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Chair

Mr. Bill Casey

Standing Committee on Health

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● (1100)

[*English*]

The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)): As we have quorum, I'd like to welcome everybody to meeting number 59 of the Standing Committee on Health.

Today we're going to study the federal framework on Lyme disease. We have three witnesses here with us in the meeting room, and we have by video conference a visitor from Sackville, New Brunswick.

On behalf of the Canadian Lyme Disease Foundation, we have Janet Sperling, board member. Then we have, as individuals, Sue Faber, Lyme disease advocate and patient; Jennifer Kravis, Lyme disease advocate and patient; and Dr. Vett Lloyd, professor at Mount Allison University, by video conference.

Welcome all. We're glad to have you here.

I'm going to seek unanimous consent to allow Elizabeth May to just make a few opening remarks because I believe we can say we're here because of her original Bill C-442, which resulted in this framework being established.

Do I have unanimous consent to allow Ms. May to make a statement?

Some hon. members: Agreed.

The Chair: Thank you.

Elizabeth May, fire away.

Ms. Elizabeth May (Saanich—Gulf Islands, GP): Thank you, Mr. Chairman, and thank you to all members of the committee. I will not trespass long on your time, because we have with us people I want you to hear.

I wanted to set a bit of context. Some of you were in that Parliament—Don, certainly—in June 2012 when I first tabled Bill C-442 for first reading. We have had tremendous non-partisan, all-party support from the beginning. The bill was supported in the House of Commons unanimously and went to the Senate, where it was also supported unanimously.

The bill's nuts and bolts required a conference to be held, bringing in medical experts, federal-provincial government health departments, and people from what we now think of as the Lyme disease community, people such as some of the witnesses before us today, Sue and Jennifer.

I wanted to give you a sense that the conference was an extraordinary success. Our public health officer at the time, Greg Taylor, was very strong in saying that we needed to do more. We've been failing our patients. We've been failing people with Lyme disease across Canada.

I wanted to say briefly that now that the framework has been published, the committee's work for two days this week is very important. I know you'll hear evidence about how serious Lyme disease is, how fast it's spreading, and frankly, the hell on earth it has been for patients with Lyme disease. One of my constituents went to 18 different specialists before finally thinking, “Okay, maybe we'll try going to the States,” and then finally got some help.

The bottom line here, I believe, is that any Canadian experiencing Lyme disease should be able to get treatment in Canada, and we're not there yet. The Minister of Health herself doesn't have a magic wand, nor does she have the jurisdiction to make it so, but the framework gives us some tools. I wanted to point us in that direction, as the positive work going forward.

In the framework document, in appendix 1 is the federal action plan. I wanted to turn your attention to point 2 on education and awareness and point 3 on guidelines. Both of these sections point us in the direction of finding ways to educate medical professionals.

Medical professionals are a very educated bunch. I have the deepest respect for the doctors of this community. In fact, the Canadian Medical Association endorsed Bill C-442. Their letter endorsing it made the point that Lyme disease is an extremely difficult disease to diagnose. The advice, which I agree with in this framework, is that the diagnosis is primarily a clinical diagnosis. In other words, lab tests are quite unreliable, no matter where they are taken. False positives and false negatives are problems.

What we need, when someone presents with a weird range of symptoms, is for every medical doctor in Canada, every family doc, to think to themselves, “I wonder if it's Lyme disease.” If you respond quickly and with early treatment, if it is Lyme disease, this person will be restored to full health, but if you delay, thinking that maybe it's something else, you can actually end up having the disease become much more serious and last much longer.

Here are the two pieces I'm referring to. Under “Education and awareness,” it reads:

> Develop a national tick and Lyme disease education and awareness campaign

—this is the federal commitment—

> in collaboration with partners, that addresses...Recognition of Lyme disease symptoms [to assist] front-line professionals [to] perform early diagnosis and treatment

Then, under “Guidelines and best practices,” in point 3, it says:

> Work with international public health partners

—because, by the way, Lyme disease is spreading very quickly in Europe—

> to share best practices and disseminate domestically

These are areas where we don't yet have a clear sense of how we're going to do it. The commitment is there. It's clear that we can't polarize this issue with good guys and bad guys. That's not appropriate. Everybody here is a good guy. Everybody is trying to figure out what to do, to use the right tools, and to start ensuring that every Canadian who experiences Lyme disease is helped.

There are many people who have had it for a very long time, and those particular patients are a represented group where the research money will be very helpful. We have $4 million for research. That money, I hope, will go towards finding a vaccine but also towards finding ways to help people who have what's either described as post-treatment Lyme disease syndrome or chronic Lyme disease. I don't want to get involved in that ideological divide. I just know there are a lot of people in wheelchairs who need help.

I've taken longer than I actually told you I would, Mr. Chair. You said I could have five minutes. I said I wouldn't need that, but at 4 minutes and 43 seconds I will stop, and I thank you for your attention.

The Chair: You had 14 seconds to go.

Thank you very much. We're all grateful to you for bringing this on.

Public awareness is a big part of this. As I mentioned a minute ago, I was watching the CBC news this morning, and they had a considerable article on Lyme disease. A mayor in Nova Scotia is calling for help on this. They feel that it's getting to a very dangerous level.

Our timing is excellent. Each witness will have 10 minutes for an opening statement.

You can start, Ms. Sperling.

Ms. Janet Sperling (Board Member, Canadian Lyme Disease Foundation): Thank you very much. I'd like to say that, speaking as a patient advocate, I'm not going to read my brief because I really want to speak from the heart here. On behalf of people who have Lyme disease and the people who end up looking after the people who have Lyme disease, we're really concerned that the framework at this point doesn't have enough patient representation.

Our expertise is really looking after these people who are very, very sick, so we have some concerns about all three of the pillars. Just as an example with surveillance, when I looked at the case definition, I was going through it, looking at it, and saying, “You know, this is looking pretty good. It's sure looking a lot better than it used to look.” Then I got to the end and I realized we only had nine provinces.

The way we undertake the surveillance is going to make a very big difference to what we see when we come out at the other end. We really need to have patient advocates pointing out some of these things that are really important because it does depend on where you are in Canada. The education and awareness needs to be locally adapted. As an example, in coastal B.C., you run into the Lyme disease tick generally in the wet winter months, and it's exactly the opposite in Ontario, so we need to have recognition that Canada is a very big country, and it is different from one end of the country to the other.

When we have this sort of standardized education, it's very important that we don't just rely on the IDSA guidelines. We need to make sure that Lyme disease as it exists in Nova Scotia is recognized, and I don't actually expect it to be exactly the same by the time we get to B.C.

I think the most important thing for the patients is that the IDSA guidelines made no attempt to apply themselves to Canada. They're looking at it from a very different perspective. We need to recognize that across the country we have variants of Lyme disease. The IDSA guidelines right now are confusing what's called surveillance criteria with diagnosing the patients. Surveillance criteria are very important, and those are the ones that need to be standardized, but the actual diagnosis and treatment of the patient don't have to rely on surveillance criteria. The IDSA guidelines fail to recognize a lot of research that shows that there is persistent infection. I do want to point out on the plus side that the really important part is that they recognize that the Government of Canada has a very important role to play.

The problem I see now with the national research network is that it stresses that you're going to consult with the provincial and territorial health regulatory authorities, but unfortunately, these are the people who have a history of minimizing Lyme disease. If you're not going to include the patients as equal partners, I see a problem. We know that early cases of Lyme disease continue to be missed because often doctors haven't understood that you can't take the serological result, especially early in the disease. We know that we have a lag time, and we're going to continue to have new cases of Lyme disease.

I'd like to quote a Canadian doctor and a professor who says, “... historical precedent repeatedly illustrates that diversity of thought and opinion, dissonance with the status quo, and openness to exploring new ideas are what moves medicine forward.” That's Dr. Stephen Genuis.

The Lyme disease network right now appears to be set up by restricting to the status quo, and science is the best tool that we have. There's no question that we have to use the very best science we have, and yet the guidelines are missing large chunks of science. If we rely on the same Lyme authorities that landed us in this situation, without inviting divergent opinions to the table, we're going to delay a Canadian solution to a Canadian problem that's continuing to get bigger.

● (1105)

Now, the infectious diseases doctors are tasked with reducing the use of antibiotics, and rightly so—there's no question there—but this does very little to support the family doctors, who are left with very sick patients. I'd like to close just by giving two very recent examples: one of them was last Friday, and the other one was as I was getting ready to leave for the airport yesterday.

Last Friday I was walking down the hall, and one of the building maintenance people stopped. I said, "How did it go? You went to the doctor, and how did it go?" He said he was afraid that the doctor looked at his girlfriend, who has a diagnosis of fibromyalgia, and said they would not make a referral to one of our highly respected Lyme-literate medical doctors. The basis of the refusal to send this very sick person for an opinion, that perhaps this could be a clinical case of Lyme disease, is that Lyme disease is a fad illness. What happened, the end result, was this very sick patient was sent home with physician-prescribed fentanyl. The poor lady is sitting on the couch, she's unable to work, she's in unbearable pain, and the response was to give her fentanyl.

The second story, which was on Monday, is of a dear friend of mine who got Lyme disease in 2008 in Germany. She got positive first-tier when she came back to Canada—and that was a positive C6 peptide—but they did a Western blot for the Lyme disease you'd get in the United States, and she didn't get a positive there. So she was considered wholly negative. Now her family doctor was listening to all this information about Lyme disease research and the framework, and he said, "Great, I'm going to phone up. I'm going to make an appointment for you to see the infectious diseases doctor because you're a classic case of somebody who's been missed." She was refused the appointment with infectious diseases because she doesn't have two-tier positive serology.

These people really need to be dealt with very differently. The rigid system, which won't even see the patients unless they have two-tier positive serology, risks now being rewarded with more funding. If the funding is going to the same people, then the treatment isn't going to be any different. The same people who have denied the consideration of Lyme disease are the people to whom the research funding seems to be flowing. So at best, this framework is a baby step in the right direction, but it risks cementing in place the same rigid structure that failed patients for the past decades.

Thank you.

● (1110)

The Chair: Thank you very much. I appreciate your focus on the framework in your remarks as well.

Now we'll move to Ms. Faber for 10 minutes.

Ms. Sue Faber (Lyme Disease Advocate and Patient, As an Individual): Thank you.

My name is Sue Faber. I'm a registered nurse by profession, with a majority of my experience as an ER nurse. I'm a Lyme sufferer, advocate, and married mother of three daughters who also have Lyme. My husband Andrew has been my rock and has focused me on this unrelenting, exhausting, and often overwhelming journey, which feels to me like mission impossible.

My personal Christian faith is my anchor, and my belief is that God often chooses to use the weak and weary to accomplish his purposes to reveal his power in the midst of what feels like a continuous raging storm.

I'm calling on each of you here today to lace up your sturdiest pair of well-worn hiking boots and join me as I take the lead for just a few moments as your guide. What qualifies me to speak to you today isn't a Ph.D. or a position of authority. My qualifications come from a personal journey into the hazy suffocating shadows of what I would like to call the Lymelands, where those affected by the same plight must band together and unite to survive.

We are the weary, the wounded, and the sick. We find each other, as we have no choice but to look for answers together. We share an illness which is insidious, disabling, and destructive. It is a disease that comes like a thief in the night to snatch away childhoods and steal careers. It is a disease that cripples active contributing Canadians, bankrupts families, and breaks down marriages. It is a disease that, in some cases, has driven Canadians to end their own lives.

I ask you to take the time to read the three Lyme letters, which I have been given permission to share in my brief, to give you a clear and disturbing picture of the reality of the suffering of Canadian adults and children alike. Jennifer and I have been brought to tears as we receive regular phone calls and read letters received through the Lyme letters campaign that I started in January of this year. We now have over 2,500 letters.

These are letters that I am waiting to hand deliver to Minister Philpott, and I truly trust that she will open her doors to receive them very soon. I believe I see Jordan Crosby here today from the minister's office. I hope he will reach out to me and that we can make arrangements for these letters to be passed to Minister Philpott, and for us to speak to them personally.

Parents are horrified and panicked as they watch their child's health disintegrate in front of their eyes. They are writhing in pain, collapsing on the floor, screaming that their brain is on fire. They have paralyzed limbs and bizarre rashes. When they take their child to an infectious disease doctor with positive Lyme tests from the U. S. or even Europe, these patients are flat out told that they are wasting their time and energy on garbage tests. Some families have been messaged that their precious children are being accused of faking or even self-inflicting their symptoms.

We have heard of an infectious disease doctor recently demanding that a child get out of their wheelchair and walk, despite their legs buckling beneath them. Parents are being pressured to commit their sons and daughters to psych wards. Parents are being threatened that they're painting their children with the same paintbrush, insinuating a Munchausen by proxy mental illness. Parents are being forced to do their own research and to sell their possessions to cover the costs of flying their disabled child to expert clinicians outside of Canadian borders. What happens to the families who don't have the money and who don't have the resources?

The reality is that these children indeed are treatable. They have a multisystem infectious illness, triggering an autoimmune encephalopathy. With appropriate and prolonged treatment, which often involves multiple antibiotics as well as other therapies, these children can regain their lives and their hope.

Many parents across Canada believe that their children contracted Lyme disease through pregnancy. I am one of those parents. I will never forget the day I happened upon an article on gestational Lyme disease. I had just been diagnosed with chronic Lyme in Canada. As I read this particular report, I was shocked. Did this mean that Lyme disease could be passed from an unsuspecting mother to her unborn child? This particular case report listed a diversity of clinical manifestations of congenital babies. I started completing a mental check box for each of my daughters. It all started to make sense, and my gut instinct compelled me to get my children tested. With all three girls, Lyme Western blots came back positive from a lab in the U.S., with undeniable evidence of exposure to Lyme. It made perfect sense to me.

● (1115)

All three of my children have been sick since birth with all kinds of unknown ailments that are cyclical in nature—fevers, joint pain, headaches, rashes, abdominal pain, vomiting, anxiety, and OCD. I was an emergency room nurse, and I didn't know what to do, and the doctors kept saying, “We don't know what it is, but just keep plugging along. You're a good mother.”

Later on, one of my daughters actually tested positive—here in Canada, using our two-tier serology—for a European strain. Funny enough, she never travelled to Europe. I also tested positive for a European strain. Also, members, I want to say to you today that I had to lie on the public health requisition to get her tested for the European strain, because the only way they would test her blood is if she had recent travel history to an endemic part of Europe. And guess what? It was positive.

I'll never forget the day I shared my daughter's positive Canadian serology results with my infectious disease, ID, doctor. I looked her straight in the eye and asked her about congenital transmission. She said she knew about case studies on maternal transmission, but she wasn't an expert in the area. She went on to tell me, in her words, that she certainly admired the fight I had undertaken on behalf of my kids. She said I was doing the right thing, and that I contradicted everything that people had been taught.

So where is the reality? I don't know.

To this day I am completely disgusted and frankly outraged that, despite diagnosing me with chronic Lyme in Canada, this expert, whom other physicians look to as an authority on Lyme disease, had been coldly silent to making me aware of the possibility of mother-to-child transmission. I had to figure it out all by myself, without any support from any Canadian physician.

There was a very recent CBC radio interview with Dr. Caroline Quach, who is the president of AMMI of Canada. Dr. Quach was interviewed as an expert in the subject matter and was asked directly by the radio host whether Lyme disease can be transmitted in the womb. Her response was that there is no evidence that this is actually happening and there hasn't been any evidence in humans that this has happened, at least none that has been reported in the literature. She flat-out denied evidence of congenital Lyme transmission. She was speaking out as an expert, and thus her words would hold considerable weight and be seen as trustworthy and an authoritative source of information by her medical colleagues.

I ask you, honourable members of this committee, does this not disturb you as it does me? Denial of truth cannot be accepted or tolerated, not in the past, not in the present, and certainly not in the future. This denial must stop now, and it is clear to me that when it comes to Lyme disease, infectious disease doctors have an alternate agenda, which must be examined. They have clear biases, which must be questioned. They must be held accountable for their actions.

My story gets more disturbing, because when I reached out to my local public health unit to discuss my concerns of congenital transmission, instead of being granted a face-to-face meeting, I was mailed a letter, which stated that both I and my daughter would not be counted or reported as positive Lyme cases in Canada. You see, we presented a rather inconvenient truth to our public health authority, so instead of acknowledging and engaging, they dismissed, denied, and erased us from the record.

Just to reiterate, the number of positive Lyme cases in 2016 did not include me or my daughter, for reasons that escape my comprehension, without any meaningful rationale, and certainly—in my mind—with completely unethical behaviour.

I was also told in the same public health letter that there was no scientific evidence of congenital transmission, so not only AMMI but also our public health authority denied the reality. Could it be that the infectious disease doctors in public health who take a lead on this illness deny the very existence of scientific research that contradicts their rigid dogma?

Yesterday, Jennifer and I had the opportunity to speak with Dr. Njoo, deputy chief public health officer. We asked Dr. Njoo why congenital Lyme transmission had not been mentioned in the federal framework, considering the available body of scientific literature and evidence, including pathology reports, case studies, and an entire chapter written and dedicated in a reference medical textbook, which I have brought with me today. It is quite disturbing that this textbook is no longer available as a reference resource, and in fact Jennifer and I had to find it through used book dealers on Amazon. I will be leaving a copy of this edition with the committee clerk today.

● (1120)

I ask that this textbook be available to the committee and anyone else who wants to learn about the devastating reality. I hope this textbook will be permanently archived as clear evidence of what I have shared with you today.

I also ask Dr. Njoo why the Public Health Agency has not mentioned the June 4, 1998 *Canada Diseases Weekly Report*, which is included in your brief. It states: “Transplacental transmission of B. burgdorferi has been documented and may be associated with an increased risk of adverse pregnancy outcome.” Why has nothing been done in 29 years to address this concern? There is no Canadian research, no further mention, nothing. Our public health officials are fully aware of this information, yet they choose not to share it. In their silence, they are allowing more children to become infected.

I have more to say, but I am going to close because I realize that my time is up.

Thank you for joining me on this uphill battle. We are still far from the top. I know we must climb to the top, because at the pinnacle of this mountain we will experience a freedom and be able to clearly see the truth. Climbing to the top can be accomplished only by reliance on and trust of those who climbed this mountain, the patients. They, and only they, can speak to their journey with clarity and insight. It is devastating that this strong and authoritative voice was completely left out of the federal Lyme framework. In fact, the voices, testimonies, and pleas of thousands upon thousands of Canadians were clearly blacked out, shut out, and, in essence, ignored.

Despite this failed framework, I still have great hope that this isn't the end of the story, but rather a fresh beginning, a reawakening to the reality of the Lyme crisis, which continues to sweep across our nation. Your decisions and actions on this issue will directly impact the fate of millions of Canadians.

Thank you.

The Chair: Thank you.

Now we'll go to Ms. Kravis for 10 minutes.

● (1125)

Ms. Jennifer Kravis (Lyme Disease Advocate and Patient, As an Individual): Hello. My name is Jennifer Kravis. I live in Oakville, Ontario. Thank you for having me here today.

I used to be a lawyer and a bank executive, but 11 years ago, at age 36, I was suddenly debilitated and bedridden by a mystery disease that took me hundreds of thousands of dollars and five years to determine was Lyme disease.

I had to go to the U.S. and pay even more money. I spent two years getting continuous antibiotic treatment, including a PICC line, which gave me my quality of life back, and my family's as well.

I still cannot work, but I advocate for Lyme disease now. There are five people in my family with Lyme, and my dog has it as well, but my dog was treated promptly with compassion and care, and he got five months of antibiotics, and he made a full recovery. My niece got early treatment with a bull's eye rash after seeing four doctors . The rest of us—me, my mother, and my two daughters—are permanently affected. As a mother, I live with the guilt and horror of discovering I probably infected my two kids. They both have chronic Lyme and multiple co-infections. One has encephalitis causing neuropsychiatric issues and arthritis in the spine, and she's 14 years old.

In the last week I've spent many hours thinking about what I could possibly say to you in 10 minutes to convey to you the suffering, the despair, the abuse, the financial ruin that is sweeping this country.

I can talk about my full story. I was financially secure, a Bay Street professional. I had money, connections, and access to the very best health care, but it did not protect me and my family, and it will not protect you.

I could talk about the 40,000 Canadians who signed our petition or who wrote thousands of Lyme letters for Minister Philpott, letters that bring us to tears on a regular basis. But on Thursday you will be told that petition comments are really about ticks, and stories are anecdotes not evidence.

I could talk about the independent, professional benchmark survey we did in Canada to ask how many people were affected by Lyme disease. The survey asked, have you or someone you know in Canada been diagnosed with Lyme disease? The answer is between 2.8 million and five million people.

Public health numbers are a joke because people are denied testing and not counted. People get false negative results, and they are not counted. People get positive results. They are told they are false, and they are not counted. People get positive tests from international labs, and they are not counted. Finally, those who, by some miracle know about Lyme, convince their doctor to order tests, pass the first tier, pass the second tier, prove they were in an endemic area, get to the doctor in time, get a bull's eye rash, and have the doctor visually inspect the bull's eye rash. Even the majority of those cases are not counted, just as Sue Faber talked about.

I thought about asking questions. Why has public health ignored 35 published, peer-reviewed tick studies compiled over the past 27 years by an Ontario researcher named John Scott? Why has public health not warned first nations that they are living in hyperendemic areas like Kenora, Ontario, where John Scott estimates ticks have been established for 50 years? Why have our doctors never heard of co-infections?

My 13-year-old daughter has Rocky Mountain spotted fever. This is a disease that could be fatal in up to 75% of untreated cases. I had to fight for this test, and when it came back positive, my GP fired us.

This leaves my going back to my original question, which is, what could I possibly say to you to convince you something tragic, shocking, and disturbing is happening in plain sight?

I decided I would speak about the truth, the real truth, the truth that nobody wants to talk about or believe. The truth is the bill was great, but the final framework is useless. It is inaccurate. It's going to cause harm to Canadians. The process was mangled by some powerful, unethical, and self-serving interests.

The truth is we have a massive global pandemic, one that is not easily prevented by pulling your socks up and staying in the middle of the paths. The truth is people are so desperate to get life-saving antibiotics they beg their vets, and they beg their doctors to try to get six weeks of antibiotics in a desperate attempt to avoid lifelong disability. The truth is there's a secret network of Canadian doctors who risk their licences to treat their patients. The truth is Lyme patients are horribly abused by doctors, but if they file a complaint to the college, they are harassed and blacklisted. The truth is millions of Canadians, including first nations and children, are walking around with the wrong diagnosis. The truth is U.S. doctors are getting paid by us to learn about this disease, instead of our own doctors gaining this knowledge and expertise. The truth is we have thousands of parents who live in agony and despair, hiding in their homes with sick, disabled children who scream and cry, have seizures, and are in horrific pain. The truth is people with bull's eye rashes in every province every day are being turned away and denied treatment, sent home to wind up disabled in excruciating, unrelenting pain.

● (1130)

Some doctors say, “I'm sorry, I can't help you; I will get in trouble and I have to protect my family over yours.” Some doctors say, “I'm not allowed to help you, but if you go to the U.S. and get treatment, you will get better.”

Many doctors say, “I guarantee you don't have Lyme disease” and, in fact, they are correct, because the system at every stage guarantees it's virtually impossible to get a Lyme diagnosis. When the Canadian test is negative, it is called gold standard; when the test is positive, it is called false; and when the test is from out of the country, it is called garbage, except if it's negative.

The truth is that surveillance is a sham and a waste of money, because ticks are dropped everywhere by migrating birds; and surveillance is not progress. It is a tool used to deny the disease. The truth is that some people don't get their Lyme test back from the national lab for months, and too many people are told their test results are lost.

The newest weapon in the Lyme war is anti-microbial resistance, which denies very sick Lyme people life-saving treatment or the dangerous side effects of antibiotics. The truth is that people with arthritis, syphilis, Crohn's disease, tuberculosis, relapsing fever, rheumatic heart fever, rosacea, MS, and acne are given months and years of antibiotics without hesitation; and cancer patients are given the choice of drugs with side effects so dangerous they can kill them.

Let's review the so-called facts of Lyme disease that we are told by public health and infectious disease specialists: one, our testing is fine; two, ticks must be attached for 24 to 48 hours to transmit the disease; three, only black-legged ticks carry Lyme; four, your risk of contracting Lyme is very low, so don't worry, and virtually zero outside of endemic areas; five, you can't have Lyme if you don't get a bull's-eye rash; six, two or three weeks of one antibiotic is all you need to be fully cured; seven, if you have any new, lingering symptoms, you have a new disease, which is called post-Lyme-treatment disease syndrome, which looks and feels exactly the same as the infectious disease you just had three weeks earlier; eight, we are told there is no scientific evidence of persistent infection or that long-term antibiotics help, and we are told there's no scientific evidence of congenital transmission.

We are told, “We don't know what all these people have, but it's not Lyme” and we're told that people fixating on Lyme could miss the chance to get a real diagnosis.

Finally, we are told other countries' tests, all of them, are invalidated, from for-profit labs, not FDA approved, purchased positives, garbage, or run by profiteers and quacks. But the truth is every single one of those sentences is untrue.

The truth is that doctors, patients, and the public are being misled, and we need you to do what no one has been able to do—despite fighting for decades—not advocates, not Bill C-442, not celebrities, not politicians, not journalists, and not even an international organization of medical doctors and scientists.

We need you to ask yourselves if it makes sense that tens of thousands of Canadians have a shared delusion about their own health and welfare, their body, and their symptoms? Does it make sense that tens of thousands of kids who've never met are suffering from a shared psychiatric disease that causes them to fake symptoms? Does it makes sense that previously rational, healthy adults are conspiring to obtain antibiotics, which if abused, give you a stomach ache and a sunburn. Does it make sense that desperately sick people bankrupt themselves for treatments that provide no relief to them?

We need you to ask the questions that always reveal the truth. Who benefits or profits from the denial and suppression of these diseases? Who benefits from patients missing the early cure with a cheap generic antibiotic, and wind up labelled with fibromyalgia or an incurable neurodegenerative disease like MS, ALS, or Alzheimer's. It's not patients, it's not taxpayers, it's not families or kids, it's not businesses, it's not our health care budget, it's not family doctors or clinicians, and it's not our economy.

The truth is that it is too late for me and my family, because there is no amount of money, drugs, connections, or treatments that will restore our health. We are here for you. We are here for all those Canadians who are so sick and in pain and feel abandoned and are on the verge of suicide. We are here for all those Canadians who will be unknowingly struck down in the parks and in their backyards. We are here because we cannot bear to hear one more story of a child with a bull's eye rash being sent away to end up disabled.

The truth is that Canadians desperately need you to stand up and do the right thing. We need your help. Please help.

Thank you.

The Chair: Thank you.

Now we go to Dr. Lloyd.

Dr. Vett Lloyd (Professor, Mount Allison University, As an Individual): Good morning.

I have speaking notes, but I won't necessarily read from them. I want to provide a bit of context about where I'm coming from. I have had Lyme, and like many others I had to seek treatment in the United States to return to health. In this case I'm speaking as a scientist, and I'm going to focus on the science of the Lyme disease framework. I apologize for the people who are now thinking they have to sit through nine and a half more minutes of science, but I'll keep the science part light.

My feeling, in reading the framework document—and in being on the conference planning committee and presenting at the conference—was that this framework fails to provide the leadership that the scientific community and the medical community need. It completely fails patients. I'm going to go through the reasons I'm saying this.

The first reason is that the framework doesn't have a place for the patient voice. The patient voice did show up at the conference, and it was a spectacular conference. It was the first time we had brought together patients, scientists, and the medical profession. All the voices were heard. They were difficult conversations, but they were respectful conversations, and I felt we were making progress. Unfortunately, none of that material ended up in either the draft or the final framework, which were fairly similar, with some differences in window-dressing.

Without the voices of the patients, we don't know what's important and anything going forward will be more or less meaningless. There's too much of a disconnect between the people who need this framework and the way the framework currently exists. I would also point out that having the patient front and centre is intrinsic to the ethical guidelines for both medicine and science. This framework fails to meet either scientific or medical-ethical guidelines.

I'm going to talk briefly about science and the framework. The term “evidence-based” is tossed about quite liberally in the framework, but it is misused. What evidence- or science-based means is not that someone somewhere has done a study, and you like the results and they're convenient, and then you just declare the results to be correct. Rather, it means that you take all the relevant peer-reviewed literature and you ask whether it all says the same thing. If it doesn't say the same thing, you have to figure out why. You don't just ignore the stuff you don't like—that's the antithesis of science.

There's been an enormous history of cherry-picking within the whole development and management of Lyme disease in Canada. We've heard stories of that so I won't go into it, but it feeds into every aspect of the problem, from how long it takes a tick to transmit the disease to whether or not long-term antibiotics will help the patient. Really, we have to do better with science—it's the only tool we have. We have to do proper science, and that also means ethical science.

I have a list of science glitches, errors in this document. I'm not going to go through it, because lists are boring, but I will point out that the first sentence of the document is factually incorrect, and so is the second. That really isn't a good start. The first figure features the dots of doom that everyone in the surveillance section at the conference agreed to—this was the one section where people achieved consensus. There was consensus that it was not a good way to represent data, but still it shows up in the framework.

The real problem, from my perspective, is that the partners named as the people who worked together to bring this framework into action and to bring out its potential include a number of partners who have no research capacity. It excludes—and I do not know why it excludes them but it does—the two federal funding agencies, NSERC and SSHRC. NSERC regulates and funds research in the natural sciences, which is critical for a disease that's transferred via ticks from wildlife. The Social Sciences Research Council is critical because we're looking at what this disease does to people, what it costs the health care system, and what it does to communities.

● (1135)

I do not understand why scientists were excluded from this document. A corollary of scientists being excluded is that $4 million will now not be available for science.

I'm going to talk briefly about non-transparency. How the framework was assembled was non-transparent. The conference was transparent, but it was not used to inform the final framework document. In addition to being non-transparent, essentially people went away and nine months later the gestated document sprang into being. There was privileged access by the AMMI membership of the planning committee and that was documented, apparently by the AMMI member of the committee, unaware that other members did not have access to the document. Some people were allowed to see the draft document and comment on it, but certainly the patient groups were not and the science people, as far as I know, were not.

It's disturbing to have preferential input into a controversial issue where there are divergent opinions. We need to pull together. We need to accept that there are divergent opinions and talk to each other, and not privilege one side or the other. That is seen in the fact that the document specifically endorses one of the two treatment guidelines available for Canadian patients, but not the other, and it does not endorse the more recent one and the one with stronger scientific evaluations. It's also not clear to me why a policy document is dictating patient treatment modalities, because that should be determined by the physician who has examined the patient.

Funding is equally non-transparent, and we can see that in the fact that the funding priorities that are picked out are not the priorities that are important to the patient groups. I don't know where they came from; they did not come from the conference. They just appeared. In addition to all the issues that are important to Canadians—we've mentioned some in terms of congenital and sexual transmission—are there other vectors out there, is our blood supply safe? These are very important issues that are not addressed, and I don't know what happened to them.

To emphasize the importance of doing good science, on Friday of last week there was an announcement that they had found that for multiple sclerosis patients, long-term antibiotic treatment was reducing by half the number of patients who showed disease progression. All of a sudden when you start treating multiple sclerosis patients with treatment that would be appropriate for Lyme disease, you're seeing an improvement. That's really frightening. People will die of multiple sclerosis—I think that emphasizes how important it is to get this right. Canadians are dying of this disease when it's not recognized.

I'm coming to the end. I'm a scientist, and as my supervisors are keen to say, no scientists should be allowed outside unescorted, so I ended with questions that I don't have an answer to. Perhaps there is expertise in this room. Is it appropriate when drafting a framework to give some experts but not other experts, and certainly not the patients, access to directing the framework?

The document is essentially written so it will be reviewed in five years, but in this field, the knowledge of science doubles in slightly under two years. So we're left with a document, which you may feel is excellent or you may feel is terrible—I'm in the latter camp—but it will be even more out of date in another two years.

● (1140)

Is there a way to make this a living document? The reference within the framework that the Public Health Agency of Canada will continue checking diagnostics is not part of being a living document. It's their mandate to be continually staying up to date. Is there a way to have input into this document, ideally patient input, and definitely science input?

I'm unclear about whether it's appropriate for policy to be dictating patient treatment guidelines. That seems a dangerous thing for a high-level document like this to be doing.

My final point is just to emphasize that the ethical guidelines in both science and medicine state very clearly that the patient must be not just consulted—consulted can mean anything from, this is what we've decided to do, are you good with that?, sign here—it means the patients must be equal partners. They must be asked, what's important to you? How are we going to get there? Patients are not just fodder for being fed into science studies, and they're not just, here, take this treatment and go away and be grateful that you got it. We have to talk to Canadians who have this illness, and we have to help people.

Thank you for your time.

● (1145)

The Chair: Thank you very much to all of our witnesses, and thank you for the emotion and the emotional aspect that you bring to make it real for us.

We're going to go to questions now and we should try to keep it on the framework, if we can, on how we can improve the framework, or what's good about it or what's bad about it.

Mr. Oliver.

Mr. John Oliver (Oakville, Lib.): Thank you very much, Chair, and thank you very much, to all of you, for very powerful and personal testimony.

I know that you're not just representing yourselves, you're representing a large number of people with Lyme disease across Canada. I do want to thank you for your advocacy. The work you've done has been great, from your advocacy that got the Federal Framework on Lyme Disease Act in place— and there's the assistance that my colleague, Ms. May, brought to that—which resulted in the draft framework. I know there's been a lot of advocacy and consultation in improving the draft framework, so I really did want to thank you and recognize that.

We have a meeting on Thursday with some of the people from Health Canada and others who were part of the framework design. How do we best talk with them? I did hear in your testimony something about the current state of recognition, surveillance, and treatment of Lyme disease in Canada, but some of that is what the framework is intended to do. I think we need to get the framework rolled out to address those issues. The three pillars of surveillance, education, and awareness, and guidelines and best practices, would address some of the concerns that I heard, particularly around primary care treatment and recognition of the disease, and best treatment protocols.

Then, in the listening stage between the draft and the final framework, there were four key areas that were amended based on your advocacy and your feedback.

One is research funding, so $4 million for the Lyme disease research network, addressed through the Canadian Institutes of Health Research. Dr. Lloyd, you and I may differ on this, but I have a great respect for the CIHR and their evidence-based science, peer-reviewed approach to this. That is looking specifically at improving diagnosis and treatment, so a big step forward is research funding.

There's the recognition that there are chronic symptoms. I know there's still a tension between recognition of chronic symptoms versus recognition of chronic Lyme disease as a case type. It identifies that research is needed yet to determine that.

Then there's improving health lab networks. I think everybody's in agreement that there needs to be better lab testing. I think all of our witnesses spoke to the need for better and more exact testing.

Then, finally, there are migratory animals and recognition that migratory animals can carry Lyme, which I think, Jennifer, you specifically mentioned as well.

From there, the easiest way for me to proceed—I have to ask questions and I only have seven minutes—is to ask what would you want me to ask the people who are coming on Thursday to make sure they hear your concerns, and that if we are able in any way as a committee to improve the framework or make suggestions, how do we do that?

I have some down so I don't repeat them.

I have, what happened to Dr. John Scott's research? Why wasn't it used? Why wasn't it referenced?

I have congenital transmission and is it true, is it not? Why is it not referenced and spoken to directly?

I have funding priorities. Who sets the funding priorities? Are they based on evidence and science?

I also then have a question around the patient voice. Why is the patient voice silent in the framework? How would the authors think that the patient voice would be best drawn into it?

That's what I have so far. Those are my four questions from your testimony.

What else would you like me, or any of the committee members, to ask on Thursday that would further, in your minds, improve the framework?

● (1150)

Ms. Jennifer Kravis: I think one suggestion would be to ask the two clinicians who are attending about the different testing modalities that are already in existence and available and could significantly improve the sensitivity of the test. Also, perhaps a perspective on—

Mr. John Oliver: Is this lab testing?

Ms. Jennifer Kravis: Lab testing, yes, and also, ask them for a perspective on how we get from here to where we need to be, which is for all medical professionals across Canada to understand the realities of this disease and how to recognize it, diagnose it, and treat it.

Mr. John Oliver: Just to be clear, in the revised framework, there is specific reference to the need to improve the lab testing and the lab work that's being done. The three pillars already include education and awareness. I understand that you're dealing with the frustration of the terrible environment that has been here. We need to think about what the environment will look like post-implementation of this framework that actually addresses those issues.

Are there any other questions I should ask that aren't addressed in the revised framework?

Ms. Janet Sperling: Yes. I'd like to see something about why the doctors who are good at making the clinical diagnosis aren't being approached to explain how they make that diagnosis, because they seem to be pretty accurate, with or without the blood test. They seem to be very good at identifying people who will respond to the treatment. I think that's a big area.

Maybe for the next five years we're going to say that maybe we have to admit that the blood test doesn't work, so for the next five years we're going to go with the clinical diagnosis and then we're going to revisit it after that. I'd like to see more emphasis on the clinical diagnosis.

Mr. John Oliver: Just to be clear on that, my understanding is the current testing requires antibodies or something, a change in your blood system in response to the Lyme disease before it appears. You have a problem with treatment based on symptoms presented in a doctor's office, the classic one being the bull's-eye ring rash, versus having to wait for the antibodies, I guess, to appear in a blood test. That can take....

Are there lab tests in the U.S. or elsewhere that are faster or better able to detect Lyme earlier than what we have?

Ms. Janet Sperling: I think the reason most people send it to the U.S. is that if you get the first-tier positive, it then goes to your second-tier positive, but the Americans will give you the banding pattern.

There are supposed to be five out of 10 bands that have to be positive, but that already exists at the national lab. They already know, if it's positive, which one of those five is positive, so a really quick thing to do would be to release that to the family doctor and say that this individual maybe only has four of 10, but if we know, for example, that this person lives in B.C, they got four out of 10, and they're sick, then maybe for that individual it's worth trying the treatment. That would be a really quick way to deal with it: to release all the information they have.

I believe that even now they've stopped giving the C6 positives. Now, in order to get the word “positive”, you have to be positive for the C6 and for the Western blot, whereas if you said, “positive for C6”, that's one piece of information, so it's positive for the Western blot and the particular banding pattern.

Mr. John Oliver: Thank you.

Sue or Dr. Lloyd, are there any other direct questions?

Dr. Vett Lloyd: I would like to have a specific question to find out why it is that NSERC and SSHRC are not included as partners. I completely agree with you that CIHR is a wonderful partner; however, their mandate is only a small part of this problem, and by not having the natural scientists and the social scientists as partners, we're losing a lot of expertise, which is present in Canada.

The Chair: Thank you.

Mr. Webber.

Mr. Len Webber (Calgary Confederation, CPC): Thank you, Mr. Chair.

Thanks as well to our witnesses for being here today.

I have a quick question on the conference that was held a year ago. I think it was here in Ottawa. Did you attend?

Jennifer, did you attend that conference? Okay.

Sue?

● (1155)

Ms. Sue Faber: I didn't, no.

Ms. Janet Sperling: I did.

Dr. Vett Lloyd: Yes.

Mr. Len Webber: During this conference, of course, many issues were brought up, and that's what developed the framework that we have in front of us today. My question is, then, was the issue of congenital transmission raised during this consultation period, this conference?

Ms. Jennifer Kravis: Yes.

Mr. Len Webber: It was brought up. You talked about it.

Was the issue of transmission through blood talked about and discussed at this conference?

Ms. Jennifer Kravis: Yes, it was certainly raised as an issue.

Mr. Len Webber: What about Lyme disease vaccines? Were vaccines discussed, talked about?

A voice: Yes.

Mr. Len Webber: That's disappointing because I don't see it in this document, this framework, other than on page 31, a brief bullet point under Research; one topic is human-to-human transmission: congenital, breast milk, sexual, blood supply, organ donation. To me, that is quite disappointing because this is a major public health concern.

What I'd like to ask Dr. Lloyd is this. With your scientific background, do you believe there can be human-to-human transmission of Lyme through the blood supply?

Dr. Vett Lloyd: Well, I'll answer that indirectly. When we do work with mice, the way we produce infected mice is that we innoculate them with blood, usually from another mouse. That's mice, not humans, but we all have blood and it works the same way.

There is no reason it would not happen. There is documentation in the literature saying that it does happen.

Mr. Len Webber: Okay.

Dr. Vett Lloyd: So, yes.

Mr. Len Webber: Yes, I believe so as well, from the discussions I've had in the past with scientists, doctors, and such.

But we aren't doing any screening here in our blood supply and this is certainly going to be a question I'm going to ask on Thursday with Canadian Blood Services. I just wanted to get your thoughts on that.

Also, with regard to infected mothers passing on Lyme disease to their children, I have some notes here. It is a travesty, and I'm very sorry to hear that it has occurred in both your families, Sue and Jennifer.

I understand there is no science to prove that it is sexually transmitted. Perhaps I'll ask this as well, Dr. Lloyd. Can Lyme disease or any of its other types of relatives be transmitted through sexual activity?

Dr. Vett Lloyd: There is science to say that it can be found in human genital secretions. It has been shown to be sexually transmitted in a number of different animals—dogs, horses for some reason, cats, and mice. There are also studies that failed to document it, but I think at this point the precautionary principle would be to say, yes, we can see it happens in animals and it looks as if it could happen in humans.

So yes, let's not take a risk.

Mr. Len Webber: Absolutely, it's certainly something I will bring up with Canadian Blood Services. I think it's a concerning issue and we need to address this.

If I go out into the mountains with my grandkids, my future grandkids, and they are bitten by a tick, are you saying that the treatment is going to be difficult for me to go to a doctor to say, “Look, this child has been bitten by a tick. What do I do now?” Is there a treatment for my grandchild?

From your experience, Jennifer and Sue, it sounds to me as if the treatment does not work well here in Canada. Can you maybe elaborate on that?

Ms. Sue Faber: Actually, if you have a child or a grandchild who does get bitten by a tick, there is treatment and the key is that it needs to be early treatment. That child needs to go to the emergency room or to your family doctor and whether they have a tick attachment still on them doesn't matter. The point is that the child has been bitten, may or may not have a rash, but we need to treat that child. We cannot watch and wait. We cannot.

● (1200)

Mr. Len Webber: So it's the diagnosis first to indicate—

Ms. Sue Faber: It's the diagnosis, so our clinicians must be aware. There are guidelines, currently available to our clinicians, that set out proper treatment for individuals, whether they are children or adults.

The problem is that many times, from many stories we have heard, children are actually presenting to an emergency room with a classic EM rash. By the way, an EM rash does not have to be a bull's eye. It doesn't have to look like a perfect target.

These children are presenting and the doctor is saying, “Well, did you pick off a tick? No? Well, let's just watch and wait.” And that watching and waiting could make the difference between that child being completely cured or suffering potentially lifelong chronic illness.

Mr. Len Webber: You watch and wait, and you end up with an advanced form of Lyme disease, such as both of you have. There is no treatment here in Canada for it, obviously. You're seeking treatment outside of Canada; Jennifer, you mentioned going to the U. S. Why do we not have treatment here? Why can we not develop treatment here like they do in the States?

Ms. Jennifer Kravis: The drugs are available. The treatment that's typically used by doctors who specialize in this field consists of multiple types of antibiotics, often used in combination.

There are two reasons. One is that doctors have not been educated on the existence of treatment guidelines that explain how to treat an infection that can be persistent and disseminated. As well, many doctors feel like they can't. They are concerned that they will be stigmatized, harassed, or sanctioned if they go past the current guideline of two to three weeks of antibiotics.

Ms. Sue Faber: May I give an example of that? I tested two-tier positive in Canada. My infectious disease doctor treated me with IV antibiotics for a set period of time. When that time period was up, she declared me cured. Within six weeks of my curative treatment I developed new symptoms that were actually worse than before, including going completely numb at the tip of my tongue and in my fingers and toes.

I went back to her and said, “I'm developing new symptoms. This feels to me like I'm starting to deal with ALS-type symptoms.” Her response to me was, “Well, I can't treat you any further because the guidelines say I can't.” She denied me further treatment and suggested I go to a neurologist.

I then went to a neurologist, who said, “You don't have ALS. I can't help you. Perhaps you should go to an infectious disease doctor.” So, unfortunately, the door to any further treatment has been closed.

I am currently on oral antibiotics, and I can tell you that on this treatment I am able to be here today. If I was off this treatment, I would be bedridden, but unfortunately this treatment has not been provided by my infectious disease doctor.

The Chair: Thank you.

Mr. Davies.

Mr. Don Davies (Vancouver Kingsway, NDP): Thank you, Mr. Chair.

I'd like to first thank all the witnesses for being here, and in particular Ms. Faber and Ms. Kravis for sharing your personal stories. It takes a lot of courage to go in public and to come before Parliament to share what we all view as a highly personal aspect of our lives, which is our health. You're doing a great service not only to this committee and this Parliament, but to Canadians across the country. Thank you for that.

Dr. Lloyd, I'm going to start with you. I think I wrote down your words verbatim, where you said the framework fails to provide the leadership the community needs, and fails patients. That's a pretty fundamental indictment of a framework that is, I think, intended to and should be geared towards making Canadians' health better.

My first question is going to be what's the first thing that needs to happen to this framework to correct that deficiency?

Dr. Vett Lloyd: We need to bring the patient voice into it, because the current framework was written by the people who basically brought us to this position in the first place, and it endorses the status quo. That's not the situation we're facing in Canada.

Jennifer and Sue have described what they are facing, and many other Canadians are doing that. If you bring the patient voice into it, we can at least have the framework start to address the questions that are important to Canadians.

● (1205)

Mr. Don Davies: Thank you.

Second, an undercurrent of this entire discussion is that there appears to be some controversy. Dr. Lloyd, you mentioned that there are divergent opinions, and your testimony was that we need a dialogue. Does the framework provide an adequate means to facilitate that essential dialogue, in your view?

Dr. Vett Lloyd: No, it doesn't. It provides no opportunity for input, or even for updating the science. We need a way of feeding in new scientific discoveries as they happen, and they're happening very rapidly. There is, essentially, no dialogue. There's no way to make this a living document.

Mr. Don Davies: My last question is for you, Dr. Lloyd.

I really like this quote by former U.S. Vice-President Joe Biden: “Don't tell me your values. Show me your budget, and I'll tell you your values.” I want to zero in on the $4 million that this framework proposes to invest in research, and get your view on whether that is sufficient in order to do the research necessary to attack this condition.

Dr. Vett Lloyd: No scientist is ever going to say, “That's enough money”, but perhaps I'll—

Mr. Don Davies: Politicians wouldn't, either.

Dr. Vett Lloyd: I might actually break tradition there. I would say that it depends on how you are going to use the money. If it's more of the same, I don't think that's a very good use of the budget whatsoever.

Canadian scientists are very good at scraping along with relatively little money, although we'd always like more, of course. What's important here is to have that funding distributed in a transparent and peer-reviewed process. The framework already identifies policy priorities, which essentially have tagged specific individuals and specific projects, and that's premature. It is premature for policy-makers to say that this is good science and that is bad science. The expertise wasn't in the room when this framework was drafted.

There needs to be a broader call, directed toward the science community as well as the medical community, saying, “What can you do? We have a pot of $4 million. Tell us what's going to help Canadians.” Then send that out to a scientific peer review.

Mr. Don Davies: Thank you.

Ms. Faber, you testified very strongly about your struggle to get the medical establishment to listen to—or, frankly, ignore—your view that Lyme disease can be passed on congenitally. I wasn't quite clear on this. Are you saying that the connection with congenital transmission is present in the literature but doctors just aren't aware, or that it is not present in the literature when it exists and it should be in the literature?

Ms. Sue Faber: It is present in the literature. That is why I am going to leave this textbook, Remington and Klein's *Infectious Diseases of the Fetus and Newborn Infant*, from 2001.

I am just going to read one little paragraph from chapter 11:

> It is uncertain how many episodes of gestational toxemia, spontaneous miscarriage, spontaneous abortion, stillbirth, culture-negative neonatal sepsis, failure to thrive, developmental delay, congenital heart disease, or sudden infant death syndrome may be due to unrecognized gestational Lyme borreliosis. ... Determination of true risk to the fetus and infant of maternal gestational Lyme disease requires prospective studies of all pregnancy outcomes of gestational Lyme disease, long-term follow-up of live-born products of these pregnancies, and improved diagnosis of Lyme disease in affected fetuses, placentas, and infants.

This chapter has over 888 references. It has been well cited.

We met with public health about a month ago and shared this textbook with them. When I met with them yesterday and asked them if they had had an opportunity to read it, the answer was no. I don't know if they knew it existed. Yesterday, when we went to them, they still did not have a copy of this textbook. I truly hope that, now that they have this resource in front of them, they will be able to understand that there is clear, defined information that points to congenital transmission.

● (1210)

The Chair: Thank you.

Mr. Kang, go ahead.

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

I thank all the witnesses for sharing their personal stories.

My questions are for Dr. Vett Lloyd.

In the public forum, there were 500 participants from across Canada. They participated over three days, and there were 100 speakers. They shared their personal experiences, either in person or online. Speakers included patients, their families, caregivers, and health care professionals.

Doctor, you keep saying that this framework is not a living document and that there is something missing from the patients' input, but you are not being specific about what is missing in that framework. Could you please make that clear?

Dr. Vett Lloyd: The conference brought together patients and scientists and medical professionals. At the end of the conference, there was a conference summary. If you go to the online version of the framework it's hyperlinked there. The summary couldn't capture all of those testimonials, but key reoccurring points were picked out. If you check those reoccurring points, few to none of them show up in the document, and others have just been put in. I presented in the surveillance section because I do ticks. One example I gave was that everyone agreed that showing surveillance maps with a dot saying there would be ticks here is not meaningful because ticks are moved around by wildlife such as deer and birds and mice, and there are not a lot of places in Canada where there are no deer, birds, and mice.

We all agreed that the way to do it is to show broader sections of Canada as being high risk or low risk, but there is actually no area that is zero risk. That didn't show up. That's one very small example, but in many ways the conference summary should have been the framework. It did a phenomenal job of capturing not only the patient voice, which is critical, but also the current science. There was current science presented on the fact that the bacteria actually survived the standard short-term antibiotic treatment, which is clinically critical, because if you under-treat the disease, then you're asking for antibiotic resistance, and this disease is bad enough as it is. The prospect of having an antibiotic-resistant Lyme disease is horrifying.

Mr. Darshan Singh Kang: Thank you.

Dr. Vett Lloyd: I can keep going, but I don't think we want to do that.

Mr. Darshan Singh Kang: No, I don't want you to keep going.

In the surveillance framework pillar, it says it will develop a national tick-borne surveillance system for Lyme disease and other possible co-infections. Don't you think what you just said will be covered in that?

Dr. Vett Lloyd: It will not unless.... We already have a surveillance system. We have to fix it and bring together all the people who think of different ways to do surveillance, as opposed to just doing more of the same thing.

Mr. Darshan Singh Kang: Okay, you just assume that it will be the same thing. It will not be anything different. Is that your assertion about this, or is it that of the scientific community as a whole?

Dr. Vett Lloyd: If it were to be different, I would think that would be indicated in the document by saying that this is something different we can do to help Canadians as opposed to making a general statement that we'll do something.

● (1215)

Mr. Darshan Singh Kang: Thank you.

My next question is for Janet Sperling. This is about the framework as well. This is about the concerns about negative testing. Concerns about the false negative testing, you also said, have led some patients to seek private testing. The development and availability of improved laboratory testing options may reduce the current practice of some patients seeking testing in private, for-profit laboratories that may not be using standardized testing.

What is the rate of false negative test results for Lyme results?

Ms. Janet Sperling: We have no idea. That's the problem. I can't give you an idea. I know that we do have a lot of false negatives. I don't know how many of these people actually have one of the co-infections. It's possible, and this is what my research is, to look at all the bacteria in the tick, and when it comes to surveillance, I think that would be a great thing to do. We could find out that, for example, in Nova Scotia, there is a lot of *Borrelia burgdorferi* and maybe a lot of *Rickettsia*, whereas in Ontario it's a lot of *Borrelia burgdorferi* and Enterobacteriaceae, something like that, and we can march across.

As far as the false negatives go, one of the other questions is how are you defining Lyme disease? If you are defining it as two-tier positive, then we have a lot of problems here. We need to have a better grasp of tick-borne illnesses, of which Lyme disease is one.

So I know it's a high rate, but I don't know what it is. I can't give you a number.

Mr. Darshan Singh Kang: Do you have any data on how often individuals seek prior testing and how many are left in Canada?

Ms. Janet Sperling: Virtually everybody contacts CanLyme, and has gone through the current medical system. They have a real reason for believing they have Lyme disease. They seek private testing, sometimes in the U.S. and sometimes in Europe. They haven't got any better answer.

Mr. Darshan Singh Kang: How are the tests used in private testing facilities? Do they differ from those used by other health care providers?

Ms. Janet Sperling: In particular, the most famous one releases the banding pattern of the Western blot. That's the big thing it does. It also looks at two strains of Lyme disease at the same time. Here in Canada we test for one strain and the big American lab tests for one on either and then reads the blot through it so you can get more information from it.

The Chair: Thank you.

We're on our five-minute questions now.

Dr. Carrie, go ahead.

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

I'd like to thank the witnesses for being here today.

Under the the proposed framework, do you feel as if your issues as a patient have been addressed? If not, what exactly do you think this framework is missing?

Could you elaborate, please?

Ms. Jennifer Kravis: I think the framework is missing an acknowledgement of the concept of tick-borne disease, as Janet Sperling has pointed out. Multiple infections, viruses, and bacteria are all part of the disease, not just one strain. It doesn't address multiple strains of Borrelia and multiple species of ticks carrying Lyme disease. It doesn't address the reality that patients can't get help from medical doctors or doctors don't understand the disease because they're not educated. It doesn't address the fact that we need education beyond “pull up your socks and put on repellent”. We need education for people on what to do if you get bitten, how to recognize them, where you're at risk, and how you need immediate treatment.

That's the main thing.

Mr. Colin Carrie: Did you want to add anything?

Ms. Sue Faber: My bent is congenital transmission but we also need areas of the blood supply and persistence looked into.

Why would someone like me be fully treated and cured and six weeks after completing treatment be very sick again and not get help? Instead of saying that they don't know what's wrong with me, let's engage and ask questions, and figure out what is wrong with me. If it is a persistent infection let's treat it. Patients need treatment.

Let's just liken it to any other illness. If you go to the doctor with pneumonia and he says your x-ray shows a whiteout on your lungs, he's going to treat you with antibiotics. If you come back a week later and you're not better, he says let's flip over the antibiotic to something else because maybe it's resistant to this one. Doctors are trained to take a critical look at the clinical presentation of their patients, and to treat them accordingly. Unfortunately, these guidelines that are being followed basically cage doctors to not being able to do what they need to do for their patients to help them live productive lives. I would like to see that changed.

● (1220)

Mr. Colin Carrie: On Thursday, we are going to have Health Canada officials here. I was wondering if I could give you the opportunity or if there are questions you'd like us to ask them. Is there one particular question?

Sue, you mentioned you have this book that is referenced quite significantly, and you've put it in front of them. When you met with them it was as if they had no knowledge of it. It's a little frustrating for us in committee here, and we'd like to work with our colleagues in the bureaucracy.

Ms. Sue Faber: It wasn't that there was no knowledge. Health Canada reported themselves in 1988; the transplacental transmission has been documented. When I spoke with Dr. Njoo, I said his agency has known for 29 years that this is happening, and asked why they hadn't done anything about it, why it wasn't in the framework. His answer to me, if I remember correctly, was that the framework was a high-level document and therefore issues like this were minor, or—

Ms. Jennifer Kravis: It wasn't minor. It was that the framework can't go into every possible study.

Ms. Sue Faber: The framework can't go into every possible study—I correct myself.

I said, “So you mean the lives of my children and of babies yet to be born are not considered high-level, highly urgent issues?”

He did not respond to me.

Mr. Colin Carrie: How am I doing, Mr. Chair, for time?

The Chair: You have another minute.

Mr. Colin Carrie: Under the guidelines, there's a call for continued support for front-line health professionals and labs to diagnose Lyme disease. Despite the call, it's well known that misdiagnoses are a major issue.

How many people are misdiagnosed due to insufficient tests? The current framework has no money allocated for better testing. Should there be? What are the consequences of continuing to ignore positive test results coming from non-accredited labs?

That's a lot for one minute.

Ms. Sue Faber: Is that for us?

Mr. Colin Carrie: Yes, or Janet.

Ms. Janet Sperling: I think that the costs of having people being misdiagnosed are actually pretty slight because most of the people who are getting the so-called false positive result get the treatment and then they get better.

One other thing, if I could.... Why aren't the patients represented? Because there's this kind of misunderstanding. In CanLyme, we have a lot of people who are doctors, research scientists, geologists. We have a lot of people and a lot of expertise. They would love to help, but they're being blocked. They're not being taken seriously. That's my real question. Why are patient advocates blocked from being in the room, asking the difficult questions?

Mr. Colin Carrie: That's fair. It's an excellent question. Thank you.

The Chair: Your time is up now.

Dr. Eyolfson.

Mr. Doug Eyolfson (Charleswood—St. James—Assiniboia—Headingley, Lib.): Thank you, Mr. Chair.

Thank you all for coming.

My first question is for Dr. Lloyd.

You mentioned that there were examples of peer-reviewed research that was ignored. I only have five minutes, so I can't go into the details of all of it. Can you give me a couple of examples of authors and what their research has shown?

Dr. Vett Lloyd: I can't give you specifics, not off the top of my head, but I will give you examples.

Depending on which public health website you look at, you will read that the tick must be attached for either 24, 48, or 72 hours in order to transmit the disease. There are, however, reports showing transmission within 24 hours.

Mr. Doug Eyolfson: I understand what you're saying, but would you at some point in the future be able to find that information and send it to us: the specifics of who these authors are and what their research was?

Dr. Vett Lloyd: Yes. Absolutely.

Mr. Doug Eyolfson: Ms. Sperling, you mentioned the test. I understand there is the two-step test. The Centers for Disease Control and Prevention talk about the enzyme immunoassay and the immunofluorescence assay, or what's called a Western blot.

Ms. Janet Sperling: I would call EIA and IFA one level, with Western blot as another. The way I understand it, you can do a EIA or IFA, followed by a more specific Western blot.

Mr. Doug Eyolfson: Okay, that's fine.

You talked about this specific blot with the banding pattern. Is this done regularly at all centres in the United States?

Ms. Janet Sperling: Yes. Absolutely.

In order to get the diagnosis of Lyme disease, you have to have that Western blot.

● (1225)

Mr. Doug Eyolfson: Will a Western blot, without that banding.... What is the advantage of this Western blot with a banding over a standard Western blot that you would get done at a Canadian lab?

Ms. Janet Sperling: It's a Western blot, but in the case of the national lab, if you have five or more bands, it's reported as positive. If you have four or fewer, it's reported as negative. You don't know if you had four out of 10 or if you had six out of 10. All we're saying is that if people could, say.... The other thing is that one of those bands is a pretty general band. It's a p41. If that one is positive, it's much less significant than some of the other bands, which are much more specific to Lyme disease.

Mr. Doug Eyolfson: Again, it's too specific for the two and a half minutes I have left now. Would you be able to forward us the literature on the accuracy of that versus the standard Western blot?

Ms. Janet Sperling: It's the reporting of the bands.

Mr. Doug Eyolfson: Yes, the reporting. Is there literature that talks about diagnostic accuracy of one versus the other? Could you forward that to us?

Ms. Janet Sperling: Each European country has a different standard. I can show you that.

I will forward information on the different European countries. Some choose three as positive. Some choose whatever number as positive. I can send you that.

Mr. Doug Eyolfson: All right. Thank you.

Dr. Lloyd, we were talking about treatment and the guidelines we're using. There is some controversy as to how long you should be treating with antibiotics and whether chronic Lyme disease is a prolonged infection or whether there are in fact more side effects due to the original damage during the disease. I know there's controversy in the literature on that.

Both the National Institutes of Health and the Centers for Disease Control recommend strongly against prolonged antibiotics. Both of these organizations state that several well-controlled scientific studies have shown no significant improvement in outcomes with them, and a number of cases of people having had to be admitted to hospital due to complications of the long-term antibiotics. We know that antibiotics themselves have their own complications, if used inappropriately.

How do you respond to that? What is the research that refutes this from these organizations?

Dr. Vett Lloyd: There are studies that show there was no improvement with longer antibiotic use. There are other studies that showed improvement.

I would point out that with some of the studies—

Mr. Doug Eyolfson: I'm sorry, I have 30 seconds left.

Can you quote at least one of the studies that shows improvement? Can you tell me the author of that study?

Dr. Vett Lloyd: I can certainly send it to you.

I will point out that the study that showed no improvement essentially repeated a non-productive intervention, and really, if something didn't work the first time, the odds of its working the second time are remote.

Mr. Doug Eyolfson: On the NIH website there are actually several studies that they are citing. It's not just one; there are a number of studies.

Dr. Vett Lloyd: Yes. They're both by Wormser.

Mr. Doug Eyolfson: I just wanted to clarify that.

All right. My time is up. Thank you very much.

The Chair: Mr. Webber.

Mr. Len Webber: Thank you, Chair.

I'm going to refer to page 12 of the framework document. Under “Guidelines and Best Practices Key Messages Summary” it indicates that, “Doctors are constrained by the current guidelines and, in many cases, lack awareness of the disease.”

It also says, “Physicians who treat Lyme disease patients outside the existing treatment guidelines should be protected from sanctions from their licensing organization.”

Do you know of cases of doctors who are losing their licences because they're going beyond the guidelines, beyond the treatment? If so, how many are there?

Ms. Jennifer Kravis: We are aware of several doctors who have been harassed or sanctioned, not necessarily specifically for prescribing antibiotics, but sometime in other areas found during investigation. There are at least three doctors who have retired because of sanction or harassment, and there is one doctor who was investigated and harassed such that he ceased to see Lyme patients in his practice.

Mr. Len Webber: That's surprising, unbelievable actually. That is why, then, when you go they say they have nothing they can do for you: because they cannot go beyond the prescribed guidelines. That is hence why you're off to some other country to seek treatment there.

You mentioned that you spent $100,000, or hundreds of thousands, just on your treatment alone going to the States? Was it you and your children?

● (1230)

Ms. Jennifer Kravis: I spent about $300,000 on my own treatment and I have just had my kids assessed by a neurologist in Manhattan. That visit cost $15,000, to get them assessed and tested for all the different co-infections they may have, because treatment is non-effective if you're not hitting all the diseases. I've been told that they're going to require possibly one to three years of continuous treatment, which will cost tens of thousands more.

Mr. Len Webber: Wow.

Also, on page 12 the document says that there's a need, of course, for more Lyme-literate doctors.

How many Lyme-literate doctors are there in Canada who are treating? I know that Dr. Hawkins in Calgary has people lined up outside his door; he can't accept any more patients. Obviously we have a shortage of Lyme disease doctors.

Do you have any thoughts on that?

Ms. Sue Faber: One other thing I'd like to say is that there are Lyme-literate doctors for adults, but there are no Lyme-literate doctors, to my knowledge, for children. Children who present with chronic systemic illness, such as my daughters, cannot seek help or treatment here in Canada. No child can receive help or treatment with chronic systemic illness in Canada, because we are told it does not exist.

Mr. Len Webber: Going back to my granddaughter and hiking again, I suggest that all Canadians stay the heck out of the woods, if that's the case, if there's no treatment for children for tick bites.

Ms. Sue Faber: It's not that they're not going to be treated for tick bites. It's the children who weren't treated for tick bites who then get systemically ill, or the children who are born, in utero with this illness, who aren't going to get treatment.

Mr. Len Webber: Rachael, I know you had some questions. Do you want to throw anything out?

Mr. Chair, how much more time do I have?

The Chair: You have one minute and 29 seconds.

Mr. Len Webber: There are many questions I have for the health agency on Thursday and for Blood Services.

The Chair: I think Mr. Arnold would like to speak.

Mr. Mel Arnold (North Okanagan—Shuswap, CPC): The proposed framework highlights the current challenges associated with Lyme disease testing. What changes do you think should be made, that aren't listed in the framework, to testing, and so on?

Ms. Jennifer Kravis: That's a great question to ask Dr. Hawkins on Thursday. He is very familiar with the science and mechanisms of the testing. He has some suggestions on using existing testing technology under a different set of criteria, which would significantly improve testing in Canada.

The Chair: Thanks very much.

Now we go to Mr. Ayoub.

[*Translation*]

Mr. Ramez Ayoub (Thérèse-De Blainville, Lib.): Thank you, Mr. Chair.

[*English*]

I don't know if you understand French very well, but my question is going to be in French.

[*Translation*]

Let's talk about the difference in the treatment of Lyme disease and the treatment of the chronic form of this disease. There seems to be an important difference from the scientific point of view. There are nuances, and some controversy. Normally physicians try to use a science-based approach when prescribing medication, and there have been all sorts of discussions on side effects and the scope of treatments.

What is your perception of the report? How is this discussed in it? What is missing? What would you like us to support in this regard, Ms. Sperling?

Ms. Janet Sperling: I think you need to speak to Dr. Hawkins. He bases his conclusions on the clinical diagnosis, and he knows whether a person will react well or not to antibiotics. Another approach may have to be taken if the antibiotics no longer work. Doctors who are very familiar with Lyme disease can make a clinical diagnosis.

● (1235)

Mr. Ramez Ayoub: Let's compare the Canadian approach to the American one. Let's use that as an example, because there are unfortunate cases of people who had to go to the United States. They get treatment there at an exorbitant cost, that is to say close to $300,000 per person. We can't imagine paying $300,000 for each Canadian. That is beyond all reason.

Ms. Janet Sperling: That is not necessary.

Mr. Ramez Ayoub: What is the difference in treatment given in the United States and what is done—and what is eligible—in Canada? How can we get definite results that will make a difference?

Ms. Janet Sperling: The big difference is that in the American physicians may prescribe long-term antibiotics.

It is more difficult for physicians because the cost of insurance is higher. In the United States a medical appointment costs $400, whereas it costs $40 here. That is the big difference. The prescription of long-term antibiotics would not be as costly in Canada.

Mr. Ramez Ayoub: If that is the case, why is there a controversy? What is the hold up? When you speak, it seems to be obvious. What is causing the problem?

Ms. Janet Sperling: The problem comes from the fact that the diagnosis is complex; it is not black and white.

Mr. Ramez Ayoub: The diagnosis is not more black and white in the United States than it is in Canada.

Ms. Janet Sperling: The systems are different. Our system is centralized, whereas in the United States there is a great diversity.

The Infectious Diseases Society of America, the IDSA, states that you only need two to four weeks of treatment. However, another group will say that things are not that clear and that you need a third option. It depends on the medical system.

I prefer the Canadian medical system, but our system recommends two to four weeks of antibiotics and that's all. There's no diversity here and everyone does what the IDSA suggests.

Mr. Ramez Ayoub: I am almost ouf of time, so I'll ask my last question.

Education seems to be key in this situation. I am thinking of Ms. Faber's testimony.

Ms. Faber, you went to several places before you found a physician who was able to make a potential diagnosis. Do you believe that education, which is discussed in the report, will allow us to deal with this problem?

[*English*]

Ms. Sue Faber: Yes, we need to train our doctors, so that they're aware of the concern in the first place.

One of the things I actually spoke to Dr. Njoo about yesterday, which we agreed on and I'm very excited about, is that he agreed to reach out to the Canadian Pediatric Society, the Canadian Society of Obstetricians and Gynaecologists, the College of Midwives, and the College of Family Doctors to make an introduction to them on my behalf and to request that these agencies, societies, and associations meet with Jennifer and me, as patient representatives and advocates who can speak to the literature that, unfortunately, has not been available in Canada. I'm really thrilled that he has taken the initiative to do that on our behalf. Hopefully, he will also be able to introduce the reality that 29 years ago Health Canada did report congenital transmission.

I'm really excited about that forward momentum because I believe that's exactly what is required. Just as Dr. Vett Lloyd and Janet Sperling have said, patients, advocates, and people, including our researchers and our physicians, need to be actively engaged, involved, and at the table together. I really look forward to those meetings and to future progress.

Thank you.

The Chair: Your time is up. However, I'd just like to follow up with a question that Mr. Ayoub had. If a doctor diagnoses me with Lyme disease and says that I need eight or 10 weeks of antibiotics, who says he can't prescribe that?

● (1240)

Ms. Janet Sperling: The doctor can get away with it once and he might be able to get away with it twice, but eventually somebody is going to start saying, "Why does that person keep having these people to whom he keeps giving long-term antibiotics?"

The Chair: What person says that?

Ms. Janet Sperling: The colleges. Certainly, I can think of three doctors right off. They didn't go in saying that they were closing them down for their treatment of Lyme disease. They said that they were going in and investigating something else. However, they happened to take every file of somebody who had Lyme disease.

I think it really comes down to the idea that it's not the patients making the complaint. The patients are generally very happy with their doctors. It's that the other doctors are saying that this doctor keeps giving out too much antibiotic and they have to shut him down. It's happening behind closed doors.

The Chair: It's the college of physicians in each province that is the police department.

Ms. Elizabeth May: I know of one too, Bill. I can give you names later.

The Chair: All right.

Mr. Davies, you have three minutes.

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

I want to focus a bit on education and awareness. One of the basic concepts that has come out for me very strongly from the testimony here today is that, wherever the differences may lie, we're looking at a serious pan-Canadian health issue with some urgency. Ideally, I think that what we want to do is educate Canadians and try to prevent. To me, sometimes the best health approach is to prevent the disease or condition in the first place.

I'm just wondering whether any of the witnesses have any thoughts that you could give this committee, in terms of guidance about the education and awareness steps we ought to be recommending to the government, so that Canadians are more fully aware and maybe can take steps to protect themselves.

Ms. Jennifer Kravis: Prevention is absolutely key because, obviously, if you don't get bitten by a tick you're not going to get sick. The reality is that ticks are so tiny; they can be microscopic, the size of poppy seeds. It's not possible to 100% prevent ticks. Education has been great on that—pulling your socks up, staying in the middle of the path, using repellent—but the education has stopped there. People now need to know the prevalence of the risk, that it's not just in endemic areas, and they need to know what to do when they find a tick. Where do they go? What do they look out for? What are the signs and symptoms of the disease, because they are varying? They need to know the urgency of immediate treatment. As well, we need education for doctors.

The issue of children is very urgent, because kids are a very high risk group for Lyme disease, one of the highest risk groups because of the time they spend outside. We need schools to have training on how to remove ticks in the principal's office. We need summer camps to train their counsellors on how to do tick checks. There is a huge gap in the education because to date it is only focused on pulling your socks up and putting repellent on. It doesn't go any further than that.

Mr. Don Davies: You know it is often said that lacrosse is the national sport of Canada, but I actually think it's determining whether something is federal, provincial, or municipal in this country. Mr. Chair raised this issue about the impact of provincial colleges of physicians and surgeons, and obviously provincial governments, which administer health care in this country.

I am wondering, being federal politicians here, what you would advise us to do in terms of helping to get the provinces to make the kinds of changes necessary—or that you think are necessary—and whether you have specific recommendations on the curricula taught in medical schools and whether that is something you'd like to see us involved in. Are you putting pressure on provincial governments, as well?

Ms. Jennifer Kravis: We will be. We've been busy the last couple of months here.

Ms. Sue Faber: I know that Dr. Hawkins is very interested in medical education, and that is something that he is highly qualified to discuss. I'm sure he would be more than happy to be involved in the development and design of proper modules to train our upcoming medical students as well as current physicians, both family doctors and specialists.

The Chair: I want to thank the witnesses very much for coming. We have the most interesting meetings at this committee. You talked earlier of the voice of victims not being heard, but your voices were heard today. You've been broadcast all through this on the Internet, and you will be on CPAC, as well, and reruns, so you're voices are starting to be heard. That's part of our process in the committee.

I think when I met with you earlier, I told you that things take a long time here, but they do happen. I believe that process is under way, thanks to Bill C-442.

I want to say thank you very much to Dr. Lloyd. I notice you broke your pen about three times during the meeting. I'm going to make sure you get a new pen from the Parliament of Canada. I'd like you to just quicky tell us what your work is in this area, in Lyme disease and ticks. I just know you've worked on it for some time, but I don't know what your work has been; and have you had any funding from the government?

● (1245)

Dr. Vett Lloyd: I've worked primarily on ticks, so figuring out what diseases they have and essentially supporting communities so that, when people find a tick on them, we test it, because that's not necessarily available in all parts of Canada. In some parts of Canada, a tick can get tested through the National Microbiology Laboratory, but in other places it cannot.

Sorry, what was the second part of your question?

The Chair: It was about government funding: have you had funding from any level of government for this?

Dr. Vett Lloyd: Yes, I'm funded by both the federal and provincial level, as well as by the Canadian Lyme Disease Foundation.

The Chair: I want to say thank you very much, and in a second I'm going to give Ms. May a minute. I just wanted to say thank you for the good work that you've done and thank you to the other witnesses. We look forward to Thursday, which will be an interesting day, as well.

Ms. May.

Ms. Elizabeth May: I just wanted to ask Dr. Lloyd something.

You mentioned earlier that you had lists and you thought they'd be boring, but if you have lists of factual errors in the current framework, if they haven't been tabled with the committee—I'm not a member of the committee, so I don't have it, but I'm hoping—can you make sure we have them? I respect you so much, Dr. Lloyd, and I know I gave a fairly favourable view of what we could do with this framework—it may be silk purse out of sow's ear time. I think the framework dodged the bullet of being really unacceptable, which was what the draft looked like, and I think we made some progress between the draft and final. But I would like very much to know of all the specifics, particularly factual errors, that you've spotted in the framework. Thank you.

The Chair: Okay, thank you.

Again, thanks to all the witnesses. We appreciate your time very much. Thank you.

We have the thalidomide letter to deal with. We're going to go into committee business. I don't think it will take long.

We will suspend.

[*Proceedings continue in camera*]

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