Patrick, in his note to Carolyn Brown, the author of the CMAJ article on junk science, comments that “99% of serious scientist doctors who have been trained in microbiology and infectious disease stand with the evidence-based approach of the mainstream IDSA guidelines.” He does not give any evidence to support this figure of 99%, or clarify his definition of serious scientists and doctors.

Dr. Patrick is correct in identifying duelling protocols as a major factor in confusion and controversy surrounding Lyme disease. This is a serious problem for the practising front-line physicians trying to make sense out of conflicting information and claims. This problem will continue until the evidence-based treating of Lyme disease is supported by unbiased, well-designed research.

If both the IDSA and ILADS are composed of established scientists and doctors within their membership and board of directors, and if both societies carry out rigorous search in Lyme, then their conclusions should be somewhat aligned. They are not. The Minister of Health must support a fair representation of these disparate opinions.

I strongly recommend to the committee that Bill 27 include a directive that the Ministry of Health and Long-Term Care must include specialists from both sides of the duelling protocols debate.

The most recent guidelines of ILADS, published on July 2014, state in the preamble that “the evidence base for treating Lyme disease is best described as sparse, conflicting and emerging.” They go on to recommend “addressing the unique circumstances and values of individual patients” to maintain patient-centered care.

Dr. Bowie, a professor of infectious diseases at the University of British Columbia, in his presentation to the federal Senate subcommittee on Bill C-442, stated that subjective criteria should not be used to identify Lyme disease. Unfortunately, most individuals present with numerous subjective symptoms, including headache, fatigue, hearing and visual sensitivities, rather than objective signs, which would include fever, swollen joints, and, in less than 50%, a history of tick bite and a bull’s-eye rash. In medical school, it was stressed that a patient’s history was central to making a correct diagnosis. We were instructed to listen well to the patient’s account of their symptoms to document their story, including subjective symptoms, in order to consider their significance in the context of the individual. Otherwise, a physician is at risk of making wrongful assumptions regarding the diagnosis, to the detriment of the patient. I found this was often true in pediatric death reviews.

I have frequently attended meetings of Lyme support groups in Toronto and Victoria. Those in attendance were from all walks of life. Many were active who

were no longer able to be active and whose quality of life had dramatically declined. I strongly recommend to the committee that Bill 27 include a directive that the Minister of Health and Long-Term Care must include representation from individuals with Lyme disease in the consultation process to develop an action plan—

The Chair (Mr. Peter Tabuns): Mr. Cormode, your time has come to the end.

Dr. Ted Cormode: I’m finished. Thank you.

The Chair (Mr. Peter Tabuns): I’m sorry; you’ve run out of time. I’ll go first to Mr. Barrett.

Mr. Toby Barrett: Thank you, Doctor. You mention that the federal legislation uses junk science. I haven’t heard that accusation yet on this one. That may come too, on this particular bill, Bill 27.

There’s no question, especially on social media, where so many of us seem to pick up information—and some of the suggestions are dubious, in my view. But we also know that there are allegations of shortcomings with respect to diagnosis amongst mainstream medicine as well. So there’s obviously a lot of work to be done, and not only on diagnosis, treatment and management.

This legislation does call for research, but as you pointed out, there are so many conflicting medical, scientific, political and social dimensions to this issue. I’m hoping that this legislation, at minimum, provides a forum or direction for the Ontario government to play a role in resolving some of these disputes.

If the experts can’t agree on things, I really don’t know what a hunter or a fisherman, or someone out in the field who is picking up ticks quite regularly—where do they lie?

I agree with what you’re saying. I’m hoping that this legislation, if it passes, does provide some direction not only to the Ontario government but to the various agencies associated with government.

Any comments?

Dr. Ted Cormode: Yes. Your comment about fishermen and hunters: It’s also the doctors who are seeing these people coming into the emergency or into their offices. I am trying to learn about Lyme disease.

The go-to people for Lyme disease information are the Infectious Diseases Society of America and the International Lyme and Associated Diseases Society.

At the end of the day, I cannot come away with a confident feeling that I know what to do for the patient that I’m seeing across the desk from me.

The European literature has been around for a lot longer, and they have more definitive things. But these two groups—the battle between the two of them is really muddying the water and making it very, very difficult for the family doctor or for the person in emergency trying to help one of these people to come up with a conclusion.

Mr. Toby Barrett: I will say—

The Chair (Mr. Peter Tabuns): You’re going to have to wrap up, Mr. Barrett.

Mr. Toby Barrett: For what it’s worth, this legislation didn’t pick sides. I don’t know about the federal legislation.

Dr. Ted Cormode: No, they did not.

Mr. Toby Barrett: They didn't pick sides?

Dr. Ted Cormode: No, not at all.

Mr. Toby Barrett: I'm not sure where the accusation of "junk science" came from.

Dr. Ted Cormode: Well, it's from the—

The Chair (Mr. Peter Tabuns): Thank you, Mr. Barrett and Mr. Cormode. We have to go to the next questioner, Mr. Mantha.

Mr. Michael Mantha: Mr. Cormode, how old is your daughter?

Dr. Ted Cormode: She is 42.

Mr. Michael Mantha: Children?

Dr. Ted Cormode: No children; no.

Mr. Michael Mantha: No children? A question I've been asking everybody: Did you take advantage and bring awareness over the course of the month of May to Lyme by taking up the challenge?

Dr. Ted Cormode: The ride for awareness of Lyme set out from Victoria. I certainly was there. I've spoken at a number of meetings. But when you say "taking up the challenge," you mean—

Mr. Michael Mantha: Taking a bite out of Lyme.

Dr. Ted Cormode: Oh, yes. Yes. I have, and I've been very active in making people aware. I've had some very interesting stories to tell, for which there's not time to tell you here.

Mr. Michael Mantha: If you had a wish list—if you have the opportunity tomorrow morning to draft a list of individuals and stakeholders who should be participating at the discussion, who is around that table?

Dr. Ted Cormode: Number one would be a patient. You learn so much, sitting in on a patient support group. These are real people. They don't want to be sick. They're not malingering. Number one would be the patient.

Number two, you've got to get people from both sides or you'll just get one side of the equation, and that's what has been part of the problem all along: The one society seems to be a lot more dominant than the other.

Mr. Michael Mantha: Mr. Cormode, thank you so very much for bringing some of your comments to the committee here this afternoon.

Dr. Ted Cormode: Thank you.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Mantha.

Mr. Anderson.

Mr. Granville Anderson: Thank you, Mr. Cormode, for coming forward. You have experience in the devastating effect of Lyme disease first-hand. How do you think this bill will support the medical community in diagnosing and treating Lyme disease patients?

1540

Dr. Ted Cormode: Yes, that's a tough one. I really think the Canadian Medical Association should be taking a much greater role in this. I know they've supported the federal bill. They've come on board supporting getting a national strategy—or, in this case, a provincial strategy.

Doctors have to feel comfortable in diagnosing Lyme based on clinical findings. That's strongly supported in the literature. The lab tests, if positive, support your clinical presentation. If negative, it does not mean you don't have Lyme. The medical profession is very uncertain about diagnosing people walking in with a list of symptoms and a history of tick bites. They want to see a positive test, and the testing is another huge issue altogether.

Mr. Granville Anderson: Previous presenters that came forward earlier today spoke about narrowing the scope, and it's something that our government has proposed to do so that we treat vector-borne disease, such as Lyme disease, separately from zoonotic diseases. Would you care to elaborate on that?

Dr. Ted Cormode: I'm sorry; the previous presenters said—

Mr. Granville Anderson: Yes, they agreed with the government position that we narrow the scope to treat Lyme disease.

Dr. Ted Cormode: Oh, narrow the scope.

Mr. Granville Anderson: Yes.

Dr. Ted Cormode: I guess Lyme disease is the most rapidly spreading of the zoonosis illnesses. I don't know why it should be. It's kept in isolation, though, but it really has to be brought front and centre. The whole issue of waiting for lab tests has got to be put well down the list. The important thing is a clinical diagnosis that comes across in your own ministry, the Ministry of Health Ontario, the federal ministry of health.

Lyme is a clinical diagnosis, and doctors need to be aware that it's okay to make a clinical diagnosis based on all the things that the patient is telling you: where they were in their history and where they travelled. Then when the test comes back in two or three weeks' time, if it's negative, it does not mean you don't have Lyme disease if the rest of the story fits. But if it's positive, it will support your diagnosis. The issues around testing are causing a lot of delay in making accurate diagnoses.

The Chair (Mr. Peter Tabuns): You're going to have to wrap up, Mr. Anderson.

Mr. Granville Anderson: Okay. Mr. Cormode, earlier during your presentation, I believe you weren't finished. Did you have anything else you wanted to add?

Dr. Ted Cormode: No, I did finish. I did finish it. I had two words to say at the end, and we got it all in.

Mr. Granville Anderson: Okay, thank you very much.

The Chair (Mr. Peter Tabuns): Great. Thank you very much.

Dr. Ted Cormode: Thank you for having me there.

ONTARIO FEDERATION OF AGRICULTURE

The Chair (Mr. Peter Tabuns): Our next presenters: the Ontario Federation of Agriculture. Gentlemen, if you'd have a seat. You have five minutes to speak and three minutes of questions from each party. I'll tell you

when you're running out of time. If you'd introduce yourselves for Hansard.

Mr. Keith Currie: Okay. Thank you for the opportunity. I'm Keith Currie. I'm vice-president of the Ontario Federation of Agriculture. I have with me today our executive member, Mark Reusser, on my right, and another board of directors member, Paul Wettlaufer.

The Ontario Federation of Agriculture, on behalf of its 37,000 farm family members, is pleased to offer its support to Bill 27. We thank Mr. Barrett for bringing this bill forward to recognize and address the need for a provincial strategy to deal with diseases such as Severe Acute Respiratory Syndrome, or SARS, West Nile virus, Lyme disease and Ebola virus.

Interruption.

Mr. Keith Currie: I thought I'd turned my phone off, and I apologize for that.

We have all seen the impacts of SARS and West Nile virus and have recently begun hearing of or experiencing the serious consequences of Lyme disease as its carriers move north into and across Ontario. These are serious public health matters that require a response, as provided for in Bill 27.

In Ontario, the Public Health Agency of Canada noted seven known Lyme endemic areas in 2012. It is estimated that by the year 2020, 80% of eastern Canada will be living in areas with established tick populations. The demands of this endemic illness are growing rapidly and require a serious strategy.

West Nile virus was first identified in North America in the late summer of 1999. People and animals can become infected from the bite of mosquitoes that are infected with the virus. Mosquitoes can contract the virus when they bite or take a blood meal from infected wild birds. Those mosquitoes may then transmit the virus to people and other animals through biting.

About 20% of people bitten by a carrying mosquito experience flu-like symptoms, such as chills, fevers, headaches, muscle weakness, nausea and vomiting, which disappear within a few days' time. One per cent of those bitten by a mosquito with West Nile develop West Nile encephalitis, a serious inflammation of the brain or surrounding tissues which can last several weeks and cause paralyzing neurological effects.

Horses are also a species that is susceptible to infection with the virus. Outcomes can include fever, paralysis of hind limbs, impaired vision, convulsions, seizures, coma and death. There is no specific treatment for West Nile encephalitis in horses, and supportive veterinary care is recommended. A vaccine is available and deemed to be 90% to 95% effective.

It is important to diagnose West Nile quickly, because infection is an indication that mosquitos carrying the virus are in the area and need to be eliminated. Elimination will prevent further exposure to people and to horses.

We support the provisions of the act that require the Minister of Health and Long-Term Care to develop a provincial framework and action plan. This will require

the establishment of a provincial surveillance program. As noted above, surveillance is critical for such diseases and enables early prevention.

OFA also supports the provision of the act requiring standardized educational materials and guidelines regarding the prevention, identification, treatment and management of vector-borne and zoonotic diseases. Ontario is only beginning to learn about the causes, symptoms and treatment for West Nile and Lyme disease. Education provides for an informed public and health care system working towards prevention, early diagnosis and more effective treatment. This will ultimately save health care dollars.

Lastly, the framework and action plan must also promote research in connection with vector-borne and zoonotic diseases. OFA is a strong proponent of research, and supports the call for scientific investigation into the cause, prevention and treatment of zoonotic disease. We believe Ontario will experience more such cases as our climate changes sufficiently to support the vectors.

On behalf of Ontario farmers, we urge you to pass Bill 27 to make the development of a Lyme disease and West Nile strategy a priority within the ministry. Lyme disease and West Nile are serious diseases with serious consequences for the victims and our health care system. Ebola and other potential vector-borne and zoonotic diseases such as Ebola could be absolutely devastating to Ontario. Ontario farmers are susceptible to vector-borne diseases by virtue of working outdoors in rural Ontario, in close contact with vector habitat. On their behalf and on behalf of all Ontarians, we urge you to work through and enact Bill 27 to address a growing health care concern.

I also brought my colleagues along with me today because they both have experiences with Lyme disease, so I'm going to turn to Mark to relate his first, please.

Mr. Mark Reusser: Just a short story to support our presentation and in support of the bill: About 23 years ago, I was giving my very young daughter a bath, and I should mention that about two weeks previous to that she was camping with her grandparents at Long Point Provincial Park. I noticed on her thigh the classic little red Cheerio-shaped rash. I recognized it right away because—

The Chair (Mr. Peter Tabuns): You have 10 seconds left.

Mr. Mark Reusser: —I had read about it in Reader's Digest. I took her to the doctor. The doctor didn't know what it was. I told him what it was. He—

The Chair (Mr. Peter Tabuns): I'm afraid—

Mr. Mark Reusser: One more sentence?

The Chair (Mr. Peter Tabuns): No, but I'll turn you over to Mr. Mantha, because I think he's about to help you.

Mr. Mark Reusser: He's going to help me? Okay.

The Chair (Mr. Peter Tabuns): Yes.

Mr. Michael Mantha: Go ahead.

Mr. Mark Reusser: Thank you very much. I told the doctor what it was. I referred to the article in Reader's

Digest. He said, "It appears to me to be just a tick bite." He said, "Nothing to worry about. Go home and don't worry about it."

The next day, he phoned me up after doing some further research—remember that this was before Google. He apparently phoned some colleagues in the US. He phoned me up the next morning and said, "Bring her in right away." He put her on a two-month regime of antibiotics. In 23 years since then she has not had a symptom.

My point is this: The general population doesn't know what the symptoms are, and doctors, I am sure, don't all know either. This bill goes, I think, a long way toward rectifying both of those issues. Thank you.

The Chair (Mr. Peter Tabuns): Mr. Mantha, if you have any questions.

Mr. Michael Mantha: You are a very fortunate person, because a lot of the individuals I've spoken to have had such a hard time getting a diagnosis. That doctor who made the decision to provide your daughter with antibiotics is a rarity, to be honest with you.

However, if your dog would have gone to the vet and they would have found a tick on it, your dog would have had first-class care of him or her, and the disease would have been cured completely. There would have been follow-up, of course, with the dog, because veterinarians have that ability to treat our animals.

It's almost embarrassing to say that we're treating our animals better than we're treating human beings here in Ontario when it comes to Lyme disease. I just wanted to mention that.

Look at all three of you fine gentlemen. Here's a skill-testing question: You weren't here for everybody else's, but did you guys take the Lyme disease awareness challenge over the course of the month of May?

1550

Mr. Keith Currie: I personally did not, but I have two daughters in the sciences and in the medical area of the sciences, and they were all over me about it. They took it.

Mr. Michael Mantha: Good stuff. Thank you, gentlemen.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Mantha. To the government: Ms. Mangat.

Mrs. Amrit Mangat: Thank you, Mr. Currie, for your presentation. As you know, our government is committed to protecting the people of Ontario from Lyme disease and also helping those who are already suffering from it. That is why our government is developing a provincial Lyme disease action plan. Having said that, my question to you is this: How will this bill, Bill 27, help advance the goals of your organization? Can you throw some light on this, please?

Mr. Keith Currie: Well, as you can imagine, farmers work outside all the time, so we have a much higher exposure rate to things like ticks, for example, other airborne diseases and all these diseases that we're mentioning. We need help to even educate our own membership as to what to look for.

Mark found a rash on his daughter and took her to the doctor. Most people would have looked at that as just an insect bite or something and maybe, potentially, ignored it, which could have led to more severe problems. We're trying to look at ways that we can educate the general public along with this, to make sure that everyone is aware of what to look for and then to take the appropriate action once it's found.

Mrs. Amrit Mangat: So just to clarify for myself, what you are saying is that the updating of existing public awareness and education materials, guidance documents and tick surveillance protocols would be of great help?

Mr. Keith Currie: Absolutely. And make sure to include the doctors in that, because there's a lot of varying opinions among the medical field as to diagnosis, as Mark explained.

Mrs. Amrit Mangat: And your organization is supportive of that?

Mr. Keith Currie: Absolutely.

Mrs. Amrit Mangat: Thank you.

The Chair (Mr. Peter Tabuns): Thank you, Ms. Mangat. Mr. Barrett.

Mr. Toby Barrett: I want to thank OFA for supporting the bill, and the 37,000 members that you represent. Beyond the legislation, if it passes, your organization is very influential, especially in rural Ontario and amongst outdoorsmen. We also received a letter from OFAH, the Ontario Federation of Anglers and Hunters. Its 100,000 members support the bill.

Beyond the law, there is so much that both your organizations can do just for your own members, but also to better educate the public, and the practical mechanisms that you could work on, whether it's prevention or education or whatever.

I'm glad you mentioned West Nile. The legislation covers West Nile. I mean, we're all worried about mosquitoes. Seven years, I was driving around with a dead crow in my car. Now I carry a tick with me, one of the four that I found on me this weekend. As you say, we pick them up all the time when we're working outdoors.

So many farmers aren't aware. I'm working with Amish fellows now on my farm, and they're not aware of this, of course, and many people are not.

One other infectious disease I'm very concerned about is H5N2, avian flu. There's something like 39 million birds that have been put down in North America. The real reason for that is in case it jumps to humans—again, an infectious disease carried by migratory birds. There's a suggestion that the tick was carried by migratory birds.

There's an awful lot of wisdom within your organization. Any action steps you could see down the road, maybe working with OFAH, some of the practical stuff you guys could do to help better educate the people?

Mr. Keith Currie: Thank you for the question. Education is key to a lot of this. We have passed resolutions at our AGMs in the past—in 2012, a resolution on taking action on this. We've had several commentaries over the years about asking the government for action in this area.

I think we need to make sure that we're proactive for future potential diseases—as you say, the avian flu potentially jumping into humans. The dengue virus was thought to have been a southern hemisphere virus for a long time and now has been found in Texas, so we need to be proactive for what may be coming down the road as well.

We're certainly happy to work with government on this in any way we can, and also continue to work with our membership to bring any information that we can get our hands on out to them for an awareness and education aspect.

Mr. Toby Barrett: Great. Thank you very much.

The Chair (Mr. Peter Tabuns): Thank you very much. Gentlemen, thank you.

Members of the committee, we are just five minutes fast. We're going to recess for those five minutes. We'll return at 4 o'clock and we'll go to clause-by-clause.

The committee recessed from 1555 to 1600.

The Chair (Mr. Peter Tabuns): The committee is back in session.

Colleagues, as you're aware, we have directions to go to clause-by-clause. This is for Bill 27, An Act to require a provincial framework and action plan concerning vector-borne and zoonotic diseases. I've had a number of amendments circulated to me. I have to ask at the beginning, are there any comments, questions or amendments to any sections of the bill, and if so, to which section? If you already have submitted amendments, you don't have to comment on those, but—

Mrs. Laura Albanese: Oh, okay. So if we have submitted them, we don't need to comment.

The Chair (Mr. Peter Tabuns): No, unless there are others. Mr. Barrett?

Mr. Toby Barrett: Yes, a comment on the government amendments.

The Chair (Mr. Peter Tabuns): You can make that comment when we go to each amendment. If you want to talk about the bill—

Mr. Toby Barrett: Yes. Maybe the big one—this would be a massive change to the legislation. I'm not saying I'm necessarily arguing against it, but as I recall, it deletes the reference to zoonotic diseases, but it does leave in coverage for vector-borne diseases like West Nile virus, the mosquito-borne diseases, equine encephalitis or malaria, I would assume, which are all—equine isn't; malaria is in the province of Ontario. But it deletes "zoonotic," and we heard in testimony the request to narrow the focus.

All the testimony, with one exception, was about Lyme, actually. This isn't a Lyme bill specifically; I mean, this covers other vector-borne and zoonotic. By deleting "zoonotic," we know that would delete any reference to Ebola, for example. As we go through it, I think it would be important to run through the rationale for that, or why we would justify removing any framework or action with respect to Ebola or whatever may be coming along next. You can't predict it—Marburg virus, or maybe this H5N2 that is in Oxford county right now,

in chickens; it's not in humans. But in North America, they've put down something like, I'm not sure—39 million birds have been put down just in the last few months because of the fear of it going over to humans.

I just have that concern. If someone said, "How come you took that out?"—I mean, last year 10,000 people died from Ebola. If H5N2, the avian flu, got into humans, you can't predict the death rate.

My only concern, and the initial impetus for this, having crafted it close to a year ago, was to deal with emerging infectious diseases. Of course, when you watched CNN last summer, it was all about Ebola. It was not about Lyme disease. We don't talk about West Nile anymore; we did seven years ago.

That's my only concern. If someone were to ask, when the next one hits, how come—we had the opportunity on committee to leave that in there, to better enable the province of Ontario, the Ministry of Health and the various public health agencies to deal with these new diseases, these emerging infectious diseases that we invariably seem to get caught flat-footed by. Whether it's HIV/AIDS 25 years ago or SARS—that was, what, 12 or 13 years ago—it's almost inevitable that we get caught flat-footed. There will be more emerging infectious diseases, and we will get caught flat-footed as a society.

That was my overall comment. I understand where this is coming from. We heard it from deputations, especially when people come here and talk about nothing but Lyme, other than the last presentation and their concern with West Nile virus and also the equine disease. If it gets into horses and it gets into humans, that cannot be treated. That's a very serious one. It's not here, but I think maybe there was one case at one point.

That was my general comment, Chair.

The Chair (Mr. Peter Tabuns): Mr. Mantha, you wanted to speak before we went to clause-by-clause?

Mr. Michael Mantha: Yes, Mr. Chair. I want to speak particularly against the elimination of the reference to Lyme in this particular bill. I think, from what we've seen here in the testimony today, it is the emerging infectious disease that is at the forefront of many across this province and across Canada, quite frankly. Families need to know that the impact of Lyme disease is going to be taken seriously and that these families are going to be taken seriously, so they need to identify with this.

However, I will not stand in the way of having the stakes move forward on this bill. I would like to see the reference to Lyme maintained in this bill. Again, there are some references or amendments that are going to be changed in here as well as changing the mandate to a discretionary ability of the government to establish this policy. I would like to see more of a set timeframe, as in the unanimously passed motion that I had introduced into the House in November, where we're going to hear a report from the ministry in regards to the development of a real Lyme strategy going forward. This could have been a good step forward towards that.

Once again, the most important thing is, when we're bringing individuals together, we're not going to be

picking and choosing who those individuals are going to be. It's going to have to be patients at the very forefront. We need that. I think that was obvious from the testimony that we heard here today.

My hat is off to the government as well. We have started a surveillance practice. That is correct. But we still need a lot of work going forward and we have the ability to do that. We need to deliver this strategy. It was obvious, with the entire testimony that was here today, that Lyme is real. Lyme is happening. We need to deal with it. Eliminating it from this particular bill will not reassure families that their concerns and their illnesses are being taken seriously. Those are my comments.

The Chair (Mr. Peter Tabuns): Ms. Albanese.

Mrs. Laura Albanese: I just wanted to address the general comments that were made just now.

The government feels that in its current form, as you've heard, the scope is a little too broad to allow for the development of an effective framework. That's why we're proposing this amendment, because, as it stands right now, the bill would require a development of a provincial framework and action plan for a very large group of diseases, covering everything from anthrax to Q fever to malaria to yellow fever.

The concern is that it wouldn't have the impact that all three parties are hoping for. As I've recently learned, there are significant differences between zoonotic and vector-borne diseases. The zoonotic diseases are infectious diseases which will spread from animals to humans. This is a very broad category of diseases which differ greatly with respect to their epidemiology and to the risk of transmission, the severity of the disease and the appropriate infection control measures.

Vector-borne diseases are infectious diseases which are spread from insects to humans. They would include Lyme disease as well. That's what we're looking at the scope to be, so that it's more effective and more focused on the specific disease of concern.

Some of the diseases cited in the bill are neither one nor the other; they are spread from human to human. That's a different category as well. This is the reason why we're proposing this amendment.

The Chair (Mr. Peter Tabuns): Mrs. Martins.

Mrs. Cristina Martins: I just wanted to add to that, where the member opposite, Mr. Mantha, talks about us eliminating Lyme disease from this piece of legislation: In fact, it's actually still included. We're never eliminated that particular disease from this piece of legislation. When we talk about narrowing the scope of the legislation to look at the vector-borne diseases, it is completely, 100% implied that Lyme disease is one of these vector-borne diseases. We actually leave the legislation open enough to address what was pointed out by Mr. Barrett, also opposite, about the new and emerging diseases that are coming up that we don't know about today.

1610

With the world becoming a smaller place, people travelling all over the world, and our bringing in new immigrants from very different countries, I can only

stress that we will be seeing a lot more emerging infectious diseases. So it's important that our government is looking ahead and is being proactive in ensuring that this piece of legislation will address those emerging diseases.

The Chair (Mr. Peter Tabuns): Mr. Barrett.

Mr. Toby Barrett: I want to comment again on definitions. We've got several terms: emerging infectious diseases, zoonotic diseases, vector-borne diseases. I trust that the researchers have got the definitions precisely cleared out so there's no confusion down the road.

Ebola: There's evidence the origin would be bush meat, a monkey, in Africa. SARS: The evidence is various species of monkey in China, where they were eaten, and the transmission was that way. That would not be considered a vector, as I understand it. It's transmitted from an animal, but it's not directly transmitted, say, by the bite of a tick or the bite of a mosquito.

I just trust the definitions are clear and that people hoping to craft the legislation—I know the lawyer who helped me in the private member's bill, we wrestled with that a bit as well.

In looking at various organizations, there's a lot of crossover. There are infectious disease organizations and vector-borne researchers. There's that crossover. I trust the legislation is fairly clear on that.

I also understand that the real reason for this is it would be easier to have the legislation separated out—in this case, it focuses just on vector-borne. The present concern beyond Ebola is Lyme. I suppose we could make it simple the other way: We could delete vector-borne and just focus on zoonotic.

I just raise this for a discussion. This is something I wrestled with in crafting the legislation.

It seems to me, and maybe it would be up to me, that we could separate out these various zoonotic diseases that are defined as strictly not vector-borne, but are of concern, like Ebola or Marburg virus or whatever is coming next. I understand that could be a separate piece of legislation, something I may work on because, again, invariably the province of Ontario and every other jurisdiction, including the World Health Organization, gets caught flat-footed when something new arrives. People didn't study it in medical school in various countries.

The Chair (Mr. Peter Tabuns): I next have Mr. Mantha, then Ms. Mangat.

Mr. Michael Mantha: I just want to thank my colleague Mrs. Martins for having clarified the amendment that the government was putting forward with regards to my concern with the mention of Lyme within this bill. As you all know, it has been front and centre in this House for a very long time. We need to let families, patients, the medical field, all of the stakeholders know that this is coming; we're going to be having this discussion.

My only concern that I do have—and I will highlight it when we come to that amendment—is changing from "shall" to "may." We need to make that decision. We need to take a step forward. I'm concerned that this bill

will go through and it will be a paper bill. Nothing will come from it.

We need to challenge ourselves in making sure that we answer the call and we answer to so many whose lives have been devastated. We need to take responsibility, and as they go to their doctors and challenge their doctors, we need to care for them. We have that opportunity now. Let's take that challenge and let's do something.

The Chair (Mr. Peter Tabuns): I'm going to go to Ms. Mangat, but before I give you the floor, just note that you may find it useful to weave these arguments into the amendments as we go through them.

Ms. Mangat.

Mrs. Amrit Mangat: Chair, our government is committed to protecting the people of Ontario from vector-borne and zoonotic diseases and our government supports Bill 27 as it aligns with our own priorities and initiatives. I understand that the Ministry of Health and Long-Term Care has met with MPP Barrett on his private member's bill. They actively worked together to move this bill forward.

Having said that, our only concern is that if the definition is too broad, it won't have the impact that all parties would want. MPP Barrett spoke about Ebola. SARS and Ebola are zoonotic diseases by origin, but their mechanism of transfer is not zoonotic as they are spread from human to human. Therefore, an action plan for those diseases would look different than an action plan for vector-borne diseases, such as West Nile, which is transferred from insect to human with no risks of human-to-human transfer. So I think narrowing down the scope would be better, and we have heard this from many presenters as well.

The Chair (Mr. Peter Tabuns): Thank you, Ms. Mangat.

I'm going to assume that you're ready to proceed.

Mrs. Laura Albanese: Yes, ready to proceed.

The Chair (Mr. Peter Tabuns): Okay. We're going to section 1 and we have our first amendment, a government amendment. Ms. Albanese.

Mrs. Laura Albanese: I move that subsection 1(2) of the bill be struck out and the following substituted:

"Interpretation, emerging vector-borne diseases

"(2) For the purposes of this act, emerging vector-borne diseases are infectious vector-borne diseases that constitute or are likely to constitute a risk to public health in Ontario."

The Chair (Mr. Peter Tabuns): Thank you, Ms. Albanese. Did you want to speak to that?

Mrs. Laura Albanese: I believe that we have just addressed the reasoning behind this amendment.

The Chair (Mr. Peter Tabuns): Is the committee ready to vote? Mr. Barrett.

Mr. Toby Barrett: Just a comment on that subsection: So, again, by way of example—and certainly it would be that Public Health Ontario identifies Lyme as a vector-borne disease and they document the number of cases. They identify West Nile. There are even more

cases of West Nile in Ontario than Lyme, and that's including probable cases. Now, the next report should be coming out in the next couple of weeks. Malaria: There are 220 cases of malaria in Ontario. You don't catch it in Ontario. Many of us, when we travel, take malaria tablets. You don't actually get it in Ontario, but it is of concern and we have to deal with people who have malaria.

The Ontario Federation of Agriculture, their concern beyond Lyme and West Nile was equine encephalitis virus—a very serious disease; no treatment at all for that one. But it has not been prevalent in Ontario for many, many years, as I understand. Yellow fever would be included; that's a vector-borne disease. It's not endemic. There's not the transmission within the province of Ontario. Like malaria, that's travel-related. So these are just some examples of vector-borne diseases. There are other vector-borne diseases. The significance isn't there that they don't show up in Public Health Ontario.

My understanding is that this legislation—we're not dealing with the flavour of the day or the concern this year or this winter—has to stand the test of time. So my understanding is, when the next one comes along—I don't even want to think about what the next one may be and whether it's mosquito or tick or whatever it would be—that this legislation would deal with it. We don't know what it is, but if it's vector-borne and we've got the framework in place, the education would kick in just like that. The surveillance will always be there and the research would continue, even though it's not here, like equine. That's my only comment.

With those caveats, I understand the reason for this and would vote in favour.

The Chair (Mr. Peter Tabuns): Thank you very much for your commentary. We'll go to the vote. Shall the amendment carry? The amendment is carried.

We shall now go to the vote on the section. Shall section 1, as amended, carry? The section is carried.

We go to section 2. We have amendment 2: Ms. Albanese.

1620

Mrs. Laura Albanese: I move that subsection 2(1) of the bill be struck out and the following substituted:

"Duty to develop provincial framework and action plan

"2(1) The Minister of Health and Long-Term Care shall develop a provincial framework and action plan concerning emerging vector-borne diseases that does or provides for the following:

"1. Enhances provincial surveillance by using data in the custody and control of the agency to properly track incidence rates of emerging vector-borne diseases.

"2. Establishes guidelines regarding the prevention, identification, treatment and management of emerging vector-borne diseases, including preparedness guidelines and the sharing of best practices throughout the province.

"3. Creates and distributes standardized educational materials related to emerging vector-borne diseases, for use by health care providers and by members of the

public, designed to increase awareness about those diseases and enhance their prevention, identification, treatment and management.

“4. Promotes research in connection with emerging vector-borne diseases.”

The Chair (Mr. Peter Tabuns): Any comment? Mr. Barrett.

Mr. Toby Barrett: My understanding of the amendment—correct me if I’m wrong—is that it deletes the one-year deadline for establishing this, the one-year deadline from the enactment of this legislation. I have a concern with that. There’s no deadline, and I have a concern. That has been an issue we hear at the witness table. In my riding, this has been going on since the late 1990s. The concern is, how much longer do we wait? That’s my concern. I don’t know whether the parliamentary assistant or the government would have any comment on that.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Barrett. I’ll see if there are any other comments. Ms. Albanese.

Mrs. Laura Albanese: Yes. I would just like to comment on this and say that this amendment was brought forward because we want to be able to properly consult and develop a thorough and effective action plan. One year could be sort of a defined period of time. It may be enough; it may not be enough.

I want to also take into consideration the fact that the action plan, or the framework, would need to be established for emerging diseases. So if it’s emerging—as the disease emerges, you have to address it.

So it’s just not to prescribe it into a certain period of time, and then you have other possibilities coming forward. It’s to be not too prescriptive. That was the reason. But I understand the urgency, the intent that you had there, putting that one year.

The Chair (Mr. Peter Tabuns): Thank you, Ms. Albanese. Are there any other comments? Mr. Barrett.

Mr. Toby Barrett: There’s no question that the major intent is to be able to have a framework there for emerging diseases. We have no idea what they are. It’s cautionary to have that framework, so we can hit the ground running when something happens, no matter what it is.

We used to have air raid sirens when I was growing up. You never knew if that was for nuclear war or what that was for, but at least there was something in place. You didn’t know why that siren was going to go off.

I wouldn’t want us to be limited, because the whole purpose is to be better prepared for the unknown. I don’t want anyone to use an excuse: “Well, we don’t know what it’s going to be.”

I’m accused of being too broad in my legislation, but I purposely kept it broad. I used terms like “surveillance” and “education” and “research,” which is very important, and “treatment” and “diagnosis,” regardless of what it is.

That’s my comment on that. I just think it’s important to have a deadline. Sometimes, deadlines do help to get action.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Barrett. I see—

Mr. Toby Barrett: One other comment on this one.

The Chair (Mr. Peter Tabuns): Mr. Barrett.

Mr. Toby Barrett: I think it was in a briefing, and I think this was from the government. There was another document. Mr. Mantha, you have this document, I see?

Mr. Michael Mantha: Yes.

Mr. Toby Barrett: It refers to section 2(1), paragraph 1. I don’t see it in the actual motion, but it indicated that this would remove the reference—this was on page 2, the lower right-hand corner. Do we have this document?

Mrs. Laura Albanese: Yes.

Mr. Toby Barrett: I’m unclear. It says it would remove the reference to tracking associated economic costs of vector-borne diseases, given limitations. Does that mean it removes reference to tracking or it removes reference to any costs, like determining the costs of these things? I’m unclear on just what that says.

They give an example: A patient could be hospitalized for encephalitis rather than West Nile, so how do you pin down the cost? In my previous career, we always had this issue: How do you determine the cost of alcoholism or drug addiction? There are so many confusing ways of measuring the cost.

First of all, I just wasn’t sure what this means. Does it remove reference to tracking or remove reference to anything in here about determining economic costs?

Mrs. Laura Albanese: Well, my understanding—

The Chair (Mr. Peter Tabuns): A second, please.

Mrs. Laura Albanese: Sorry.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Barrett. Other comments?

Mrs. Laura Albanese: Yes. I think we need to read the sentence as a whole, so “Remove the reference to tracking associated economic costs of vector-borne diseases, given limitations related to linking treatment cost to a specific vector-borne disease.” What I read into the sentence read out loud as a whole is that it’s difficult to determine what is the economic cost of one specific disease versus another, always talking about vector-borne illnesses. It’s not the tracking as a whole but it is the tracking of each and every one of them. For example, a patient could be hospitalized for encephalitis, but then turn out to have West Nile virus. I guess it’s the fact that it’s volatile, especially with emerging diseases.

Mr. Toby Barrett: It’s hard to measure.

Mrs. Laura Albanese: Hard to measure; I guess that’s what that sentence is saying. It’s that it is hard to measure, at the moment at least.

Mr. Toby Barrett: But I know when I think of SARS—

The Chair (Mr. Peter Tabuns): Thank you, Ms. Albanese. Mr. Barrett, you wish to speak? Then I’ll have Mr. Mantha after you. Please proceed.

Mr. Toby Barrett: Sorry, Chair. I don’t mean to challenge the Chair. I go next?

The Chair (Mr. Peter Tabuns): Yes, you do, and then Mr. Mantha.

Mr. Toby Barrett: I think of, for example, SARS in Toronto. We were given cost figures, the tourism cost—

afterward, of course, but we were given the cost. We were given the impact on restaurants. Many of us tried to help out—I won't get into the details—to support certain restaurants.

The global cost of SARS was \$40 billion; this is what I read. Somebody worked it out after the fact. I think that's so important. I mean, if government can't do anything, and if we're to help mobilize other organizations, whether it's OFA or OFAH or the Magnotta Foundation or other groups or the private sector, to help out, and if you can give them the economic impact—this just isn't out there. You're going to see absenteeism in your workplace. If it's something in the alcohol and drug field, you try to put an economic cost on absenteeism.

I just feel that's important for the cause, to help mobilize people, the direct link between, say, disease and absenteeism, and the impact on economic activity. Absenteeism in the health field itself—nurses or doctors who aren't there for whatever reason. That's why I thought it was important to have the economic cost in there.

The Chair (Mr. Peter Tabuns): Thank you, Mr. Barrett. Mr. Mantha.

Mr. Michael Mantha: I think I understand, but I just want to make sure that I'm understanding the right way. If we look at 2(1), the last sentence, "or provides for," is underlined. If we look in the analysis, the second paragraph, it says "provides for" is added in the last line to reflect that the framework action plan itself wouldn't do the actions described in the following paragraphs, but would instead provide for the government to do these things. "The amendments to paragraph 1 would"—and it goes on to list some of Mr. Barrett's concerns, is what he was saying.

Going back to his point, it says, "Remove the reference to tracking associated economic costs of vector-borne diseases, given limitations related to linking treatment cost to a specific vector-borne disease." I just want to understand: How is that covered under 1, 2 and 3 of the proposed amendment? Or is it not?

The Chair (Mr. Peter Tabuns): Thank you, Mr. Mantha. You made a comment; the government may or may not comment.

Ms. Albanese, would you like to comment?

Mrs. Laura Albanese: I think—yes, you try, Cristina.

Mrs. Cristina Martins: Can we just do a five-minute recess here, Chair?

The Chair (Mr. Peter Tabuns): Is everyone agreeable to a five-minute recess? Yes.

Mrs. Cristina Martins: Thank you.

The committee recessed from 1631 to 1638.

The Chair (Mr. Peter Tabuns): Could I please have the members back in their chairs? Ms. Albanese, would you like to set up the situation here?

Mrs. Laura Albanese: We have legal counsel present from the Ministry of Health here with us. We would like to call you up so that we can have a more technical and clear explanation for that. Please come forward.

The Chair (Mr. Peter Tabuns): Sir, if you could join us, please. If you could identify yourself for Hansard.

Mrs. Laura Albanese: We have two people, right?

The Chair (Mr. Peter Tabuns): We have another person joining you?

Interjection.

The Chair (Mr. Peter Tabuns): Okay. If you both would introduce yourself with your titles, then we can proceed.

Mr. Paul Kaufman: My name is Paul Kaufman. I'm legal counsel with the Ministry of Health.

Ms. Roselle Martino: I'm Roselle Martino. I'm the executive director of the public health division, Ministry of Health.

The Chair (Mr. Peter Tabuns): I understand that there were questions. Ms. Albanese, did you want to direct particular questions, or just open—

Mrs. Laura Albanese: I will just direct to answer the concerns that were brought forward by MPP Barrett.

The Chair (Mr. Peter Tabuns): Mr. Barrett, do you have questions for counsel and policy?

Mr. Toby Barrett: I think Mr. Mantha has some comments as well.

We have a cheat sheet from the ministry. Looking at page 2, in the lower quarter, it states: "Remove the reference to tracking associated economic costs of vector-borne diseases, given limitations related to linking treatment cost to a specific vector-borne disease." I guess I just wanted to clarify. My understanding is the framework or the action plan doesn't really do any economic analysis, evaluation or monitoring at all of the impact beyond maybe mortality and morbidity. Is that what we're looking at here?

1640

Where I'm coming from is, when these things hit—I think of SARS. The figure in my mind was always \$40 billion worldwide. Various diseases, when they do hit, there's absenteeism. Again, I think of SARS in Toronto and the impact it had on restaurants, for example, even down in my riding. Many of us tried to help out because of people's misinformation. But there was an economic hit, which is a compelling argument in many areas for the cause: We've got to deal with this stuff because it's not just somebody getting sick who you don't know; it means that it could impact the transportation system or tourism. The hit on tourism in Toronto, I understand, was very significant. Americans weren't coming up here because of SARS. So this isn't strictly a health bill in that sense.

I think that's the point that I was making.

Mr. Paul Kaufman: You are correct that the proposed government motion would remove the requirement to track the economic costs of the incidences of those diseases, although I think you made the other point about tracking generally, and the general obligation to track incidence rates of emerging diseases would not be taken out. That would still be in there.

As to the issues associated with tracking the economic impact stuff, Ms. Martino, I think you can speak to that a bit better than I can.

Ms. Roselle Martino: Yes, absolutely. I want to reiterate that we'll absolutely continue the tracking of the

various vector-borne diseases, as we said. I think MPP Mantha mentioned that as well.

What we were saying was challenging to do was, because the costs for hospitalization are not associated with a vector, but associated with the treatment or a presentation of a symptom—for example, we couldn't say we're associating a certain cost to West Nile or a certain cost to Lyme disease for hospitalized patients because they would present with encephalitis or a certain condition. As part of our surveillance—and we're looking at disease prevalence and burden of disease in the province—we could look at clusters of diseases, absolutely, and look at the impact of those diseases in our province, but we're not tracking specific costs of a specific vector because that would be really challenging to do. But we could certainly look at clusters—

Mr. Toby Barrett: Vector diseases, yes.

Ms. Roselle Martino: Yes. For example, you think about all ticks and how many variations of ticks there are or how many variations of mosquitoes there are exactly. We're just being a bit more precise in terms of what we'd be able to track, but we're absolutely tracking all those vector-borne diseases for sure. It would not take that away.

Mr. Toby Barrett: Or the surveillance.

Ms. Roselle Martino: Yes.

Mr. Toby Barrett: And even in the health field, what's a very important factor is, I'd say, the cost of alcoholism, absenteeism, lateness and accidents, serious, serious costs that can be quantified, partly in economic terms: the cost of drug abuse, the cost of the common cold—get your flu shot—the cost of the flu to business, industry and hospitals. If nurses don't get their flu shot, they get the flu and they don't come to work for a few days.

Ms. Roselle Martino: Yes. You're looking at productivity, absenteeism—

Mr. Toby Barrett: Teachers: We have a lot of supply teachers in the province of Ontario. If they all got their flu shot, they wouldn't phone in sick with the flu.

I always thought that health took the lead on that in part. Maybe we'd leave it up to someone else, the chambers of commerce or someone, but these dollar figures always seem to be associated with some of the broader diseases, not a specific, rare disease, but more the epidemic-type diseases.

Ms. Roselle Martino: Yes. I think what we would look at is—I think you're absolutely right. The flu shot is something tangible. Right? If you don't get it, then there are potential consequences.

Mr. Toby Barrett: But you never know when someone phones in sick. Maybe they've got the flu, maybe it's a bad cold.

Ms. Roselle Martino: That's right.

Mr. Toby Barrett: Some people seem to get the flu more than once a year. I don't understand that. From an absenteeism point of view—

Ms. Roselle Martino: All we were saying in respect here is that we were suggesting not tracking specific,

individual costs for patients in terms of treatment for various vectors. Rather, we would look at the clusters of the—the impact of those. What is the impact of West Nile in the province and how does that translate into economic burden? Because there are so many factors that come into that kind of cost calculation.

That was separate from tracking, is what we were trying to say. We would look at it in a population way and look at the impact of those as burden of disease would occur in this province. We'd apply the same lens to the vector-borne diseases.

Mr. Toby Barrett: Yes. Someone is probably going to do it, but I think of the cost of H5N2 in agriculture. I mean, you can quantify that. You've got the mortality figures.

Ms. Roselle Martino: I'm just saying there's a formula that would have to be applied for various classes of the vectors. That could certainly be done. We were just separating it from individual tracking and being clear that we're tracking the vector-borne diseases, and the incidence and prevalence of those.

Mr. Toby Barrett: All right. Do you think it's going to continue to be done anyway with various outbreaks of this and that?

Ms. Roselle Martino: From my view, yes, it will continue to be done. I think it's going to be clear that it's being done perhaps in a more clustered way. It's taking into consideration the number of influences that impact the economic burden of any kind of disease, right? So I'm saying it's going to be done and there are going to be different approaches applied to how it's done, but that's not taking away from tracking. I really want to be clear about that.

Mr. Toby Barrett: Evaluation—

Ms. Roselle Martino: Yes.

Mr. Toby Barrett: —or even surveillance, for that matter.

Ms. Roselle Martino: Yes, surveillance is critical.

The Chair (Mr. Peter Tabuns): So Mr. Barrett—

Mr. Toby Barrett: Okay, yes.

The Chair (Mr. Peter Tabuns): Mr. Mantha.

Mr. Michael Mantha: Clear as mud for me.

The Chair (Mr. Peter Tabuns): Did you have further questions, though?

Mr. Michael Mantha: No, I'm good.

The Chair (Mr. Peter Tabuns): Nope? Okay, that's fine. Thank you very much.

It looks like we've had a fairly fulsome debate. Is the committee ready to vote? Shall amendment 2 carry? Carried.

We go to amendment 3. Ms. Albanese.

Mrs. Laura Albanese: Thank you. This one is very simple: I move that subsection 2(2) of the bill be struck out.

The Chair (Mr. Peter Tabuns): Any discussion?

Mr. Toby Barrett: This removes legal responsibility. Is that what that does?

Mrs. Laura Albanese: Well, in the—

The Chair (Mr. Peter Tabuns): Wait—

Mrs. Laura Albanese: Sorry.

The Chair (Mr. Peter Tabuns): So you've made your statement?

Mr. Toby Barrett: Yes.

The Chair (Mr. Peter Tabuns): Does the government have a statement?

Mrs. Laura Albanese: Yes. I was just going to direct Mr. Barrett to the cheat sheet we all have. It suggests deleting this clause. It is unlikely that the minister would need to introduce new legislation in order to implement a framework/action plan. Even if that was necessary, the general obligation to develop the action plan and framework seems broad enough to include doing those things that are necessary in order to operate—oh, my God—

The Chair (Mr. Peter Tabuns): Operationalize.

Mrs. Laura Albanese: —operationalize the plan.

The Chair (Mr. Peter Tabuns): Okay. Are there further comments? The committee is ready to vote? Shall this motion be carried? Carried. The motion is carried.

Amendment 4: Ms. Albanese.

Mrs. Laura Albanese: I move that subsection 2(4) of the bill be amended by striking out “the minister shall” and substituting “the minister may”.

The Chair (Mr. Peter Tabuns): Any discussion on this? Mr. Mantha.

Mr. Michael Mantha: I want to speak against the “may” and “shall.” I think we need to get some action on this one and we need to move forward.

There's a point of clarification, and I'm not sure who to address. I'll address it to Mrs. Albanese. It reads, “For the purpose of developing and administrating the provincial framework and action plan, the minister may consult with any other affected ministries, the agency, boards of health, the Public Health Agency of Canada, the federal government or any other persons”—this is what I'm interested in—“or entities that the minister considers appropriate in the circumstances.”

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My question is, what is “any other persons or entities”? Does that include patients? I want to have a clear understanding of what that means, please.

The Chair (Mr. Peter Tabuns): There may or may not be a comment from the government.

Ms. Albanese.

Mrs. Laura Albanese: It may include patient advocates as well.

In any case, the amendment calls for striking out “the minister shall” and substituting “the minister may,” and I just wanted to address that as well. It's because it's not only the minister but you'll also have the ministry and Public Health Ontario that would be involved. It's not only the minister. So “may” is the preferred word compared to “shall” because it's not only the minister who consults.

The Chair (Mr. Peter Tabuns): Mr. Barrett?

Mr. Toby Barrett: I have a concern, too. This debate has been going on for years about “shall” versus “may.” “May” is a softer approach. It means that he doesn't have

to do anything, actually. That's the concern: that you could neglect consultation completely.

We put in the phrase “other persons or entities the minister considers appropriate in the circumstances.” That may refer just to other persons or entities. What if, instead of “or any other persons,” we put in “and any other persons”? Again, the operative phrase, “that the minister considers appropriate in the circumstances”—but he shall consult.

We heard so much at deputations at the witness table that nobody is consulting with the patients and nobody is consulting with the patients' experts or the patients' associations. I think we all believe in consultation, although even this process—it's a pretty short timeline to get people to come forward to participate in the process.

So we've always had that problem when you take a word like “shall” and put in the word “may”—it's kind of a meaningless word. He might do it; he might not. That's always the concern. It's a red flag that jumps up when you see this put in.

The Chair (Mr. Peter Tabuns): Ms. Martins?

Mrs. Cristina Martins: I think we were both in this committee room when we heard the alliance present this afternoon. If I recall correctly, they did make mention that the Ministry of Health and Long-Term Care has been consulting with their organization and has been consulting with patients.

I'm very confident that the change that is currently being proposed would continue to ensure that the ministry would be consulting with patients and the appropriate stakeholders, that the appropriate stakeholders are being consulted along the way, and that we're not consulting for the sake of consulting, that we are definitely consulting the right individuals and that this is not going to be just a paper bill.

Action is already in place to address Lyme disease and vector-borne diseases. This bill will continue to support the work that is already under way.

I'm very confident that the changes currently being proposed would in no way hinder the minister from consulting with patients and consulting with the appropriate stakeholders at the right time to ensure that everyone is being heard around the table.

The Chair (Mr. Peter Tabuns): Mr. Mantha?

Mr. Michael Mantha: Again, I would rather see the word “shall.”

Just going to the last sentence of this wonderful cheat sheet, it says, “The word ‘shall’ may require the minister to consult with persons not required to be consulted.” Who makes that determination in regard to who is required to consult? I think an individual who wants to bring a contribution needs to have that ability. What this last sentence is telling me is that the minister is going to be picking and choosing who he wants to bring forward. Essentially, that's what it says. “The word ‘shall’ may require the minister to consult with persons not required to be consulted.” So in his mind, if he says, “I don't want to consult with them,” then he won't. That's what that is telling me.

I'm going to be opposing this amendment, and I'm going to be asking the Chair for a recorded vote on this one.

Mrs. Cristina Martins: Can I just add to that?

The Chair (Mr. Peter Tabuns): Ms. Martins, if you have a comment?

Mrs. Cristina Martins: I understand Mr. Mantha's concern, but the way I read this, nowhere there does it say that the Ministry of Health and Long-Term Care staff would not be meeting with anyone who is wanting to present anything on this particular issue, so they would always be heard. It speaks specifically to the minister, so anyone wanting to speak on this—or anything else regarding this particular bill or this disease or any other vector-borne disease—moving forward, would always have that ability to present their case and speak to that.

The Chair (Mr. Peter Tabuns): Ms. Albanese.

Mrs. Laura Albanese: I just wanted to add that because the minister is mentioned, it may be too prescriptive in language because, as I mentioned at the beginning, you also have ministry departments that will meet and consult and Public Health Ontario that will meet and consult. So if we say, "the minister shall"—especially the Minister of Health and Long-Term Care; it's a very big ministry—that may bind the minister to meet with any and all stakeholders on one specific framework where he has a very big mandate. It doesn't mean that he wouldn't, but that it's not prescriptive only to the minister is the intent. That's the way I understand this.

The Chair (Mr. Peter Tabuns): Mr. Barrett.

Mr. Toby Barrett: Yes, my understanding with the term "minister"—the government, the agencies and staff—it refers to many people, not just the minister himself. That's my understanding.

Secondly, the phrase is in here, "that the minister considers appropriate in the circumstances." That's the default position or the out—I shouldn't say "out."

Maybe it's semantics, but this "may" versus "shall" has been going on for years and years.

Mr. Granville Anderson: When I was a trustee, you could spend two hours debating—

The Chair (Mr. Peter Tabuns): I'm sorry. Mr. Barrett, are your remarks in?

Mr. Toby Barrett: Yes. I wanted to hear Granville.

The Chair (Mr. Peter Tabuns): Mr. Anderson, do you have comments? Please proceed.

Mr. Granville Anderson: I was just saying, yes, it's semantics: "may," "shall" or "will." You could debate that ad infinitum. That's all I'm saying.

The Chair (Mr. Peter Tabuns): We may well have debated that ad infinitum.

Is the committee ready to vote? There was a request for a recorded vote.

Ayes

Albanese, Anderson, Dhillon, Mangat, Martins.

Nays

Barrett, Mantha.

The Chair (Mr. Peter Tabuns): The motion is carried.

We now go to the vote on the section as a whole. People are ready to vote? Shall section 2, as amended, carry? Section 2 is carried.

We go to section 3. We have no amendments. Is the committee ready to vote? Shall section 3 carry? It is carried.

We go to section 4, and we have amendment 5, a government motion. Ms. Albanese.

Mrs. Laura Albanese: I move that section 4 of the bill be struck out and the following substituted:

"Short title

"4. The short title of this act is the Provincial Framework and Action Plan concerning Emerging Vector-Borne Diseases Act, 2015."

The Chair (Mr. Peter Tabuns): Is there any discussion? There being none, a vote on amendment 5. All those in favour? Carried.

Since it replaces section 4, for clarity, shall section 4, as amended, carry? Carried.

We go to the last few votes. We go to the title, and we have amendment 6. Ms. Albanese.

Mrs. Laura Albanese: I move that the title of the bill be struck out and the following substituted:

"An Act to require a provincial framework and action plan concerning vector-borne diseases."

The Chair (Mr. Peter Tabuns): Any discussion? There being none, the committee is ready to vote? Shall amendment 6 carry? It is carried.

Shall the title of the bill, as amended, carry? Carried.

Shall Bill 27, as amended, carry? Carried.

Shall I report the bill, as amended, to the House? Done.

Thank you, colleagues. The committee stands adjourned.

The committee adjourned at 1700.

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Mr. Michael Mantha (Algoma–Manitoulin ND)

Mrs. Cristina Martins (Davenport L)

Also taking part / Autres participants et participantes

Mr. Paul Kaufman, legal counsel, Ministry of Health and Long-Term Care

Ms. Roselle Martino, executive director, public health division,

Ministry of Health and Long-Term Care

Clerk / Greffière

Ms. Valerie Quioc Lim

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Mr. Bradley Warden, legislative counsel

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