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Chair

Mr. Bill Casey

Standing Committee on Health

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● (1105)

[*English*]

The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)): Welcome to meeting number 60 of the Standing Committee on Health. We're going to continue our study of the federal framework on Lyme disease.

Today, we have a number of witnesses who have taken the time to come and visit with us today.

We have, from the Public Health Agency of Canada, Dr. Howard Njoo, acting assistant deputy minister, infectious disease prevention and control branch. From Canadian Blood Services, we have Jean-Paul Bédard, vice-president, public affairs; and Dr. Margaret Fearon, medical director. As an individual, we have by video conference Dr. Ralph Hawkins, clinical associate professor of medicine, University of Calgary. Also as an individual, we have Dr. Elizabeth Zubek, family physician, Shepherd's Hill Medical Clinic.

Welcome to you all.

Each of you has 10 minutes for an opening statement. At nine minutes I will hold up a little red card just to remind you.

We'll start with Dr. Njoo, with the Public Health Agency.

Mr. Len Webber (Calgary Confederation, CPC): Mr. Chair, I do have a point of order, if you don't mind.

Please, Dr. Njoo, don't take this personally.

I thought that, according to our discussions in past meetings, we were going to have Dr. Theresa Tam here to present to us. Dr. Tam is the one who is pictured in the report, the framework, and it's just appropriate, I think, that she be here to present to us. Again, I have no beefs with having Dr. Njoo here, but is there a reason that Dr. Tam is not here today?

Dr. Howard Njoo (Acting Assistant Deputy Minister, Infectious Disease Prevention and Control Branch, Public Health Agency of Canada): It's just due to a scheduling conflict.

I'm also the deputy chief public health officer, just below Dr. Tam. If that suffices, I'd be pleased to speak.

Mr. Len Webber: All right.

I just wanted to make you aware of that. If there are other reasons why.... I see her as the one who's pictured here on the framework. Normally, it's the minister who is pictured on the front page of any report, especially a much anticipated report. I question why Minister Philpott's picture is not on this report, but that's just another thought.

I do have one more point of order, Mr. Chair.

In past meetings, we've discussed and even put a motion forward about this meeting in particular being televised. Is it being televised? I don't think it is. We passed a motion that it was to be televised. May I ask why it is not?

The Chair: I'm told we weren't able to have it televised because of the video conference.

The Clerk of the Committee (Mr. David Gagnon): It was already booked. The other rooms were already booked by another committee. We tried, but it didn't work.

Mr. Len Webber: I just think it's important because there are a lot of Lyme sufferers who are very much anticipating this meeting today and wanting to watch it. It's just disappointing that we don't have it televised for them. Instead, they'll have to read the committee Hansard, I guess.

I woke up on the wrong side of the bed this morning, and I have a couple of beefs.

The Chair: They're all good points. We're glad you're keeping us on track.

Are there any more, or is that it? Okay, I just wanted to make sure.

Dr. Njoo, you may go ahead.

Dr. Howard Njoo: Thank you very much.

Members of the committee, thank you for the opportunity to contribute to your deliberations on the federal framework on Lyme disease.

I would also like to take this opportunity to acknowledge and thank the witnesses who spoke here on Tuesday, as well as the witnesses and members here today for contributing to raising awareness and supporting Canadians with Lyme disease. As a deputy chief public health officer and a physician, I am aware of how difficult and challenging infectious diseases can be. They can be even more difficult for patients when they are left feeling as though they have not been heard.

The front-line health professionals rely on guidance developed using an evidence-based approach and the principles of the scientific method. Ongoing discussions like the one we are having here today are an important part of the response to this and other public health issues.

[*Translation*]

Lyme disease has received attention from the public and from parliamentarians and led to the introduction and passing of the Federal Framework on Lyme Disease Act in December 2014.

[*English*]

The framework is intended to help guide a way forward in areas where the federal government has a role, including national surveillance, guidelines and best practices, and education and awareness. Federal activities will continue to support the provinces and territories in their role in the delivery of health care services to Canadians.

Since the passing of the act in 2014, we have worked to provide Canadians with multiple opportunities to provide their input into the framework.

[*Translation*]

For example, last year the Public Health Agency of Canada hosted a conference in May to inform the development of a federal framework on Lyme disease. The conference brought together over 500 patients and their caregivers, health professionals, and federal and provincial representatives.

[*English*]

Earlier this year, we launched an online public consultation on the draft federal framework. The intent of this public consultation was for Canadians to review the draft framework and provide their feedback.

Through this public consultation process, over 400 individual or collective submissions and comments were received. These comments were carefully considered in the final federal framework.

[*Translation*]

On May 30, the Minister of Health formally introduced the Federal Framework on Lyme disease.

As you heard on Tuesday, Lyme disease is one of the most rapidly emerging infectious diseases in North America.

[*English*]

Environmental changes driven by climate change have been shown to affect the emergence and re-emergence of vector-borne diseases transmitted by mosquitoes and ticks, including Lyme disease. As the geographic range of disease-transmitting vectors expands northward, there is increased risk to Canadians of being exposed.

[*Translation*]

The Government of Canada is committed to preventing and controlling the spread of vector-borne diseases through a number of measures.

The Public Health Agency of Canada has been monitoring Lyme disease for over a decade. We have seen cases increase from 144 in 2009 to an estimated 841 in 2016.

[*English*]

The Public Health Agency of Canada conducts vector-borne disease monitoring and surveillance, including diseases such as Lyme disease and West Nile virus. We also work collaboratively with our partners, such as the Canadian Institutes of Health Research, to undertake research on vector-borne diseases. All of this supports the development and delivery of well-informed and evidence-based infectious disease control frameworks, strategies, and interventions.

[*Translation*]

Effectively responding to the increased risk from vector-borne diseases requires ongoing investments in disease monitoring and surveillance, knowledge and information sharing, research, professional and public education, as well as collaboration with partners and stakeholders to facilitate innovation.

Since 2016, the Public Health Agency of Canada has directed almost $3 million to better understand and respond to Lyme disease in Canada. This is in addition to Lyme disease and tick-borne disease investments made by other federal departments, like CIHR and Parks Canada.

[*English*]

A few key areas where the Government of Canada has been working with partners on Lyme disease include an enhanced surveillance program with provinces to collect more detailed and timely information on cases of Lyme disease; researching tick-borne diseases and providing reference laboratory testing for provinces and territories by our national microbiology laboratory; increasing awareness among Canadians on how to protect themselves and their families; and providing information to health care providers to support early identification and diagnosis of Lyme disease.

[*Translation*]

Emerging vector-borne diseases are and will continue to be a public health concern for Canadians. The prevention and control of vector-borne diseases, including Lyme disease, requires collaboration among all levels of government and non-governmental organizations.

[*English*]

As guided by the provisions of the Canada Health Act, provinces and territories are primarily responsible for the delivery of both direct health care services and local public health activities. Provincial and territorial public health authorities and indigenous public health authorities also undertake prevention and control activities specific to their own jurisdictions.

The framework is accompanied by a federal action plan on Lyme disease. This action plan identifies three areas for concrete action. Under the first pillar of surveillance, we will be exploring the costs associated with this disease. We will also be working with partners to establish a tick-borne surveillance system for Lyme disease and possible co-infections.

[*Translation*]

Under the second pillar of education and awareness, we recognize that clinicians can't diagnose what they don't know exists. So one of our main goals is to get the message out to health care professionals that Lyme disease is here. We will work with partners to educate health professionals on the symptoms and support them in their ability to diagnose and report cases.

As such, our action plan commits to deliver national education and awareness campaigns, so as to remedy the lack of communication regarding prevention and intervention.

● (1110)

[*English*]

Under the third and last pillar of guidelines and best practices, we recognize that the federal framework on Lyme disease does not address treatment guidelines. Clinical diagnosis and treatment of Lyme disease fall under the purview of professional associations representing front-line health care practitioners. We have committed to working collectively to strengthen evidence-based approaches through further research.

On May 30, 2017, as part of the budget 2017 investment under the pan-Canadian framework on clean growth and climate change, the Hon. Jane Philpott, Minister of Health, announced a joint effort between the Public Health Agency of Canada and the Canadian Institutes of Health Research to establish a Lyme disease research network. Investing up to $4 million in new funding, the objective of this research network will be to generate new knowledge in an effort to improve diagnosis and treatment.

The Government of Canada will also continue to support front-line health professionals and provincial laboratories through the Canadian Public Health Laboratory Network in the laboratory diagnosis of Lyme disease. All partners, including provincial and territorial health care regulatory authorities, will be consulted on innovative, evidence-based approaches to address the needs of patients.

[*Translation*]

The Public Health Agency of Canada will work with public health authorities, health care professionals, patient groups and other interested parties as we move forward together on all three areas of action.

In closing, I would like to reiterate that Lyme disease is a reality in Canada. Its effective prevention and control requires a coordinated multi-partner and stakeholder engagement approach. Through our collective efforts, Canadians will be more aware of the disease and recognize its symptoms.

[*English*]

As the interim chief public health officer indicated in the framework, “We will accomplish much by working together in a collaborative manner to identify and implement the solutions.”

Thank you very much for your time.

● (1115)

The Chair: Thank you very much for your comments.

Now, we go to Canadian Blood Services.

Do you want to split your time? You have 10 minutes, any way you want it.

Mr. Jean-Paul Bédard (Vice-President, Public Affairs, Canadian Blood Services): Mr. Chair, thank you for the opportunity to be here.

[*Translation*]

I will first use a few minutes to talk about our organization. I will then give the floor to my colleague, Dr. Margaret Fearon, who will go into more detail about the dossier we are presenting.

[*English*]

Canadian Blood Services is an arm's-length organization within the larger health care system. We're there, really, to manage the blood system for Canadians, with the exception of the province of Quebec. That mandate was given to Héma-Québec.

We are regulated by Health Canada, and we are funded by the provinces and territories. The ministers of health of the provinces and territories are actually our members, our shareholders, and they appoint our board of directors.

[*Translation*]

We manage blood reserves, blood products and stem cell reserves, as well as related services for all of the provinces and territories except for Quebec, as I explained earlier.

We also manage the National Public Cord Blood Bank, and we are the only authority responsible for the supply, contract manufacturing, and distribution of plasma protein in Canada.

[*English*]

In addition to those responsibilities, we lead an integrated interprovincial system for organ donation and transplantation for all of Canada. As part of this work, we operate the groundbreaking Canadian transplant registry and related programs.

We take many actions to protect the blood supply and ensure a safe and effective system for all Canadians. Educating donors, assessing risks via our donor questionnaire, and testing donated blood are at the heart of our multi-layered approach. Comprehensive and timely surveillance of infectious diseases also helps us to monitor the blood supply and ensure it is as safe as possible. This means we test blood donations for transmissible diseases, investigate possible transfusion-transmitted infections in blood recipients, and scan the horizon for potential or emerging threats.

We also stay current with the activities of blood operators around the world. By learning from our peers, we collect even more knowledge, data, and evidence to support appropriate policies and processes for our country.

Now I'll ask my colleague, Dr. Margaret Fearon, our director of medical microbiology, to speak to the specifics of how we approach the issue of Lyme disease for Canadians.

Dr. Margaret Fearon (Medical Director, Medical Microbiology, Canadian Blood Services): Thanks, Jean-Paul.

As I'm sure the committee is aware, the bacteria that causes Lyme disease is Borrelia burgdorferi, which is a spirochete, a type of organism similar to syphillis but with many different characteristics.

To date, there has been no evidence of transfusion transmission of this bacterium. In spite of the fact that several studies have looked at donors who have been infected with Lyme disease and are bacteraemic and at the recipients of blood products from those donors, there has been no evidence of transfusion transmission. In all cases those patients tested negative for Lyme disease.

Canadian Blood Services does not test blood donors for Lyme disease, and we are not alone in this. There is no blood supplier in the world that tests blood donors for Lyme disease, including the United States, which has a high prevalence, as I'm sure you know, of Lyme disease, particularly in the northeastern U.S. No one, then, tests blood donors for Lyme disease.

Given that none of the blood operators globally has expressed a demand or a need for testing for Lyme disease, none of the companies that produce these assays has developed a test and submitted it either to Health Canada or to the FDA for approval. As you know, at Canadian Blood Services all of the testing we use for screening our donors must be approved by Health Canada.

That said, the move towards pathogen reduction technologies removes the need for specific testing for each type of pathogen. Pathogen reduction technologies prevent transfusion-transmitted diseases by very effectively killing bacteria, parasites, and most viruses that may be present in the unit. The bacteria that causes Lyme disease is no different. It would be inactivated by this technology.

These technologies are gradually becoming available in Canada. There is currently a Health Canada-licensed product for the treatment of plasma, and there is another product currently under review by Health Canada for the treatment of platelets. Unfortunately, there is no pathogen reduction technology yet on the market for the pathogen inactivation of red blood cells. That is a more challenging process.

There are, however, several companies that are in clinical trials, so we're hoping that such technology will be available within the next couple of years. While there is currently no evidence of transfusion transmission of Borrelia burgdorferi, the implementation of pathogen inactivation technologies in the future would eliminate even a theoretical risk.

Today, what we currently do is defer any donors who are diagnosed with Lyme disease from donating blood. If a donor comes in and says, “I recently was told I have Lyme disease”, they are told that they are not allowed to donate until they are feeling completely well and are finished any treatment they may be on.

We also ask donors, as the first question when they come in to donate blood, “Are you feeling completely well today?” If the donor cannot answer that question with a yes, they are told that they are not allowed to donate that day.

We also ask about medications. We ask about whether donors are under a physician's care for any reason, and we defer donors if they are. This is not only for the protection of the recipient but also for the protection of the donor, because we don't want a donor who is feeling unwell donating blood, obviously.

We also ask donors, if they become ill after their donation, to contact us and let us know, and donors frequently do this. If they develop an infection or respiratory symptoms post-donation, they often will call us and let us know, and then we can make a decision on whether the unit they have donated needs to be quarantined or not.

It should be noted—because I am often asked whether we ask about tick bites—that blood suppliers in North America do not ask about a history of tick bites prior to donation. This is because individuals are often unaware that they have been bitten by a tick, and so the history in that respect is unreliable. However, if a donor volunteers that they've recently had a tick bite, we ask them to not donate that day and to come back in six months' time.

Our work and engagement in this area has been long-standing. We've been actively monitoring concerns over transfusion transmission of Borrelia burgdorferi and we have actually had many discussions about this, not only within Canada but on the committees that I sit on, which include the AABB transfusion transmitted diseases committee, and also the European Blood Alliance's emerging infectious diseases committee. There is active monitoring of this around the world.

● (1120)

As part of our ongoing commitment for transparency and openness, we have also engaged with stakeholders and, a number of years ago, met with patient advocates to address their concerns. We commit to continue to do that.

Thank you.

The Chair: Thank you very much.

Now we will move to Dr. Hawkins.

Dr. Hawkins, if you are ready, we'll have a 10-minute opening statement.

Dr. Ralph Hawkins (Clinical Associate Professor of Medicine, University of Calgary, Cumming School of Medicine, As an Individual): Thank you very much, Mr. Chair.

My name is Ralph Hawkins. I'm a physician with a practice in an academic medical setting in Calgary. I'm told anecdotally that my practice seeing my patients is one of the largest in Canada. Since 2012 we have evaluated more than 300 patients presenting with alternatively diagnosed Lyme disease, and we presently have over 200 patients on a waiting list to be seen. We have recently had to suspend intake of new patients onto the wait-list due to the sheer volume of demand.

My father was born in rural Saskatchewan in 1914. He died just over five years ago, but last week would have been his 103rd birthday. I want the committee to know that I admire my father and try every day to emulate his example. There were a number of things he could not abide, and being overly negative was one of them. He insisted that we always look for something good coming out of every situation, so with that lens applied, I wish to make some positive observations about the framework itself.

I appreciate the interest of parliamentarians in passing the framework act in the first place. I appreciate the efforts made by the Public Health Agency of Canada under the leadership of Dr. Taylor to engage and collaborate with all stakeholders. Those efforts paid off with the framework conference, which was noteworthy in getting stakeholders together in one venue to discuss the issues and set some priorities.

I wish I could be as positive about the activities of the Public Health Agency—I'll refer to them as PHAC from now on—in the several months following the framework meeting. Unfortunately, the framework document called “Lyme Disease in Canada” was created by PHAC without the same collaboration and engagement with stakeholders that was evident in the planning process.

I appreciate that the document mentions that human risk is increasing outside of known risk areas. I appreciate that the document mentions that cases are likely under-reported. I appreciate that the document lists as a foundation statement that all stakeholders, including patients and their advocates, health care providers, and public health authorities have important interests in making progress on Lyme disease. The document identifies three priorities that I will speak to briefly in turn.

First, on surveillance, in February 2017 provincial and territorial authorities met and agreed to implement “less burdensome” methods of tick surveillance than had been employed in the past. This concerns me if this means that surveillance will be de-intensified. The Canadian case definitions for Lyme disease were revised in 2016 and released by publication in February 2017 and demonstrated a heavy reliance on laboratory corroboration of diagnosis for reporting. This has been demonstrated to be highly insensitive in practice.

A recent publication looking at commercial diagnostic kits identifies that the sensitivity of laboratory kits presently used in practice is in the 40% to 50% range. This means that false negative test results are generated for patients truly suffering from Lyme disease in the magnitude of 50% to 60% of the time. Additionally, the number of cases counted through laboratory surveillance is magnitudes lower—perhaps fivefold to tenfold different—than cases actually occurring in provincial jurisdictions.

Second, on education and awareness, education to enhance tick awareness is needed. It is important that educational materials be accurate and contemporary. All of the pictures of the classic erythema migrans rash in educational materials are demonstrated on Caucasian white skin, but the reality of Canada in the 21st century is that we are increasingly a country of ethnic and racial diversity. The fact remains that we have erythema migrans rashes that look different on pigmented skin.

● (1125)

Another example is that the PHAC framework report employs maps of brisk areas that are not consistent, meaning that they are too confined when compared to contemporary published scientific literature. Additionally, the risk areas are undoubtedly going to expand over the five-year lifespan of the framework, yet the maps of risk areas will remain in the hard copies of the document for the five years. This speaks to the need for the document to be a living document with frequent updates during its lifespan. The document also states that Lyme risk occurs mainly in areas of established tick populations, but this is an unproven conjecture. The clinical diagnosis of Lyme is heavily biased by the definition of a case emphasizing exposure in a risk area.

Next on guidelines and best practices, it is a positive step that the framework acknowledges the existence of ILADS', International Lyme and Associated Disease Society's, treatment guidelines. It demonstrates a bias within the PHAC authorship that it refers to IDSA , the Infectious Diseases Society of America, guidelines as being “used by the broader medical community”, and that it relegates the ILADS guidelines to a subordinate position followed by “a small number of front-line health professionals”.

I am very concerned that the document identifies the Canadian Public Health Laboratory Network as providing the sole leadership on diagnostics. Test methods in common use in other jurisdictions are not offered in Canada due to this network's exclusion of legitimate alternative testing methodologies. For example, Liz and I attended the Best Brains Exchange on Lyme diagnostics in June 2015 where use of the T-cell test called ELISpot was discussed. The action items arising from that meeting included suggestions for lab physicians and clinical practitioners to collaborate on innovations, such as investigating the use of ELISpot, which would be useful in assisting front-line practitioners to improve diagnostic sensitivity. In the two years since this CIHR-sponsored event, however, no collaboration or innovations have been forthcoming.

As a result, practitioners still make use of laboratories in the United States or Europe to obtain lab work that could be provided in Canada. The patients are left to pay the bill for these investigations. This framework is lean on specifics of research, particularly upon who will define the research priorities, ensuring that patients and front-line providers are involved in setting the research priorities, monitoring the investments in research, and tracking outcomes. An example of how such monitoring could occur would be the U.S. Congress's recent 21st Century Cures Act, which establishes a Lyme research oversight committee with equal representation of stakeholders, including patients, caregivers, researchers, funding agencies, and legislators to set the Lyme disease research agenda and to closely monitor its progress. Your standing committee, which oversees CIHR activities, has the power to implement exactly such a measure if you choose to.

The framework has its deficiencies. It is silent on the plans to monitor congenital transmission, the blood system, or for the emergence in Canada of novel Borrelia species, including new North American and European Lyme strains.

I will close by reminding the committee of the scores of patient testimonies and the hundreds of letters that patients suffering from the disease have brought forward. These patients are suffering today. The framework gives them no hope that things will be different soon. My patients this afternoon in clinic will still be obliged to pay for out of Canada testing.

Lyme disease sufferers are an identifiable group who are being systematically wronged by a system not responsive to their plight. We are in the midst of a tragedy of our own making. During the framework conference last May, I had the honour of taking my then 13-year-old son to the House of Commons to witness the long-overdue apology for the *Komagata Maru* incident. It made me proud to witness a system that could be introspective, that could see and admit its wrongdoing, and to make amends for it.

● (1130)

I believe our system's intrinsic tendency to eventually do things right persists. Lyme disease sufferers today are being wronged. Wrongdoing is not always deliberate. Institutional wrongdoing is more often inadvertent. I would recognize the hardship of Lyme disease suffered in Canada exists today as a result of systemic institutionalized wrongdoing. As a private citizen, I would suggest to this committee that a formal inquiry would be the appropriate remedy, or perhaps my son, in his later years, will someday attend Parliament to witness the long-overdue apology to Lyme sufferers for our inaction today.

Thank you.

The Chair: I thank you very much.

Now we'll go to Vancouver and Dr. Zubek for 10 minutes.

Dr. Elizabeth Zubek (Family Physician, Shepherd's Hill Medical Clinic, As an Individual): Good morning. I'm Dr. Elizabeth Zubek, and I am a clinical instructor with the University of British Columbia Faculty of Medicine, department of family practice. I've also worked, from 2013-14, as a UBC consultant on the treatment of Lyme disease, with the university's complex chronic disease program, which was created to be a central provincial referral site for patients with Lyme disease. I now work in private practice, with the treatment of tick-borne infections occupying about 20% of my time.

I'm honoured to be chosen to speak at the House of Commons Standing Committee on Health regarding an action plan, the federal framework on Lyme disease. You, as our federal MPs, listened to the suffering of Canadians with chronic Lyme disease. You responded to the thousands of people in your constituencies who presented evidence that Lyme disease is not being properly diagnosed and treated in Canada. You had the courage to vote unanimously to create an action plan to correct these issues. Now it's time to take this information, designate the funding, and create a solution for all Canadians.

I urge you to remember the why, the impetus behind Bill C-442: Canadians becoming disabled from a treatable disease. This should inform our decisions.

Three pillars are addressed by the framework: surveillance, education and awareness, and guidelines and best practices. I would like to address each of those three pillars in succession. I'll address these from the perspective of a family physician and from the perspective of one of the few Canadian physicians specializing in the treatment of chronic tick-borne illnesses.

On surveillance, although surveillance is already being funded by the Government of Canada for Borrelia burgdorferi, we know that data obtained becomes obsolete quickly due to climate change and due to migratory birds, as they travel, spreading ticks into new areas. There is no region in Canada that can be considered safe from Lyme disease. As a family doctor, I assess the patient in front of me. If that person was bitten by a tick and develops an unusual rash, or neurological or arthritic symptoms, it doesn't matter to me whether the rate of infection in ticks in my area is 5% or 20%, I treat the person in front of me, and I need appropriate testing for tick-borne disease in that scenario.

We know there are multiple species of Borrelia, at least 10 of which cause human disease, and multiple strains among each species. There are then other Borrelia species that cause a relapse and fevers. We know that ticks carry multiple other bacteria, viruses, and parasites. I think it's more important to allocate our resources to test the sick human for the presence of disease rather than count how many ticks in a field contain the Borrelia bacteria. Surveillance has its role, and new Lyme cases are reported, but this already has some funding. Sick people need diagnosis and treatment, not more regional statistics.

Education and awareness is the second pillar. This is very important to prevent new cases of Lyme disease and to recognize symptoms of chronic infection. I believe the entire process of this framework has robustly increased education and awareness in Canadians. There's been so much press about Bill C-442, the all-party support, the controversies involved, and the media has effectively done more than any print campaign the government could have devised. As such, my recommendation would be that the dollars attached to this area of education and awareness be designated towards physician education.

I work in a region of B.C. that's considered endemic for Lyme disease, yet I frequently hear physicians saying, “Lyme disease isn't found in B.C.”, or physicians suggesting a Lyme test immediately after a tick bite, when the test couldn't possibly be positive yet. I teach final year medical students who have not learned about acute and chronic manifestations of Lyme disease. It is to physicians that educational efforts must be directed.

The third pillar is guidelines and best practices for diagnosis and management. On best practices for diagnosis, this framework recognizes that testing with better sensitivity is needed. We cannot accept the current two-tier tests, which as Ralph said, only have a 40% chance of picking up disease, and that's only if you're lucky enough to have your disease caused by one particular strain, B31, of one particular species, *sensu stricto*, of Borrelia.

● (1135)

Better tests exist now. I recommend that funding go toward evaluating the ELISpot test in our Canadian population. The ELISpot is a lymphocyte transformation test. This type of testing is accepted in Canada as the gold standard for assessing active versus latent or dormant tuberculosis, which is another spirochete disease.

The ELISpot can diagnose 84% of Borrelia infections, is positive earlier in the course of disease, and will go down to zero when treatment is completed. This has added benefit in areas of high endemicity, where a person can be reinfected after the treatment was completed. ELISpot testing currently costs between $200 and $400. Patients, as Ralph said, are now paying for it out of pocket. But it is being used by most of the treating doctors I know in Canada. Better testing for Canadians must be a top priority.

Finally, there are best practices for management. The framework recognizes there are two different approaches to management. One guideline is supported by the Infectious Diseases Society of America, IDSA, and the other is supported by the International Lyme and Associated Diseases Society, ILADS.

In evaluating the trustworthiness of any set of guidelines, specific criteria must be met, as outlined by the respected Institute of Medicine. Guidelines must include regular review and monitoring as new research becomes available. A multidisciplinary panel of experts and representatives from key affected groups, patients, update the guidelines.

Only one set of guidelines meets these criteria, the ILADS guidelines of 2014. These are on the U.S. National Guideline Clearinghouse website and used internationally. Strangely, we in Canada have not publicized these very current and evidence-based guidelines for doctors to use in Canada. We still post the old IDSA guidelines, published over a decade ago, in 2006, never revised, and which were discarded from the U.S. National Guideline Clearinghouse well over a year ago.

This is a critical point to address. There has been an explosion of research on Borrelia this past decade. We have discovered that Borrelia has three different shapes or morphologies and it switches easily between them. The three forms include a corkscrew shaped spirochete with a cell wall, an intracellular form, and a round body that is a more dormant form. It takes a different type of antibiotic to treat each one of these three forms. As a result, the most effective protocols use three different antibiotics all together or in a pulsing pattern.

I looked on the PHAC website just last night for any treatment advice for late Lyme disease, and in its “for physicians” section, it linked me only to a 2006 article of treatment protocols. Those old protocols use only one antibiotic by itself for only two to four weeks, even when the brain is affected. We need PHAC to acknowledge the updated 2014 ILADS guidelines and formally post this most up-to-date information for physicians on their website so that doctors can manage their patients appropriately.

In summary, priorities for funding must align with the priorities of people affected by Lyme disease and their experts. The top two priorities would be diagnosis and management related. For diagnosis, we must evaluate the use of a more sensitive yet still specific diagnostic test such as the ELISpot, and make it available to Canadians immediately as a part of that evaluation. For management, Canadian clinical practice guidelines must consider the most up-to-date research and meet Institute of Medicine standards.

We must do broad education for physicians in all specialties and in general practice. We also need to train up a cohort of physicians with special expertise in the treatment of people with chronic manifestations of Lyme disease. Physician expert engagement must include the College of Family Physicians of Canada, which has a mandate to provide holistic patient-centred care. Family doctors are the ones on the front lines, from diagnosing initial infection to caring for complex systemic diseases.

● (1140)

Finally, it is very important that patients be an integral part of the research direction and research network.

Thank you for your attention today.

The Chair: Thank you to all of you for your contributions here. We're all learning a lot in a very short time.

We're going to go to our question period now. We'll have a seven-minute round of questions, starting with Ms. Sidhu.

Ms. Sonia Sidhu (Brampton South, Lib.): Thank you, Mr. Chair.

Thank you to all of the presenters for their valuable testimony.

My question is for Dr. Hawkins and Dr. Zubek.

This week we heard from patients that physicians need more training and need to properly handle this disease, as you also said in your testimony. What kind of education awareness do you want to see that has not been incorporated in the framework?

● (1145)

Dr. Elizabeth Zubek: My feeling on that is that we need to publish the ILADS guidelines because they tell physicians that patient preference is important: here's the evidence; how long do we want to treat for; what are the options. Physicians can look at the research and at the patient preference for treatment. These evidence-based guidelines are a very valuable tool for physicians to have access to.

The second thing I mentioned was developing a cohort of physicians where people like Ralph and me and the very small group of us who treat chronic infections can train a larger cohort to spread that knowledge further in Canada.

Ms. Sonia Sidhu: Thank you.

Dr. Hawkins, can you point out any research that has not been incorporated in the framework?

Dr. Ralph Hawkins: A really short answer to that question is yes.

Ms. Sonia Sidhu: What do you want to see?

Dr. Ralph Hawkins: I would like to see included in the framework the literature from Dr. Samuel Donta, for example, that addresses cohorts of patients who have received longer duration treatments with oral antibiotic therapies with outcomes that have been really quite satisfactory. This is not addressed in the framework.

I accept what Dr. Njoo is saying, that the framework doesn't specifically address treatment guidelines. Whether it should address treatment guidelines is a different question. I think it should, but I accept that he is telling us that it doesn't.

There is an abundance of literature. I have a personal library of well over 1,000 reference papers on Lyme disease that address various aspects of the disease that are not covered in various ways by the IDSA approach to Lyme disease and are certainly not addressed by the framework document in front of you.

Ms. Sonia Sidhu: Okay.

My next question is for Canadian Blood Services. I want to clarify a point that was brought out during the last meeting on the subject. Some witnesses claim that they contracted or transmitted Lyme disease through pregnancy. However, the CDC claim "there is no evidence that [the] disease is transmitted from person-to-person."

Can you comment on the validity of CDC findings in reference to the transmission of Lyme disease?

Dr. Margaret Fearon: I can't really comment on transmission through pregnancy. That would be better addressed by Howard.

Ms. Sonia Sidhu: Dr. Njoo, can you explain that?

Dr. Howard Njoo: With respect to the question about transmission through pregnancy, as I said before, one of the things that everyone is looking for is answers to questions such as this.

I go back to the fact that science takes time. There is something called the scientific method that has been well established as a principle for natural science research since the 17th century. The fact is that we need cumulative evidence to answer any one question, and no single research finding is able to do that on its own.

I'm aware there are various types of studies purporting to show potential transmission risk in different types of settings. I think Dr. Hawkins mentioned, for example, congenital transmission. To date, there's been no conclusive, definitive evidence that those modes of transmission actually exist. Therefore, I certainly support that further research needs to be done in these areas to hopefully one day have definitive evidence one way or the other.

Ms. Sonia Sidhu: Concerning "Lyme Disease in Canada—A Federal Framework", what research gaps exist, in your opinion, with respect to Lyme disease?

Dr. Howard Njoo: I could go on about a number of research gaps. Certainly I would defer to other experts in the field. We'll be working closely with our colleagues at the Canadian Institutes of Health Research and also with researchers and stakeholders, as mentioned before, to determine what the research agenda should be.

As a starting point, we recognize that there are gaps in knowledge in terms of diagnosis and treatment. All of us in one way or the other have mentioned that, and surely that will be a focus of the research we need and of what we'll do going forward.

● (1150)

The Chair: Ms. Sidhu, Dr. Hawkins wanted to make a comment on your previous question.

Dr. Hawkins.

Dr. Ralph Hawkins: Thank you for allowing me to interject.

Dr. Njoo just alluded to my name and then mentioned that there was no definitive evidence of transmission of Borrelia.

I know that this committee has been given in evidence a textbook that was published in the late 1990s on neonatal disease. I know that Dr. Njoo is aware of that textbook as well. I would like to point out to this committee that the World Health Organization identifies in sub-Saharan Africa a danger of maternal fetal transmission of another Borrelia species causing epidemic relapsing fever in newborns. This is an active World Health Organization pursuit: looking at Borrelia species transmitted neonatally.

I don't think, then, that Dr. Njoo's statement that there's no definitive evidence of transmission of Borrelia species should be left unchallenged.

The Chair: Thank you.

Ms. Sidhu.

Ms. Sonia Sidhu: What are some of the barriers to accurate diagnosis of Lyme disease? Can Dr. Hawkins or any of you explain what the barriers are?

Dr. Ralph Hawkins: The barriers to the accurate diagnosis of Lyme disease start with the patient's presentation for medical assistance. When patients present and give a clear history of a tick bite, they're often greeted with a rebuff, as Liz has already suggested —"Lyme disease doesn't exist here; you don't have a picture; you didn't bring the tick in, etc."—so that often patients are dismissed at the outset.

Later on, blood testing may be done. The blood testing that is done in Canada, the present gold standard test, is a test called C6 ELISA, which in its best performance carries about a 75% sensitivity for the diagnosis to be established. It's a screening test. That means that 25% of people who have the disease are going to be dismissed on the basis of a screening test that isn't sensitive enough.

The people who pass that phase then go on to have a second test called a Western blot, which in its best performance, particularly in the later stages, has about an 80% sensitivity, which means that overall, 60% of the people who have blood testing are going to be identified, in the best-case scenario, as having a positive test result.

Then we have to embark on treatment. Many doctors are either not educated or are reluctant to prescribe the durations of antibiotics that are required to achieve satisfactory treatment of this disease. It is well established, furthermore, that if treatment is discontinued before symptoms are gone, relapse is almost universal.

The gaps or barriers in treatment, then, have been right from the time that the patient presents for care through the investigation and treatment paradigm. There are financial barriers, because many of the treatments require personal financial expense. Some of the investigations, because they're not offered by our health system, for reasons that have yet to be explained well to me, need to be done internationally at patient expense, so there are expense barriers. Often these patients are mobility challenged, and so they can't come to doctors' visits and can't get to the laboratory as frequently or as easily as they should.

There are myriad barriers to addressing this disease, Ms. Sidhu.

Ms. Sonia Sidhu: Thank you.

The Chair: Thanks very much.

Mr. Webber.

Mr. Len Webber: Thank you, Mr. Chair.

Dr. Fearon, you talked about the screening procedures at Canadian Blood Services and the fact that you don't ask about tick bites. Why not, especially when we see in the report a detailed map of the areas that are infested with ticks? They're growing and, of course, you're collecting blood from these areas. Why would you not ask if people have had tick bites?

● (1155)

Dr. Margaret Fearon: Many people who have been bitten by ticks don't recall it. If we did ask about tick bites, we might get a few people saying yes, but the majority of people—maybe even folks who have or have had Lyme disease—may not remember that tick bite, so it's not been found to be a reliable question.

Mr. Len Webber: I just think it would take a matter of one or two seconds to ask that question, and you would get that one or two who would then admit that they had been bitten. I think it's something you should put into your questioning, your screening.

Dr. Hawkins, may I ask you about what I think is a strain of Borrelia called Babesia? I know from studies done in the United States that it has been confirmed that Babesia can be transmitted through transfusions. Can you talk a bit about Babesia, Dr. Hawkins? Is it a threat?

Dr. Ralph Hawkins: Sure. Thank you, Mr. Webber.

The Babesia duncani and Babesia microti are both intraerythrocytic parasites that are similar in some ways to the malaria parasite. They are not Lyme disease, but they are tick-borne infections. They're transmitted by the same ticks that carry Lyme disease, and the areas that Babesia is showing up in are the same areas of risk where Lyme-disease-carrying Ixode ticks are showing up.

Babesia is transmitted through blood transfusion. I am aware that there are jurisdictions in at least certain counties in the United States that are now actively screening for Babesia in donated blood. There has been a reported case of Babesia domestically acquired in Manitoba, so there is no question that this is a concern and a potential risk within the jurisdiction of Canada.

Mr. Len Webber: Thank you.

I'll go back to Canadian Blood Services.

You say you test donated blood. How do you test in the laboratory? Do you test all blood donations in the laboratory? Do you test for particular diseases: HIV—

Dr. Margaret Fearon: We test for HIV, hepatitis C and B, etc.

Mr. Len Webber: But you test nothing to do with any of the strains here of Lyme disease?

Dr. Margaret Fearon: No.

Mr. Len Webber: What would it take to put these tests in place? Of course, there would be a cost involved, but it can be done, correct?

Dr. Margaret Fearon: Well, there would have to be a Health Canada approved test before we would be allowed to implement it.

Let's get back to the Babesia question because that is of concern to Canadian Blood Services and to Héma-Québec.

A couple of years ago we carried out a large donor prevalence study because we were well aware there were cases of transfusion transmission of Babesia, particularly in the northeastern U.S. where it's, as you know, transmitted by the same tick as Lyme disease. This does cause illness in transfusion recipients.

Because Babesia is not a reportable disease in Canada, we really don't have much data on babesiosis in this country. In this prevalence study, we looked at donors for antibodies to Babesia to see whether donors had recently been infected or had ever been infected. Out of the approximately 14,000 donors that we tested, zero were positive, so we did not see any Babesia in the blood donors that we tested.

However, we are well aware there was a case of transfusion transmission of babesiosis in Canada in 1998. This was a case where a donor had travelled to Cape Cod. Then there is the recent endemic case that you described in Manitoba. We are repeating that prevalence study next year. We're in the planning phase for that, and we will increase the number of donors that we survey.

Mr. Len Webber: Great, thank you. I don't mean to cut you off. I just have some questions here, and I'm limited by time.

Dr. Zubek, I have a couple of quotes here from you—and you mentioned this in your presentations—about the outdated guidelines. You also urged the Minister of Health to reject the framework and insist on a real Canadian action plan for Lyme disease. This needs to be created in partnership with people who are affected by Lyme.

With respect to the guidelines, obviously the guidelines are insufficient because you can only prescribe so much antibiotic before you're not allowed to anymore. Is that why doctors are saying to these chronic Lyme sufferers that their hands are tied, that they cannot do any more treatment for them, and that these sufferers must go down to the United States or somewhere else in the world to seek treatment? Can you talk about that, please?

● (1200)

Dr. Elizabeth Zubek: Doctors are quite afraid to go outside the box of published guidelines. If they look on the PHAC website and it links them to 2006 protocols that say you have a central nervous system infection with Lyme disease, and they then give one antibiotic for two to four weeks, they're wondering whether they're going to get into trouble if they prescribe more. I've seen so many doctors caught in that dilemma in which they've seen massive improvements and they know they want to go further but wonder whether they will get into trouble with their licence.

Mr. Len Webber: Exactly. These guidelines have not been changed, even after the conference that.... Has the new framework not changed those guidelines at all?

Dr. Elizabeth Zubek: It has not changed what PHAC posts on their website. They post a link to these 2006 guidelines and do not say that there are other much more evidence-based and current guidelines available. If a physician could look on the website and find those other guidelines, they would then be able to use their clinical judgment, with a bit more relief that there will not be any governing bodies out after them.

Mr. Len Webber: Dr. Hawkins, when you treat your patients you're only allowed to prescribe so much by way of antibiotics. Once they achieve the maximum, you cannot treat them anymore, even though they may still have these conditions. You are suggesting, then, that obviously the guidelines should change and that you should be able to prescribe more antibiotics for these patients so that they can, hopefully, be cured of this horrible disease.

Dr. Ralph Hawkins: Mr. Webber, my practice in prescribing to my patients is not constrained by the guidelines and is not constrained by any arbitrary time limit. The guidelines actually contain a very small disclaimer at the outset identifying that they are voluntary and that they are not meant to supersede the judgment of an expert physician.

The protocols I follow are published protocols from the literature that employ much longer durations of antibiotics, so I follow those protocols rather than the arbitrary guidelines.

Mr. Len Webber: It certainly seems obvious to me that they need to change these guidelines and allow more antibiotic prescriptions to these patients. Would you agree?

The Chair: Your time is up.

Dr. Ralph Hawkins: Yes.

Mr. Len Webber: Thank you.

The Chair: Mr. Davies.

Mr. Don Davies (Vancouver Kingsway, NDP): Thank you, Mr. Chair, and thank you to all the witnesses for being here today.

I want to focus a bit on the framework, if I could, because I think that's the subject of this study right now.

Dr. Njoo, last meeting we heard testimony from a witness about the funding priorities, indicating her view that the funding priorities in the framework did not come from patients and "did not come from the conference", referring, of course, to the conference that was set up and required under legislation.

Where did the funding priorities in the framework come from?

Dr. Howard Njoo: The funding priority, as I think is mentioned in the framework, is going to be directed toward research, and I think that patients, other stakeholders, physicians, professionals, public health authorities, and others who attended all agreed that further research needs to be done. Therefore, the minister announced $4 million in additional funding for research.

I think that kind of funding is significant, and I think the next step is for the partners, including the Canadian Institutes of Health Research, us, and others, to determine what the priorities should be. I think the minister mentioned at the beginning, and also based on the input from patients, that initial priorities in research should be on diagnosis and treatment.

Mr. Don Davies: Okay. Thank you.

Dr. Njoo, witnesses, I think, gave some pretty trenchant first-hand testimony and informed testimony from other Lyme patients. They complain about the lack of effective diagnosis in Canada versus what they claimed was better diagnosis in the U.S.

What is your response to that complaint?

Dr. Howard Njoo: I will say that it's true, as many have said, that laboratory tests currently in use could be improved. Certainly the current tests are more valid in diagnosing infection some time after the infection occurs and sometimes not in the early stages.

However, having said that, the diagnostic methods we use in Canada are the same as those developed and used by the U.S. Centers for Disease Control and Prevention and also endorsed by other public health organizations around the world, such as in the U. K. Also, it has been validated and accepted by experts within our Canadian Public Health Laboratory Network and the public health laboratories throughout the country.

The other laboratories referred to, for the most part in the U.S., are private laboratories that offer tests that—certainly I'll defer to my laboratory and other experts—are using assays that have not been adequately validated and established for use generally. Therefore, we go with what the U.S. CDC and other public health authorities indicate are there.

● (1205)

The Chair: Mr. Davies, Dr. Zubek wanted to make a comment.

Mr. Don Davies: I'll come back to Dr. Zubek in just a moment.

The Chair: She wanted to make a comment on your last question.

Mr. Don Davies: I know, but I'm not finished with Dr. Njoo on this question first.

I'm not clear about your answer. Is it the view of the government or your department that there is not a differential in diagnosis in the U.S. versus Canada? I'm unclear from your answer, because you seem to suggest we adopt the same standards.

Dr. Howard Njoo: Yes, the U.S. Centers for Disease Control and Prevention is at the national level, in a sense our counterpart in the U.S, as are such other similar public organizations as the Health Protection Agency in the U.K. We use the same laboratory diagnostic standards.

The other types of testing you're referring to are offered, as I mentioned, by private laboratories in the U.S. The types of testing they offer sometimes use methodologies that have not been validated and established as being accurate.

Mr. Don Davies: Dr. Zubek, I have another question for you, but on this question, is it your view that there are significantly better standards or results in the U.S. than in Canada?

Dr. Elizabeth Zubek: In the U.S., there are a number of different private laboratories. I choose to go to Germany, myself, and the ELISpot test I use from a few different labs in Germany is available in a certain lab in the United States as well.

Diagnosis is very difficult. The standard in the U.S. is looking at a certain number of bands, whereas other countries have said that this makes no sense: either you have five bands or you have nothing. What about somebody who's very suggestive and has four bands? We need to report that out, because if the picture is really suggestive, how can you set such a hard and fast limit, which the infectious disease people set 20 years ago as their criteria?

Mr. Don Davies: Okay.

Dr. Njoo, I'll come back to you. I want to put one last comment to you, which I think we got from testimony last week, to get your view on it. The witnesses complained very clearly about their lack of access to sufficient, in their view, appropriate antibiotic treatment in Canada as compared with the U.S.

What would be the department's response to that? Is there superior antibiotic treatment in the U.S. as compared with Canada?

Dr. Howard Njoo: No, I wouldn't say that.

First of all, I'll make a couple of points. Health care, as we know and as I mentioned in my opening remarks, is the responsibility of the individual provinces and territories. It's their jurisdiction, and therefore it's difficult for the federal government to intervene in what is a provincial and territorial responsibility.

When it gets to the point of clinical diagnosis and treatment, as I mentioned before, that is also in a sense the purview of the experts on the front line, the clinicians who are represented by various professional organizations and are in the best position to look at the evidence around the world and make a.... They're taking the best available evidence into account to develop guidance for their members. In that sense, I would defer to those experts who are on those committees in those professional organizations to develop the guidance.

In terms of various guidance out there, we certainly respect the fact that IDSA, which has been referred to, has developed guidance. In a sense, our counterpart here in Canada, known by the acronym AMMI, the Association of Medical Microbiology and Infectious Disease Canada, also concurs with the guidance put out by IDSA.

Mr. Don Davies: I'm probably running out of time, but Dr. Hawkins, I see you itching to get in. What are your comments on any of the subjects I've raised?

Dr. Ralph Hawkins: I am itching to get in.

Dr. Njoo has not been completely open about the differences in testing between the United States and Canada. The national medical laboratory authored a paper, which is in the medical literature, in February 2017, on the diversity of test results in Canada. Within that article, there's a specific sentence that I'll read: “The proportion of C6-positive/equivocal tests that tested positive by WB [Western blot] was much lower than in reports from the U.S.” The two-tier system is performing less well in Canadian populations than the same testing applied in American populations.

It is not being forthcoming to this committee to suggest that the performance of the testing is the same, when the national medical lab is reporting exactly the opposite.

● (1210)

The Chair: The time is up.

Mr. Oliver.

Mr. John Oliver (Oakville, Lib.): Thank you very much for your testimony and for sharing some of the concerns.

We certainly heard some very powerful and emotional testimony from some of the victims of Lyme disease. I have to say that I think some of their concerns were still expressing the environment that exists today, because the framework is just being released, and the work that needs to be done around the three pillars has yet to fully take weight. I'm very much looking forward to it.

One of the key pillars is guidelines and best practices. Dr. Zubek, were your concerns around the 2006 guidelines about diagnosis? Was there a concern around treatment?

Dr. Elizabeth Zubek: They were about both diagnosis and treatment.

Mr. John Oliver: Focus on the treatment for me, would you, please?

Dr. Elizabeth Zubek: For the treatment, those guidelines say two to four weeks of antibiotics, but with one single antibiotic—

Mr. John Oliver: I'm sorry, I didn't ask the question well enough.

Are there better guidelines than the IDSA 2006 guidelines?

Dr. Elizabeth Zubek: Absolutely. Yes, the ILADS guidelines are far better.

Mr. John Oliver: What was your source? What were these other guidelines?

Dr. Elizabeth Zubek: They're the ILADS guidelines, which are published on the U.S. National Guideline Clearinghouse.

Mr. John Oliver: What was the name, again? I didn't hear it.

Dr. Elizabeth Zubek: It's published on the National Guideline Clearinghouse. It's by Drs. Cameron, Johnson, and Maloney. It has a big, long name, “Evidence assessments and guideline recommendations for tick-borne infections, erythema migrans...”. The name is a paragraph long.

Mr. John Oliver: I'm on the Centers for Disease Control and Prevention site looking at the IDSA guidelines. The 2006 guidelines were last reviewed in 2016 by the Centers for Disease Control, the National Center for Emerging and Zoonotic Infectious Diseases, and the Division of Vector-Borne Diseases. They say that the guidelines "were re-evaluated and upheld by an independent scientific review panel whose members were certified to be free from any conflicts of interest by an independent ombudsman", and that the CDC supports the IDSA Lyme disease guidelines as continuing to provide "comprehensive, accurate information that patients can use in their health care decisions."

Dr. Njoo, there's a conflicting source here for guidelines. There's clearly a very heavily scientifically weighted opinion through the CDC, but there's an online group that the doctor has referred to. Can you talk to me about how PHAC discerns among guidelines so that as you're going out in the framework you are issuing the best scientific evidence-reviewed guidelines?

Dr. Howard Njoo: Thank you very much for your question. Yes, we work closely with the CDC and also with other public health organizations throughout the world, such as the one in the U.K.

What I will say is that when we look at the evidence, as the U.S. CDC has also done, we look at the preponderance of evidence in terms of the types of guidance put forward. I will say that, for example, the IDSA actually, in a sense, represents the majority of the research scientists, the clinicians, the infectious disease specialists in the development of the guidance that they put out.

We acknowledge that there are other groups out there who have their own view of what the science shows them and who have developed their own guidance, but we certainly go with the majority expert opinion and review of the evidence.

Mr. John Oliver: Just to be clear, I think the doctor respectfully referred to them as 2006 guidelines, as though they were significantly outdated, but I think it's important to note that they were extensively reviewed again in 2016.

One way to resolve these kinds of debates is to ensure, as we go forward, that besides the scientists, the doctors, and the others whom PHAC would be engaging, there's also the community of caregivers, such as our doctors here, and some of the patients' or advocacy groups that have formed around people with Lyme disease.

Do you see a way of engaging those voices in reviewing guidelines, in ensuring that we're staying current, and that alternative guidelines are being considered through the engagement of patients and—

● (1215)

Dr. Howard Njoo: Yes, certainly. As we did at the conference, we recognize that it is important to engage all the stakeholders, including patients' advocates, as we move forward.

One thing I mentioned before is that as we go forward with guidance we need to stick to what I believe are the principles of the scientific method. I respect patients being engaged in the process. I understand that they certainly have an important role to play in developing the types of research questions and the answers we need to look for. When it comes down to actually reviewing the evidence, however, they could certainly be involved, but I think that at the end of the day we all need to collectively agree that we need to look at using the rigour of the scientific method.

Mr. John Oliver: Another question that we had from the previous group was.... I don't know the gentleman, but there's a person named John Scott who I think did a lot of research around...maybe it was surveillance research; I'm not sure. They felt that his research was ignored and left out of the framework.

Do you have any comment on that?

Dr. Howard Njoo: I don't think any particular researcher or research finds were ignored in the framework. The framework, in a sense, is higher level. It doesn't get into pointing out any individual piece of research or research findings. It really maps out, in broad strokes, the way forward, recognizing that there are many different types of research already out there involving surveillance activities, diagnostics, and so on, and that as we move forward we need to be open-minded to basically receive and look at all the types of research there are without ignoring anything that could be of value.

Mr. John Oliver: In the final framework, there was a commitment of $4 million, I believe, to CIHR for research on diagnosis, treatment, and the ongoing chronic effects of Lyme disease.

There was a question about NSERC at the last meeting and why NSERC wasn't part of the funding award. Can you comment on CIHR versus NSERC, and the decisions around the research funding?

Dr. Howard Njoo: NSERC was involved in the development of the framework. Our closest partner in terms of human health research is CIHR, the Canadian Institutes of Health Research, but we'll certainly engage other federal departments, as appropriate, as we go forward with the research agenda.

Mr. John Oliver: Great.

The lab testing and diagnosis questions come up a bit. What are your thoughts on that? There was an understanding in the final framework that there is a need for improved lab testing and improved sensitivity of testing. How far away are we from seeing that? For the community, and for Canadians who have been bitten by a tick, that testing is pretty important. Do you have a sense of a time frame to get that lab improvement up?

Dr. Howard Njoo: Personally, I couldn't give you that kind of estimate. I would defer to my experts who work in laboratory science.

As we put out in the framework, we do need to improve testing. Our national microbiology laboratory and the other members of the Canadian Public Health Laboratory Network are well positioned. They have scientific experts who can look at the evidence of new testing methodologies that come to the forefront for review and evaluation. They work closely with their counterparts in other countries as well, including the U.S.

Mr. John Oliver: Is there a big difference between Canadian and U.S. lab testing?

Dr. Howard Njoo: At the national level, in terms of the U.S. CDC and us, no, there isn't.

The Chair: Thanks very much.

We'll go to our five-minute round now, with Dr. Carrie.

Mr. Colin Carrie (Oshawa, CPC): Thank you, Mr. Chair.

My first question will be for Ms. Fearon. I'm going to ask in advance for a short answer, if I can, because we have limited time.

Did you say in your opening statement there is no evidence that Lyme could affect the blood supply?

Dr. Margaret Fearon: No, I said that there has been no evidence yet of transfusion transmission of Lyme disease.

Mr. Colin Carrie: Are you aware that back in 1992, John Scott, the researcher my colleague brought up, sent information over to the Red Cross that this could be affecting the blood supply and hence could be affecting transmission?

Dr. Margaret Fearon: No, I haven't seen that.

Mr. Colin Carrie: Okay. Maybe we can get back to you on that.

My next question is for Dr. Hawkins.

First of all, I just want to say that when we are looking at the original Bill C-442 around the table here, I am very proud to have worked.... To get a private member's bill passed by a government is a great feat, actually, but I think the original intent was to have a framework come out that was going to make Canada's the most up to date one around the world.

From the evidence I've been hearing in the last couple of days, as far as guidelines, diagnostics, and treatments are concerned, it seems that our latest framework is failing in that regard. The bill did call for treatment. Dr. Njoo said we should be focusing primarily on diagnostics and treatments. I do realize there are jurisdictional issues there, but I'm worried that we didn't quite get it right.

Dr. Hawkins, the framework highlights the current challenges associated with Lyme disease testing; however, it doesn't actually offer any recommendations for replacing or repealing the current methods being used. I know you commented earlier today, but could you give us some specific guidelines? What changes do you think should be made, and what are the consequences of continuing to use these old methods?

● (1220)

Dr. Ralph Hawkins: Thank you, Dr. Carrie.

I agree with you. I think the framework has missed the mark. I think the reason it has missed the mark is that there are people within the mechanism of health delivery in Canada who do not want to cut the umbilical cord from the CDC in Atlanta. You've heard answers this morning pointing to there being a reluctance to deviate from what the CDC has put forward for this or that or the other thing.

Mr. Oliver was on the CDC website earlier. I would ask him, just as an example, to look at the case definitions for Lyme disease and then look at the Canadian case definitions. There's a deviation. The Canadian case definitions for Lyme disease are not as encompassing as the CDC's guidelines. That is something that would pose a question, in my mind, to the Public Health Agency.

To get on with testing, the testing that's being done right now is surveillance testing, and surveillance testing is biased in favour of being specific. That means when they say a positive test is found, they want to make absolutely sure that it's a positive test, and they're willing to not count every case for the sake of the specificity of the test. On the other hand, a front-line provider such as Liz or me is not interested in that approach. We're interested in sensitivity of diagnosis for our patients.

There's a very simple way of improving the sensitivity of diagnosis. Dr. Njoo will be an expert in this, because this is basic epidemiology. It has to do with parallel testing rather than in-series testing. Parallel testing will increase the sensitivity of what you do, and the parallel testing that we could be doing in Canada today would be to do the C6 assay that every province is already doing and simultaneously do the ELISpot.

If that approach is used, the sensitivity we would expect to see would be in the 96% range, and the specificity would be in the 93% range. This is very strong clinically. This would give us positive predictive values greater than 10 and negative predictive values less than 0.1. But the mechanism that runs medicine in Canada isn't prepared to be innovative.

Mr. Colin Carrie: Thank you very much for that positive suggestion, because that's what we're really looking for: to improve things for people who are suffering with Lyme disease.

The government claims that the framework is based on the best available research evidence. Would you agree with that statement, or do you feel a lot of the cutting-edge research introduced at the conference has been completely ignored?

Dr. Ralph Hawkins: I would point to the researchers' getting together at Queen's University two weeks before the framework conference to have a closed meeting, by invitation only, to set up their research network as being an example of how these evidence-based expert types of things come forward. They have a closed group, talk to each other, and they reinforce each other's opinions.

Mr. Colin Carrie: Okay, that—

The Chair: Time's up, Dr. Carrie.

Now we go to Mr. Kang.

Mr. Darshan Singh Kang (Calgary Skyview, Lib.): Thank you, Mr. Chair.

I'd like to thank all the witnesses for their enlightening testimony.

My question is for Dr. Njoo.

When a person falls sick, they start to get second opinions and they start to talk about what options they have. Does the federal framework on Lyme disease address any treatment options?

● (1225)

Dr. Howard Njoo: No, the federal framework acknowledges that the development of actual treatment options is best undertaken by the professional organizations for the front-line practitioners, and it respects that expertise.

Mr. Darshan Singh Kang: It doesn't fall under the responsibility, then, of the federal framework.

Dr. Howard Njoo: Yes, another point is that the actual delivery of health care services and public health services is a provincial and territorial jurisdiction.

Mr. Darshan Singh Kang: I was thinking about a vaccination. We have a flu vaccine. Is there any vaccine being developed? Is the Government of Canada supporting the development of a vaccine for Lyme disease, or is something in the works?

Dr. Howard Njoo: For the Government of Canada specifically, we don't have any ongoing research into a vaccine for Lyme disease. I'm not personally aware, but I'm sure that probably researchers around the world are looking at developing a Lyme disease vaccine.

Mr. Darshan Singh Kang: Okay.

My next question is for Margaret. I want to put it on the record that my son works for the Canadian Blood Services in Calgary. You were talking about testing blood for Lyme. Can you describe any risks that Lyme disease or other tick-related infections may pose to the blood supply? Is there any chance that Lyme disease in affected donors could pose any risk to the blood supply?

Dr. Margaret Fearon: So far, there is no evidence that transfusion transmission to recipients occurs, even from people who are known to be infected with Lyme disease, so the answer is, there is no evidence at this point.

Mr. Darshan Singh Kang: Then we don't have to worry about addressing any risks? Do you have something to fall back on if there is a risk?

Dr. Margaret Fearon: There are several ways to deal with emerging infectious disease risks. I think the way of the future for most blood operators will be the implementation of pathogen inactivation, as I mentioned before. This is a way of treating blood products to kill infectious agents.

As I mentioned, there are technologies, one already approved by Health Canada and one under review, that will allow pathogen inactivation for two blood components, which are platelets and plasma, and a technology for the treatment of red blood cells that is still under development.

I think that rather than looking at implementing a test every time there is a new disease that comes along, it makes a lot of sense to move towards this kind of technology.

Mr. Darshan Singh Kang: Thank you.

The Chair: You have another minute.

Mr. Darshan Singh Kang: I have another question for Dr. Njoo.

Why aren't the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council partners in the framework? Are they or are they not?

Dr. Howard Njoo: Other federal departments, including NSERC, were involved and engaged in the development of the framework, and certainly as we move forward with the research agenda as the questions get further developed, I'm sure we'll engage with them as appropriate.

Mr. Darshan Singh Kang: There were a lot of issues around the framework, including that the patients' input was not included in the framework.

My question is for Dr. Hawkins. What more could be done in order to make this framework inclusive?

Dr. Ralph Hawkins: Thank you very much, Mr. Kang.

I think that, moving forward, this framework needs to be supervised by an oversight committee. I would propose that an oversight committee similar to what has been put forward by legislation in Congress would be an excellent idea, with equal representation of patients and advocates, front-line practitioners, researchers, parliamentarians, and the funding agencies. I think that type of an oversight committee for Lyme disease research will give us policy direction, will give us supervision, and will give us accountability.

Thank you.

● (1230)

The Chair: Thank you. The time is up.

Ms. Harder.

Ms. Rachael Harder (Lethbridge, CPC): Thank you very much.

My first question is for Dr. Njoo. One of the things we've heard from the witnesses, and which we've alluded to already today, is that at our last meeting, when we heard from the patients, the people who have suffered from Lyme disease, they did not feel that they were made equal partners in the development of this framework. That was one of the things they were calling for.

I give that quite a bit of weight, coming from them. My question for you would be this: how could we further expand the framework in order to make them equal partners? In particular, how do we make them equal partners in speaking to testing, to diagnosis, and to treatment?

Going forward, it would be my hope that we would strengthen this framework. In so doing, I believe that these individuals need to be called to the table and made equal partners. What would that look like going forward?

Dr. Howard Njoo: Thank you very much for your question.

Certainly, we believe that the patients you mention were obviously engaged. They were participating at the conference. If you look at the framework, you see that the actual proceedings of that conference are, in a sense, attached to the framework. My sense is that a lot of submissions, I think over 400 submissions and comments, were received from patients—

Ms. Rachael Harder: Sorry, but is there something that can be done better, though? I understand. I've read the framework and I know the process, but what could be done better to strengthen it going forward?

Dr. Howard Njoo: I think it's fine as it is as a starting point. Moving forward, as you mentioned, I think that if we start looking at the research questions in terms of diagnosis and treatment, I certainly believe there is a role for engagement and involvement of patients and patient advocates in the process as we elaborate the types of research areas we should focus on.

Ms. Rachael Harder: I'm going to turn my attention to you, Dr. Hawkins. How would you answer that question? How could we better make patients equal partners?

Dr. Ralph Hawkins: I've answered Mr. Kang's question almost the same way. I think this entire process needs an oversight committee that has equal representation and a little bit of power.

Ms. Rachael Harder: Thank you very much.

My understanding is that there's the potential for developing a vaccine, and I don't see any discussion with regard to that in the framework here. Perhaps, Dr. Hawkins, you can comment on that. Is there potential for developing a vaccine? Should there be further research in that direction?

Dr. Ralph Hawkins: Vaccines for Lyme disease are available for my dog.

Vaccines have been developed for humans. A LYMErix vaccine was developed in the late 1990s. When it was applied, the vaccine caused a number of Lyme-related symptoms in recipients and was removed from the market.

The research on Lyme vaccine development is still ongoing. There is a lot of money to be made if a vaccine comes forward, so a lot of the main researchers who feed information into the CDC are actually the people involved in this very lucrative Lyme vaccine discovery effort. At this point, nothing safe has been forthcoming. It remains to be seen if a safe vaccine can actually be developed.

Ms. Rachael Harder: Thank you.

Here's my last question. We have a write-up here from the College of Family Physicians of Canada. One of the things they've said is "the sensitivity of current laboratory testing is insufficient to use it as the primary method of diagnosing Lyme disease in clinical cases."

We've talked a lot about testing in terms of different tests that are available and their sufficiency. Dr. Hawkins, I believe you've given a really good summary of the problems we're facing and how we could solve those going forward.

Dr. Njoo, I'm wondering if you could comment on this. You seem to be saying that we're fine, that we have the technology, the science, and the tests available that we really need, and that the framework is comprehensive. The College of Family Physicians clearly disagrees with you on that. What would your response be?

Dr. Howard Njoo: I don't think I'm disagreeing with the College of Family Physicians. As I mentioned before, one of the areas that we do recognize needs to be improved is diagnostics. Therefore, with the funding for research, we are focusing and saying that it is one area, along with treatment, that needs to be further dealt with in terms of research.

I also mentioned that in terms of the current testing, it is pretty good in terms of some time, a few weeks, after infection, but certainly, in the early stages after infection, it's not as ideal as it could or should be. Therefore, as I said, that's an area where we need further research.

● (1235)

Ms. Rachael Harder: Mr. Hawkins, would you care to comment?

Dr. Ralph Hawkins: I disagree with the statement that Dr. Njoo has just given about the testing being pretty good after a few weeks. Clearly, he is not a clinician. Clearly, he doesn't see Lyme disease patients. The testing is not reliable. At its best performance, the test, when it is subjected to external assessment, has about 40% to 50% sensitivity. That's atrocious. In clinical medicine, we want testing that's at least 90% sensitive and at least 90% specific. I've already elaborated on an approach that would provide that.

The Chair: Mr. Bratina.

Mr. Bob Bratina (Hamilton East—Stoney Creek, Lib.): Thank you.

Could I address Dr. Zubek first of all? I'm filling in for Doug Eyolfson, who, I understand—

Dr. Elizabeth Zubek: Oh—

Mr. Bob Bratina: So he did actually go to medical school. Is that an affirmation?

Voices: Oh, oh!

Dr. Elizabeth Zubek: He did.

Mr. Bob Bratina: It's heavy sledding for me. Ask me about steam locomotives.

A couple of things caught me in your presentation. You reference the insufficient diagnostic utility of the Canadian two-tier test and compare it with the two-tier test recommended by the Centers for Disease Control. Could you explain the difference?

Dr. Elizabeth Zubek: First, it depends on what type of test you're using.

We used to use a different type of ELISA first, followed by the Western blot, and now we have a C6 ELISA first, which is a better tool. However, then we were still following it up with the Western blot, and if the Western blot was negative, we were saying that you didn't have Lyme.

As Ralph was saying, the C6 by itself should be diagnostic of Lyme disease, and in parallel we could do an ELISpot to pick up the people that C6 misses.

Mr. Bob Bratina: Okay.

In terms of the lymphocyte transformation test, the CDC is recommending against the use of this test, which, it has now been validated, gives an unacceptably high level of false positives. The reference is as recent as 2014. Why is that?

Dr. Elizabeth Zubek: I don't know what references they're using. The references we have and that Ralph has published there show the 84% sensitivity, which is much higher than we're getting from any other test, and we still have good specificity. A 94% specificity means that if we tested 100 people who don't have Lyme disease, six of them might have a positive test, but 94 will be a true negative. That is quite good for the tests that are available now.

Mr. Bob Bratina: Could I ask why the Government of Canada does not support the development of a Lyme vaccine? Perhaps I'll put this over to our deputy, Dr. Njoo.

Dr. Howard Njoo: I wouldn't say that we do or don't support the development of any vaccine. As I said, there are a number of players. Certainly, vaccine manufacturers and researchers are in the process of trying to develop vaccines for a wide range of infectious diseases, including Lyme, HIV, and so on.

Certainly in the Canadian context, once there are promising results, our colleagues at Health Canada, who are the regulators, would undertake to review the evidence in terms of the safety and quality of any vaccine. If a vaccine were actually to be shown to be safe, have good quality, and be effective, then it would be licensed for use in Canada.

At this point, as Dr. Hawkins has mentioned, we're still waiting. Nothing has come forward.

Mr. Bob Bratina: Let me ask you, Dr. Hawkins, are family physicians being overwhelmed by the evolving knowledge base of medicine? I have a particular interest in the impacts of lead on children. It's not generally.... I've heard public statements from responsible officials saying that lead is something that you do over 50 years and you might get sick from it, and that's really not true. There's so much new evidence in every field. How do we keep physicians up to date on everything, including Lyme disease?

Dr. Ralph Hawkins: It's a real tall order. I'm a specialist. I'm not a family physician. Maybe Liz should be talking to this question as well, but from the perspective of being a specialist, I feel the pressure to do the reading of contemporary literature in my little silo area, and I have trouble keeping up. I'm amazed by and in awe of the family physicians who see a cardiovascular patient, move to the next room and see a pediatric case, and then move to the next room and do an obstetrical case.

Clearly, we need to educate in an efficient and effective manner.

Liz, did you want to weigh in?

● (1240)

Dr. Elizabeth Zubek: I'd love to weigh in here.

Family physicians are overwhelmed by an abundance of information, but we also have a relationship with the patient. We've known them for years. We've known them before they got sick; we see the changes in them, and we are not willing to accept the guideline that says two weeks of antibiotics should be enough. We want to find solutions. I get family physicians calling me from all across Canada asking for help, asking about different guidelines, wanting better information, and wanting to treat their patients better.

The College of Family Physicians of Canada has put out quite a strong statement in telling AMMI that they are not supporting AMMI's response. AMMI wanted their support to say that their testing is good enough and the diagnosis is good enough. The College of Family Physicians said, “Not for our purposes: we need to look at the holistic care of patients and we need better tests.” Look at the evidence of the College of Family Physicians. They referenced these new guidelines when they talked to AMMI. That represents 52% of the physicians in Canada, who are family physicians and who want these new types of guidelines to help us.

Mr. Bob Bratina: Thank you very much, Mr. Chair.

The Chair: I was hoping for a steam engine question there, but maybe next time.

Mr. Davies.

Mr. Don Davies: Thank you, Mr. Chair.

Dr. Hawkins, just quickly, you referenced your narrow area of specialty. What is that area?

Dr. Ralph Hawkins: I'm an internal medicine specialist. I was trained as a nephrologist, which is the study and treatment of kidney diseases. My career has spanned about three decades. I now practise in a cardiovascular risk reduction area. I see a large number of diabetic patients, and I do a lot of lecturing and teaching on diabetes. As a more senior physician in my division, I see the patients who have medically unexplained symptoms—chronic fatigue, fibromyalgia. This was the seed that started my interest in chronic Lyme disease.

Mr. Don Davies: I see. Thank you.

At the last meeting, a researcher joked about not letting researchers out unescorted. I would think that would maybe pale in comparison to letting politicians meddle in science or medical diagnosis. The more I read about this, it seems clear that an emerging issue in this area is the fact that the science does seem to be contested. In fact Dr. Timothy Caulfield, whom I'm sure you're familiar with, of the Health Law Institute at the University of Alberta, is quoted as saying that the science in this area is extremely contested. He quoted articles in *The Lancet* and *The New England Journal of Medicine*.

First of all, Dr. Hawkins, is it a fair comment to say that the science in this area is contested?

Dr. Ralph Hawkins: Yes, that would be fair. The science in this area is contested. There is no keeper of 100% truth with this issue.

Mr. Don Davies: Okay.

I have only a minute left, Dr. Zubek and Dr. Hawkins, so perhaps you could briefly explain what the major points of contention are and what advice you'd give this committee in terms of improving the framework to help resolve those conflicts.

Dr. Elizabeth Zubek: To me, the major point of contention is this: do we need to have a fixed treatment end point, or can we have the flexibility to do multiple "n of 1" trials, as we call them? We look at whether this is working in a person. If they get 50% better, do we push it further? We need to exercise clinical judgment.

Another issue of controversy is whether or not the patient has a voice. We need to think of it in a way that's similar to cancer care. Would you say that we're going to treat all cancer in Canada with the same chemotherapy, no matter what organs are affected, no matter what stage, no matter what's happening? No. We have to look at the individual cases, the individual preferences, and tailor it there. That's what we're saying as family doctors.

Mr. Don Davies: Dr. Hawkins.

Dr. Ralph Hawkins: I would boil down the entire controversy to a competition in science. One group is wanting to have very fixed guidelines for the purposes of having everyone follow the same pattern or recipe. The other group, I think, is looking in a more holistic fashion at the outcome for an individual patient, with that individual person's risks in mind. I suppose it comes down to a matter of trust. Do you trust that you have educated your medical professionals to exercise their professional judgment, or do they need to be overseen by an arbitrating body?

● (1245)

Mr. Don Davies: Very good.

Thank you, Mr. Chair.

The Chair: Once again, I want to thank all of our witnesses for very enlightening testimony. We learn so much at this committee. It's just incredible.

Dr. Zubek and Dr. Hawkins, I appreciate your passion and commitment to this. It's obvious that you care a great deal about it and are very helpful.

I want to thank our table guests as well.

Dr. Hawkins, you referred to Samuel...?

Dr. Ralph Hawkins: Samuel Donta. He is a retired infectious diseases specialist, still living. He practised at Boston University and was at the forefront of infectious diseases doctors when the Lyme disease epidemic first came to the fore back in the 1970s and 1980s. He was able to practise in Lyme disease back in an era when there were not constraints from the organizations and when individual judgment was allowed to be practised, because there were no guidelines at that time. His writings are very, very helpful.

The Chair: Thanks very much. I just wanted to clarify that reference.

I want to tell you that I first encountered Lyme disease in about the fall of 2015. It was the first time I'd ever heard of it. A constituent came to me. I went to two local health care providers, and both health care providers gave me the impression that they didn't really believe there was such a thing as Lyme disease. So I believe we're making progress.

Dr. Njoo, you said in your comments that "Lyme disease is one of the most rapidly emerging infectious diseases in North America". I think we are making some considerable progress. Why do you say it's one of the most rapidly emerging infectious diseases?

Dr. Howard Njoo: In terms of surveillance, since Lyme disease became a notifiable disease in 2009, the number of reported cases to the Public Health Agency of Canada went up from 144 to over 800. We also recognize that there probably is a degree of under-reporting. As we move forward, one of the key things we want to improve is surveillance, as we mentioned with regard to the framework, for both the human illness and the ticks. That's one of the areas we will be focusing on.

The other point I want to make is that I would agree with Dr. Hawkins and the others that, yes, the science is contested. As in any area of science, there will be varying points of view. I guess what I would say is that, as I've mentioned before, we're going with where the main body of evidence leads us. I would say that Dr. Hawkins and others are probably in the minority compared with the majority of the scientists and infectious disease specialists who belong to organizations such as the IDSA and AMMI in Canada.

The Chair: Okay.

Thank you very much, everyone.

We have a little bit of committee business to do. We'll suspend for a few seconds while our witnesses pack up.

Thank you again.

● (1245)

(Pause)

● (1250)

The Chair: Do I have a motion to approve the budget?

I have a motion and a seconder.

Excuse me. First, are there any questions?

Mr. Davies, you have a question.

Mr. Don Davies: Mr. Chair, is this the budget for the study that we just completed?

The Chair: Yes.

Mr. Don Davies: Would it not be proper procedure to vote on the budget prior to having the study? Theoretically, if we voted this down, we would not have the funds to pay for what we've just done.

I would just suggest that we have the budget passed prior to engaging in the study.

The Chair: It can be done both ways. The clerk had it available for the last meeting, but I didn't raise it.

Mr. Don Davies: Okay.

The Chair: Yes, Mr. Webber.

Mr. Len Webber: I concur with Mr. Davies. Have we finished with Lyme disease?

The Chair: We've finished with the witnesses.

Mr. Len Webber: What is the next process now? Where are we going from here? Are we just hearing these witnesses and leaving it at that?

I suggest that we now put together some sort of document that we can give to the minister, whether it's in a letter form, similar to thalidomide, or we put together a bit of a report of what we've heard in these last two session meetings and perhaps encourage the minister to take some action on Lyme disease.

The Chair: Couldn't we vote on the budget and then address your concern?

Mr. Len Webber: Well, this budget is specifically for our study on Lyme, is it not?

The Chair: It is.

Mr. Len Webber: Will we incur further costs with respect to where we move from here on Lyme? If we do, then perhaps this budget number is not sufficient. I don't know. That's a question I ask of you.

The Chair: We can approve another one, if necessary, but we think it's adequate. We've done our witnesses and our teleconferencing and our travel.

Mr. Kang.

Mr. Darshan Singh Kang: Mr. Chair, I would make the comment that we are dealing with the budget only. If there's anything else you want to add, we can deal with it after we approve the budget. There's a motion on the floor for the budget.

The Chair: Are there any more comments on the budget?

(Motion agreed to [See *Minutes of Proceedings*])

The Chair: The budget is passed, but this raises an issue. Do you want us to have a budget prepared before we start a study? We can do that.

Yes.

Mr. John Oliver: This came up very quickly. We identified the need and we wanted to get the witnesses aligned and set up. I would not want to set up a process that doesn't allow us to be nimble as a committee.

I think it's really great that as the health committee we're dealing with topical issues, real topics for Canadians as they're emerging, and I would hate to see a committee process get in the way of being relevant, that's all.

The Chair: Mr. Davies and then Mr. Webber.

Mr. Don Davies: I don't disagree with John, but really there are two separate issues here. One is that this committee passed a motion to study Lyme disease and have witnesses for I think two meetings. That wasn't just imminent; I think that happened several weeks ago. Separate and apart from that is the budget. You could conceivably pass the motion to have the study and then have issues with the budget.

I just think it's best practice to have both of those things passed prior to incurring the expenses. As I said, in theory this could have been voted down, which leaves us in the awkward position of having incurred expenses that we didn't approve.

The Chair: The chair would have to pay for it himself, and we don't want that—

An hon. member: All in favour?

Voices: Oh, oh!

The Chair: In future, if we have time and we're able to, we'll prepare a budget and present it first.

Before I go to Mr. Webber, I want to compliment all of you on your questions. I think we do a good job. I think you did a really good job today with questions. I think you got the best out of them that you could get. I'm proud of you all, and I just want to say that. Great job.

Mr. Webber, you had a point with regard to where we go with our Lyme study.

Mr. Len Webber: There were a couple of suggestions throughout our study with the witnesses on where we should go, in particular by Dr. Hawkins in his testimony today, with regard to perhaps encouraging the minister to put together another committee, with not only—

● (1255)

The Chair: For oversight.

Mr. Len Webber: It would be an oversight committee, exactly, to address the issues that weren't put into the framework. I would like to see that as an ask to the minister. That, I think, is most important. Whether we put it in a letter similar to our thalidomide letter or not, I just think we have to take some action here now to address the concerns that were brought out during this study.

The Chair: I'd say that if there was a consistent message, it was that this is an evolving situation, and five years is too long to let it go without a comment and oversight.

Mr. Len Webber: That's a very good point.

The Chair: Did you have your hand up?

Mr. John Oliver: I'm conscious of the time, so I don't think we have time to debate the content, but I do think a letter is where we should be headed. Perhaps the committee could instruct the analysts to prepare a letter based on the testimony we've heard. We can start with that, when we get it, to look at what should be in it. But I don't think we have time, with three or four minutes left, to start debating the content of the letter.

The Chair: Dr. Carrie.

Mr. Colin Carrie: I agree with John 100%. I would ask the clerk maybe to just take a look at something. I believe that when the minister announced the framework, she said that she's open to the committee taking a look at it. If you could see what her comments were and maybe what the intent was, I think maybe we could look at this a little bit more, given the testimony that we did receive. I think an appropriate response right now is a letter, and we'll review it.

The Chair: Mr. Davies.

Mr. Don Davies: I would hope that we could carry this conversation over a little bit into the next meeting, so we could have a chance to absorb the testimony and think a little bit about what our next step is. I agree with Mr. Webber that, since we have asked for an opportunity to review the framework, there should be an output. There should be a letter to the minister.

What I'm thinking about right now and what's come out of the testimony is that there clearly is another perspective on Lyme disease that has not really come out through the testimony. I've reviewed some of the literature in preparing for this, and I know, for instance, there's a Dr. Patrick in Vancouver. There is a perspective that the science around Lyme disease is not as consistent with, I think, some of the anecdotal perspectives we're hearing. I'm just wondering if we want to have one day of hearings to hear a few of those other perspectives to round out our perspective on this before we write the minister.

I'll summarize it by saying this. It seems to me, clearly, there's no question there are Canadians who are suffering legitimate issues. They go to their doctors and there seems to be a real lack of understanding of Lyme disease in this country, so they don't get a diagnosis. That causes them to go do their own research, and, in some cases, to consult private clinics and get private diagnoses. They become convinced they have Lyme disease, but there's a large body in the medical establishment in Canada that does not believe that. They don't accept that it's Lyme disease. It's not that they don't believe that they're sick, but they don't believe that it's necessarily Lyme disease. We haven't heard any of that testimony from anybody. I'm in my colleagues' hands on this, but I'm wondering whether, if we're going to be writing to the minister, we want to hear that voice to be complete before we consider....

The Chair: My own thought is that your last question hit the nail right on the head: there is a divergence of opinion. If we get another opinion, it's just going to confirm your question. Every one of the witnesses agreed that there was a divergence of opinion on the science, and I think that's what we will learn from more witnesses.

Mr. Webber.

Mr. Len Webber: Very quickly, Dr. Hawkins also mentioned a retired doctor in the United States, and you took his name and suggested that we look at the research he did and the work that he did back 20-some years ago when there were no guidelines. I think that would be very interesting to maybe send to the committee and to perhaps include in our final report or letter as well.

The Chair: Was that Samuel?

Ms. Karin Phillips (Analyst): Yes.

The Chair: Okay.

Mr. Oliver.

Mr. John Oliver: With respect, I do think we've heard from the other opinions. They're buried in the CDC's work and in others of our established science-based research groups that are looking at disease and taking new and emerging practices. As I said, the 2006 guidelines were reviewed in 2016 by three very significant authorities on disease tracking, management, and treatment.

I think we have a very strong science-based view, which is CDC's, and then we have a number of types of experiential evidence that is out there. I don't think that, as a committee, we can be in a position to judge the merits of research. I just don't think we have the skill set to determine what is the best research.

I think we can advocate for a process that makes sure that the patient voice and the provider voice are present with the research bodies so that there is a challenge of rigour in making sure the best diagnosis and best treatment processes or protocols are in place, and that the researchers and the scientists are looking at the new material regularly as it comes up. I think it's setting a dynamic process as to where the committee can best do its work, versus hearing from different research bodies about what it is.

● (1300)

The Chair: What about if we propose that this committee review this in 24 months, review the progress?

Go ahead, Dr. Carrie.

Mr. Colin Carrie: Perhaps I could ask the clerk again to check what the minister stated in her comments. I actually think she gave us that opportunity. Whether the timeline was in there, I'm not sure. Could you get back to us in the next meeting?

The Clerk: Sure.

The Chair: Go ahead, Mr. Webber.

Mr. Len Webber: I have a very quick comment, and you brought it up, as well, about the five-year period in the framework. To me, that is just not satisfactory. I'm glad you brought it up. As well, 24 months is still a long time, Mr. Casey.

I would like to see a review of this sooner than that, but it's up to your discretion when to do it.

The Chair: Go ahead, Mr. Davies.

Mr. Don Davies: I'll pass.

The Chair: We'll ask the analysts to draft a letter. We'll look at it when it's ready and decide what to add or subtract from it, and then we'll go from there.

I guess that's it. I think we did a good thing.

Thanks very much, everybody.

The meeting is adjourned.