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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.)): I call our meeting to order. This is meeting number 54, and we are studying the thalidomide survivors contribution program.

I welcome our guests.

Members, I want to say initially that we've passed around the list of witnesses who we invited to appear, because there was some question about why they didn't appear. There were several who were not able to. We've provided that list to members so you would understand why they're not here.

We do have excellent witnesses today. First I want to introduce them, and then we'll ask them to make an initial presentation.

We'll start with Canada's Still Forgotten Thalidomide Survivors, represented by Terry Bolton, the founding member. We also have with us Mr. Douglas Levesque, appearing as an individual. Joining us by video conference from Sweden is Mr. Ralph Edwards, professor in medicine.

We're going to start with the two witnesses here at the table. Then we'll invite Mr. Edwards to make a presentation. Each presenter has a maximum of 10 minutes for an opening statement. Then we will move to questions.

Mr. Bolton, would you like to make an opening statement?

Mr. Terry Bolton (Founding Member, Canada's Still Forgotten Thalidomide Survivors): Thank you, Mr. Casey and ladies and gentlemen.

I would like to start by thanking the Canada's Still Forgotten Thalidomide Survivors group for appointing me spokesperson for our group today and thanking the health committee for allowing me to appear as a witness.

In 2012 I was informed by a heart specialist that I had a unique condition with the organs in my heart. I was born with an extra valve, which branched off the right side of the main aorta, causing my heart to make an extra beat every time it cycled. This syndrome is known as Wolff-Parkinson-White syndrome. I remember my mom telling me that I had been born with a murmur. I was also born with phocomelia, affecting my left arm, and with an extra digit on my right hand, which was surgically removed at birth.

I had other problems at birth as well. I was and still am missing internal organs in my left eardrum, which has caused complete tone deafness from birth. The hearing in both ears has now deteriorated to the point that, as recently as 2012, I am considered legally deaf in both ears.

As an eight-year-old, I also had surgery to remove what is called Meckel's diverticulum from my intestines. This condition is known to occur in only 3% of the human population, while Wolff-Parkinson-White syndrome is known to occur only in only 2% of the population.

I started researching and found that thalidomide side effects included almost everything I have had happen to me. I went to my mother's sister, my aunt Eileen, to ask whether there was a family secret. I knew enough then to know that I wasn't just a gift from God. I needed the truth. That's when she broke down and admitted to me that my mom had taken a morning sickness drug pretty well all through her pregnancy.

I tried diligently to obtain my birth records and medical records, as requested by Crawford. As a child of eight or nine, I remember my orthopedic surgeon, Dr. John Hazlett, telling me, “We have enough X-rays of you to make six complete skeletons.” According to my birth hospital, which is Kingston's Hotel Dieu Hospital, all records and X-rays have been destroyed due to their retention policy.

I did further research and found out that there was a fire in the records building in the mid-seventies. I believe it was in April 1977, because I remember being in the hospital at that time for my 14th birthday. We were locked into our rooms because there was a fire in the basement. There were also two fires in my hometown of Gananoque, one that destroyed the pharmacy my parents used and the other at my family doctor's office.

I believe other survivors in our group have similar stories to tell.

It would really seem as though there is something more to this, but history cannot be brought back. Records can't be recovered. Most of our mothers' doctors are dead or, as I've heard in some cases in our group, fail to remember. As for prescriptions, a pharmacist with over 25 years' working experience told me that no one keeps these records after 10 years.

This now leaves me with the number three criterion: you must already be registered on a government list. After calling the number we were provided by Crawford to see if by some miracle I was on this list, I was told no.

In 1991 I was still under the belief that my problems had “just happened”, so I never sought recognition or compensation. I worked at many jobs, including jobs in factories, from the time I was 17 until eight years ago when my back gave out. I could no longer do the job I had with the Town of Gananoque.

I returned to school and obtained my AZ licence, but no one would hire me—I suspect because of my age and because they believed I could not do the job. I then went to St. Lawrence College and obtained my solar photovoltaic systems installer certificate. Basically, I can set up a solar farm and service it. Again I had the same problem. I was passed by for each and every job I applied for.

In 2003, with my mom still alive, I left her and went overseas to Afghanistan to work for the Department of National Defence. I was a civilian. I served my country that I love so much.

All I am asking here today is that the health committee see to it that the proper qualified professionals examine our medical records that we have managed to obtain and physically interview each one of us so they can make an educated decision as to whether we qualify for the compensation package that we justly deserve.

● (1105)

Finally, it's time to right a very big wrong.

Thank you.

The Chair: Thank you very much.

Now we'll go to an opening statement from Mr. Levesque.

Mr. Douglas Levesque (As an Individual): Good morning. Thank you very much for taking the time to hear our stories.

I was born on September 27, 1963, with seven fingers on each hand. The extra ones were surgically removed when I was 18 months old. I have pronounced webbing on both hands and feet, and I have extra-short feet with a 6E-plus width. My right leg is more than an inch shorter than my left leg. I've also had 13 spinal cord tumours, which were dermoid cysts or ganglions. These were referred to by Dr. McCredie on page 11 of a WHO report from the Geneva World Health Organization summit of 2014, when she talked about ganglions being evident in the spine.

I have back spasms three or four times a week—sometimes daily—and they're only controlled by medication that is not covered under our health plan. I've had two surgeries on my right ankle. I have poor circulation in both legs; arthritis and inflammation throughout my body; bowel and bladder problems; sleep apnea; hypoxia; and, ongoing intestinal problems. I have a right knee replacement scheduled for early July. I've been denied by WSIB in terms of repetitive strain in both my wrists; they refer to it as a “previous injury” because I was born with the extra fingers on both hands.

I've seen many doctors, naturopaths, acupuncturists, chiropractors, and reflexologists in my relentless search to find out what is the cause of my pain. As the years go on, it's not getting any better. I have two older siblings who are in perfect health, and there is no evidence in my parents' lineage, on either side, of anybody with extra fingers or any extra digits.

I believe that in the government's extraordinary assistance plan for thalidomide, which was brought out in 1991, all the discussion was on three criteria, but in actual fact, there were four criteria.

One of the criteria was a mother's statement, preferably sworn, that she took thalidomide at the relevant time, with an indication of its source, which was not necessarily a prescription. I am a sample baby. My mother received the thalidomide pill on two occasions, once at the Copper Cliff clinic in Sudbury, and one other time, a week later, at a hospital. Even though the drug was stopped in 1962, the doctors in the rural Sudbury area continued to use it. I have spoken to one doctor who received samples in 1964, when he took his practice to Sudbury.

I've had some of my genetic testing done through CARE for RARE here in Ottawa, out of CHEO. I don't have any results yet, because it was a research study. We will receive those results at the end of this month.

Crawford informed us, in their wording, that this is deemed final. They didn't inform us that we could appeal or anything along those lines. I really don't agree with their statement, which says that there are 167 people, because my file number was 138, and I know people whose file numbers are in the 300s and others whose numbers are in the 400s. I don't know how they do their filing system, but I think there are some inconsistencies there that we have to look at.

Also, when I called Crawford, I received no help from them. They just kept harping away on the three criteria. That was it. That was final. When I called the TVAC, it was the same situation. There was no help at all from them either.

● (1110)

It's interesting to find out how many people at Crawford had affidavits from a parent and were still denied. Crawford had a list of applicants whose medical records were destroyed either by flood or by fire. My records and my mother's records were both destroyed in a flood. When you talk to all the people who were undocumented, it's common how many people's files have disappeared by way of either fire or flood.

Thank you very much.

The Chair: Thank you very much for your testimony.

We're going to move to Professor Edwards now, by video conference.

We very much appreciate your time, Professor.

Professor Edwards is the past president of International Society of Pharmacovigilance and a frequent expert witness in legal actions relating to adverse drug effects. He was previously the director of the Uppsala Monitoring Centre, which monitors drug safety worldwide.

Professor Edwards, you have the floor for 10 minutes.

● (1115)

Dr. Ivor Ralph Edwards (Professor in Medicine, As an Individual): Thank you very much.

Thank you for asking me to be part of this important meeting.

My main interest started when I was about to become a medical student and heard, of course, of the Distillers action in the U.K. when the story of the thalidomide problem first broke. Thalidomide was in fact the start of the discipline that I've worked in since 1980, namely pharmacovigilance.

Pharmacovigilance is a discipline that looks for problems with medicines and tries to establish a causal link between a medicine and the harm. The difficulty is how to establish causation. That was the difficulty that faced the investigators in the early days in Germany and in the U.K. It's a real problem because, given the extreme disability caused or thought to be caused by thalidomide, what they were tasked with was, how do you decide on what is caused by thalidomide?

They were actually seeing individuals and trying to work out what was the causative link between thalidomide and a variety of defects. They put together what we would call a "syndrome of defects", which they were sure—or pretty sure—followed the exposure to thalidomide. Knowledge of the exposure was a critical factor. The first point I must make is that it isn't just being exposed to thalidomide: it's being exposed at a critical time, during the first three months while the baby is forming essential organs. That is a critical factor in the cause-and-effect situation: to know exactly when the drug was taken by the mother.

The second thing is that the thalidomide syndrome was rare. Therefore, each expert at the time would see perhaps a maximum of 200 patients. Indeed, in the research I'll talk about shortly, we have been able to have only around about 200 people who we're sure took thalidomide during those early three months of pregnancy, so therefore we could be as sure as we possibly could be that there was a cause-and-effect relationship.

That work was done a long time ago. Things have moved on since then. It's important to note that there's a kind of gap. We do know that thalidomide is still being used for inflammatory diseases and cancer, but that usually means that it's not given to women of child-bearing age.

● (1120)

It is used in the treatment of leprosy to counteract the negative effects of Dapsone, and therefore it is given to some young people. In Brazil, for example, we know there are about 400 women who have had children with the obvious features of thalidomide exposure. The trouble is that we haven't been able to look at them closely because they're in rural areas and the facilities haven't been made available for us to update our knowledge.

I was asked by The Thalidomide Trust in the U.K. if I would help them bring together a meeting of experts within the WHO umbrella to see what we could firmly state about the cause-and-effect relationship between thalidomide and congenital defects. The short answer is that we were only really able to confirm for sure what was thought all those years ago.

There is research, and it was actually all presented at a meeting, about the way in which the thalidomide-type drugs might affect a growing embryo, and it's in all sorts of ways. Unfortunately, that is only experimental work, and we're left with a feeling that there might be more. There is some excellent work going on, but as I say, we don't have anything that goes from the experimental work in animals and other models to what happens in human beings who are exposed now.

There is a final thing I want to say by way of introduction. When the thalidomide embryopathy was first discovered, it was thought that it was going to be unique because it was so rare. People were saying that it only occurs with thalidomide, that it doesn't occur naturally. Since then, we've found that unfortunately there are genetic reasons that similar limb reduction and other defects can occur because of a family history of genetic problems. That makes it very difficult.

I think I would prefer to answer questions, but I want to mention one thing. We have worked out a "decision tree" way of making a diagnosis of the conditions that might be caused by thalidomide in a human being, based on this historic evidence and based on Europeans. It really only confirms the very limited views that we have about the effects that are well known to be caused by thalidomide.

● (1125)

We haven't been able to say any more. Indeed, what we have been able to say is that some of the conditions where thalidomide has been a possible cause have in fact been explained by other genetic problems. Genetic testing is a key issue.

As I say, I think I would prefer to answer questions.

The Chair: Thank you for your initial remarks. We appreciate them very much.

Now we're going to seven-minute rounds of questions.

Mr. Oliver.

Mr. John Oliver (Oakville, Lib.): Thank you.

Thank you for your testimony today and for coming in and talking to the committee and sharing very personal health stories and health conditions with us.

Also, thank you, Doctor, for your testimony.

As an opening statement from me personally, as a member of the committee, I'd sooner see the Canadian compensation plan err on the side of compensating people who perhaps weren't necessarily thalidomide victims rather than err on the other side of denying compensation to thalidomide victims. I'd sooner see the error happen in that positive way.

Nevertheless, both in 1991 and in 2015, the criteria in Canada were limited to the knowledge of exposure and proof of exposure to the drug. We have heard from other witnesses that other countries have used more of a mixed model.

Both of you began with testimony about your health factors and conditions. Can I conclude from this that you both would present those birth conditions as being in the cluster of thalidomide-like birth defects that would fall into these medical evaluation criteria?

Mr. Terry Bolton: Yes. I believe that for the conditions that we both show or whatever, if you were to look into the research that TVAC has done, all these things are listed.

Mr. John Oliver: TVAC is the Thalidomide Victims Association of Canada. Unfortunately, I don't think we've had testimony from the association, but can I conclude, then, that there is a list of the cluster of symptoms—

Mr. Terry Bolton: Yes.

Mr. John Oliver: —that the Thalidomide Victims Association has identified as being likely consequences of thalidomide exposure?

Mr. Terry Bolton: Yes.

Mr. John Oliver: Okay.

Dr. Edwards, I have in my notes here that in 2014 the World Health Organization held a meeting of experts on thalidomide embryopathy to try to develop diagnostic criteria for thalidomide embryopathy. Were you part of that group? Do I understand that you were the convenor?

Dr. Ivor Ralph Edwards: Yes. I convened it and chaired it.

Mr. John Oliver: I thought I heard you say the outcome of that was there were limited conditions that you felt would be verifiable as thalidomide exposure conditions. Did I understand that correctly?

Dr. Ivor Ralph Edwards: Yes. They, of course, are the well-known ones: limb reductions, hearing problems, some cardiac problems, small jaw, and all of these things.

The problem we all have is that it's a catch-22. Those things that were recognized by the experts were the things that stood out. Other things that were included didn't happen very often and didn't happen with all of the victims, so we're left with a group of conditions that could easily be caused by something else, something more common than the exposure to thalidomide. That is the scientific difficulty.

Mr. John Oliver: One of the other witnesses talked about genetic screening. Genetic screening isn't necessarily saying "yes, thalidomide". It's saying no, that it's probably related to another cause. If you bring in genetic screening, will that winnow down the population we're unsure about?

● (1130)

Dr. Ivor Ralph Edwards: In our research subsequent to the meeting, where we tried to devise a diagnostic algorithm to help us, we certainly conclude that genetic screening is a very important tool.

Mr. John Oliver: Looking forward, then, if we were to re-engage with a program here in Canada that added an element of clinical evaluation and screening on top of the eligibility criteria we have, there certainly would be a body of some limited conditions that would be reasonably strong indicators of thalidomide exposure. If you coupled that with genetic screening to ensure that it wasn't related to other underlying causes, would you recommend that as a way to make our program a bit more robust?

Dr. Ivor Ralph Edwards: I think so, yes. That's exactly what we did. It's our main finding, the genetic screening and of course the family history, which obviously is linked with the genetics. Yes, I think it's important.

Mr. John Oliver: Mr. Bolton, you indicated that you felt that for those who had been denied, there should be a review by proper qualified professionals. Has the Thalidomide Victims Association identified that pool? Are there Canadian experts on this that you have identified who would be able to review clinical conditions where the proof of exposure is no longer available?

Mr. Terry Bolton: The only experts I've come across are the three we've had here so far. I don't know if there's anybody in Canada.

Mr. John Oliver: Okay.

Mr. Levesque.

Mr. Douglas Levesque: The geneticist who comes up twice a year from Toronto to Sudbury said there was one in B.C., but we're talking over 50 years ago now, since this became evident. Most of these people who did have any knowledge about it are all retired now, so I'm not aware of anybody.

Mr. John Oliver: Okay.

In terms of my earlier question, Dr. Edwards, if you were to give direct advice to the committee or that we could pass forward, it sounds like there is a limited cluster of like conditions that would qualify people if they don't have records. With a genetic screening test to confirm their cause, do you think that is sufficient to deal with the unrecognized group? Or do you feel that's inadequate?

Dr. Ivor Ralph Edwards: It won't really deal with the unrecognized group. As I said, the hard evidence tells us that the extreme limb reduction, the deformities, and the deafness stand out as things known to be caused by the drug. The rest is speculative. We have other possible causes—as I said, the genetic causes in particular and the other embryopathic drugs that we ought to take into account.

The Chair: Mr. Brown.

Mr. Gordon Brown (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC): Thank you very much, Mr. Chairman. I want to thank you for your leadership on this issue and the committee for undertaking this study.

Thank you to our witnesses for their presentations today.

I also want to say that I am very encouraged that Mr. Oliver told us that he would rather see us be more inclusive than work to exclude people. I know that Crawford's directive was quite clear in terms of the criteria.

Unfortunately, Mr. Bolton and Mr. Levesque, you were unable to meet the criteria. When we come up with some recommendations coming out of this study, I think we should recommend to the minister to direct Crawford to be more inclusive, with the opportunity to try to include people such as you, who have had challenges in finding the documents to meet the criteria.

Mr. Bolton, I understand from your presentation that you have missing documents. You've told me this a number of times, so obviously that's correct. Can you describe what you were able to find and what you were able to present to Crawford?

● (1135)

Mr. Terry Bolton: I was able to present Crawford a photocopy. I still have the hard copy with me right now. It is right from the registry at Kingston's Hotel Dieu Hospital. It states right on there that I was born with a deformed left arm and an extra digit that was removed right at birth. I still have the scar.

Mr. Gordon Brown: We heard from Mr. Johnson the other day at a previous meeting on this study that if thalidomide was present and available in certain areas and if a mother took it during that period of time, there was a high degree of confidence that it could be the cause of phocomelia and other health challenges like those you've been facing over the years. I was quite happy that this was in fact his view.

To me, the real issue is that Crawford is hamstrung because the directive from the government is to meet the criteria. If this committee makes a recommendation to the minister to direct Health Canada—and then by extension Crawford—to undertake in-person interviews and examinations.... I think that's what your group has been asking for. As you know, I've met with your group. You had about 15 or 20 members come to Ottawa in October. That was exactly what they were asking for. Is that correct?

Mr. Terry Bolton: Yes.

Mr. Gordon Brown: One of the questions would be, first of all, have you had a genetic test?

Mr. Terry Bolton: No. As of yet, I have not.

Mr. Gordon Brown: Would you be willing to submit to that?

Mr. Terry Bolton: If I could come up with the money to afford it, yes, I would be more than happy to have a genetic test.

Mr. Gordon Brown: Okay. In your view, how should the criteria be changed so they would be more inclusive of the people who are, as we clearly have heard with a high degree of confidence, victims of thalidomide? How do you think those criteria should be changed by Health Canada?

Mr. Terry Bolton: For the criteria, they can leave the three pre-existing ones—everybody knows that we're not going to make those anyway—but they need to include another one, because when we were first given this package, they told us that if we didn't meet the first three, there was a condition five, where, if we submitted our medical evidence, they would take that t into consideration. I don't know if they even looked at it or who looked at it.

Mr. Gordon Brown: When you were rejected, you were given an opportunity to reapply, but with no change in the criteria, that was really a moot point.

Mr. Terry Bolton: Yes. When I phoned Brenda Weiss from Crawford to inquire about my rejection letter and its saying that it was deemed final, she suggested that I go to my previous family doctor, who is now in Oshawa, and try to get him to sign an affidavit that he saw something in my records stating that there was thalidomide exposure. If my records were destroyed in 1975 in that fire, there wouldn't have been anything in there anyway.

Mr. Gordon Brown: Right. In fact, Mr. Bolton, I remember that fire at the pharmacy and the one at Dr. Miller's at the time.

Mr. Terry Bolton: Yes, Dr. Miller.

Mr. Gordon Brown: I can attest that those fires in fact happened.

Mr. Levesque, do you have any views on the challenges you faced dealing with Crawford?

Mr. Douglas Levesque: On dealing with Crawford, they just kept coming back with the three criteria. They said that if I could get a letter from a doctor.... Well, most doctors are retired. The one doctor I did speak to said that when he started his practice in Sudbury, he received a sample of thalidomide from a distributor in 1964. With doctors being old school, and with the technology back then, a lot of them didn't get the message.

● (1140)

Mr. Gordon Brown: They were not offering an opportunity to have an in-person interview. Basically, it was a final decision, and unless you could meet the criteria, there was no opportunity to continue with your claim.

Mr. Douglas Levesque: That's correct.

When I submitted a sworn affidavit from my mother, they said it wasn't good enough. Even though it was part of the criteria in 1991, it was not good enough for today's day and age, because it's only the three criteria that are set out today.

Mr. Gordon Brown: Right, so it simply rests on the Minister of Health giving Crawford the directive to make this more inclusive.

Mr. Douglas Levesque: Yes.

The Chair: Thank you.

Mr. Davies, go ahead.

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

Thank you to all the witnesses for being here.

Mr. Bolton, I want to start with you. Mr. Levesque I think already made a reference to the potential number of claimants, of forgotten survivors. Do you have view on this as to how we can help put some shape on how many people in Canada we're talking about who are likely thalidomide survivors but who have not received compensation? Do you have any idea of how many people that might be?

Mr. Terry Bolton: I wouldn't want to speculate, but from what I've heard, and judging by the way I grew up and tried to basically hide this, I believe that there are a lot more than 400 of us out there. As to whether they're still living or not, that's the other issue.

For this Wolff-Parkinson-White syndrome that I mentioned earlier, there was a 40% mortality rate at birth for thalidomide babies. They now believe that what was causing it was this Wolff-Parkinson-White syndrome. Like I said, it only occurs in 2% of the population. It states right on the TVAC site and in other medical journals I've read that it's more so in people exposed to thalidomide.

Mr. Don Davies: I see.

Our information prepared by our analysts suggests that 167 individuals applied to the contribution program, to Crawford, and were informed by Crawford that they did not meet the program's eligibility criteria.

Mr. Levesque, you seemed to suggest through the file numbers that you think there are more people than that who have been rejected by Crawford.

Mr. Douglas Levesque: Yes, I believe there are more people, because I've heard of people with file numbers in the 400s and some with their file numbers in the 300s. Mine was file number 138, and I filed in the middle of May. Also, with there being a distribution of over six million thalidomide pills in Canada at that time, you would think that the numbers should be a lot higher than they actually are.

Mr. Don Davies: Do either of you know if there's any kind of relatively accurate number? Or is it your view that there are thalidomide victims out there who have never applied because they're just not aware?

Mr. Terry Bolton: They're afraid to come forward.

Mr. Don Davies: They're afraid to come forward. Okay.

Mr. Bolton, my other question is, did you or Mr. Levesque apply in 1991 when the extraordinary assistance plan was established?

Mr. Terry Bolton: I personally did not because, as I've stated before, at that time, I was still under the impression that this “just happened”.

Mr. Douglas Levesque: My mother was told when I was born that I was gifted. It was just their way of pushing it under the carpet type of thing....

Mr. Don Davies: Okay. Thank you.

Dr. Edwards, like in most things scientific, it sounds to me like one can never be 100% sure that there's a causal connection between taking thalidomide and the subsequent birth consequences. Am I correct in that?

Dr. Ivor Ralph Edwards: You're absolutely right, and this is a particularly difficult thing because of the rarity of the condition and the fact that it happened so long ago when there was very little understood about any of these things.

I've often thought that it's sad that the scheme was ever introduced, in the sense that it's picking out one cause of serious birth defects when of course anyone who has a birth defect needs special assistance and they don't get it.

● (1145)

Mr. Don Davies: Right. Well, I very much agree with my colleague Mr. Oliver in that I think we're coming down to a policy decision where my view as well is that it would be far wiser to err on the side of providing compensation to people who clearly have consequences, birth defects that have occurred. Regardless of the origin, I'd rather see them compensated than prohibited from getting compensation, simply because we can't be certain, and in any event, it sounds like we can't be.

Dr. Edwards, even if we knew that a mother took thalidomide in 1963, and even if that child was born with the cluster of symptoms, scientifically we still can't be 100% sure that there was a cause-effect even in that case, can we?

Dr. Ivor Ralph Edwards: Certainty is very elusive in medicine in general. The issue really is a rather rare one, in the sense that there are only a few weeks in those first three months of pregnancy when if someone took thalidomide there's a good chance that they would get the problem.

Also, one thing we don't know is how many people took thalidomide during pregnancy and never got a problem. Those are the scientific issues, so—

Mr. Don Davies: I want to ask your opinion, Doctor, but I keep interrupting you. I'm sorry, but there's a delay here.

Dr. Ivor Ralph Edwards: No problem. Go ahead.

Mr. Don Davies: It seems to me that the criteria established by the government are extraordinarily narrow. It essentially comes down to how one must have documentary proof that the mother took thalidomide, and it excludes what I think I'm going to refer to as probability factors. I'm going to ask you about those probability factors.

If we knew a child was born with the cluster of defects that are associated with thalidomide syndrome, if we knew the mother was pregnant at a certain time period when we knew thalidomide was being prescribed, and if we knew the mother was in an area where we knew thalidomide was being distributed, would you suggest that those probability factors would be a better test than simply relying on a piece of paper that proves thalidomide was dispensed at that time?

Dr. Ivor Ralph Edwards: Yes. Of course, you should be able to view the work that was done in our meeting and after the meeting in relation to this, but the direct answer to your question is that we would be roughly 95% sure, given everything you've just said, that the person was damaged by thalidomide.

Mr. Don Davies: My time is up. Thank you.

The Chair: Dr. Eyolfson.

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

Thanks to all of you for coming today.

Dr. Edwards, before this, we were talking about genetic testing. We were speaking with another witness who has found that it is unlikely to find actual genotypical abnormalities when the embryopathy is due to thalidomide.

You've just said that if you had a given syndrome of abnormalities and all the criteria that Mr. Davies talked about, you would have probably a 95% probability that it was thalidomide. If you had someone in this group, and your genetic testing then showed no abnormalities, would that even further increase your likelihood that this is thalidomide and not a genetic cause?

Dr. Ivor Ralph Edwards: Yes, of course. The thing is, there are a number of genetic syndromes that we get to find out more and more about, where the syndrome is really very close to thalidomide, with the limb reduction that's so typical of thalidomide, but there are differences, and certainly a genetic cause has been found in several of them.

● (1150)

Mr. Doug Eyolfson: Are you saying you know that there are these non-thalidomide causes—these genetic diseases—and it is straightforward to find a genetic cause for those syndromes?

Dr. Ivor Ralph Edwards: Yes. They're known, and the genetic testing is relatively straightforward and gives a fairly clear result.

Mr. Doug Eyolfson: Okay. Particularly in these cases where we cannot find medical records—because, as we've said, it's so long ago, back in the days of paper records and with fires and floods happening—would you advocate for a combination of physical examination and genetic testing to further increase your probability that this is thalidomide?

Dr. Ivor Ralph Edwards: Well, my difficulty is that I really have trouble...and I think this is what we all feel: if someone has severe limb reduction deformities—no arms, no legs—and it's due to a genetic cause, what do we do? Do they not get compensation?

I think what we're doing is really trying to find out whether thalidomide caused this rather than thinking about their disabilities. That's a political and social problem, not a scientific one. I've tried to give you a scientific causal view about it. We would, for example, rule out your two witnesses today. I have every sympathy for them, but they would not pass the test, because they don't have more than a fifty-fifty chance of being able to prove their exposure, and their disabilities, I think, could be much more likely to be due to things other than thalidomide exposure.

Mr. Doug Eyolfson: Absolutely.... How do the criteria we have in Canada right now compare with those of other jurisdictions, such as European jurisdictions, in terms of their programs?

Dr. Ivor Ralph Edwards: I'm not familiar with the Canadian.... The only things I'm really familiar with are the U.K. and Swedish jurisdictions. They are about the same as you are. I think there's a feeling that people with some ocular disturbances and also a hearing disturbance with the loss of the external ear are more likely to be compensated in Europe now.

Mr. Doug Eyolfson: All right. If I hear you, you are of the belief that it is appropriate to compensate when you have a series of these abnormalities, and that you shouldn't have to rely on the confirmed use of thalidomide. Is that correct?

Dr. Ivor Ralph Edwards: That's what I feel as a human being and as a physician. As a scientist, I ask the question, “Was this caused by thalidomide?” I really would want proof that the mother had taken thalidomide at the right time.

Mr. Doug Eyolfson: Yes, but as a physician, you would agree with the criteria that Mr. Davies talked about. If you had a likelihood of probability—the baby was born at the time and in an area where it was being distributed—you would have enough to say as a physician that, yes, this is someone who should be compensated.

Dr. Ivor Ralph Edwards: That's what I would guess because, as I say, we've done our scientific work on the basis of a fifty-fifty probability that the mother did take the drug and then on the other criteria that we all know about.

● (1155)

Mr. Doug Eyolfson: All right. Thank you very much.

The Chair: That completes the five-minute round.

Dr. Edwards, I just wanted to point out that the reason we're homing in on thalidomide victims is that in 1991 the Government of Canada created an extraordinary assistance plan, and I believe it was because Health Canada approved the drug and some other countries did not. I think there was a feeling of responsibility specifically for thalidomide victims. That's why we're homing in on thalidomide victims.

Now we'll go to our five-minute round, starting with Dr. Carrie.

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

I want to take this opportunity to thank the witnesses for being here today. I also want to thank Gord Brown for his persistence in getting this to committee.

As well, I'm very pleased to see a lot of political goodwill, because as the chair just said, the purpose of the program was to right a historical wrong. We around the table understand that science evolves, and the government originally put forth their criteria before that WHO meeting in 2014. I'm really pleased to have Dr. Edwards here as an expert on pharmacovigilance to give us some advice. That's what I'm going to be asking questions on.

Dr. Edwards, could you give us some insight? For Canada's program, to meet eligibility, you basically had to have one in three eligibility requirements. As my colleague Don Davies said, at the end of the day, it's going to come down to a political decision, a policy decision. What advice would you give the minister if we're going to revisit the criteria?

From your experience, how do the eligibility criteria for the thalidomide survivors contribution program compare with the eligibility criteria and assessment processes of similar compensation programs for thalidomide survivors in other jurisdictions?

What advice could you give us and give the minister?

Dr. Ivor Ralph Edwards: To answer the second bit first, the criteria have been and still are the classic phocomelia and some others. I won't read them out, but there are half a dozen criteria that pick out the most obvious candidates who sometimes have other problems. They are pretty strict criteria, but they are dependent on a clinical view of the patient, rather than.... It seems as though your criteria are based on some evidence of exposure being accepted by some organization that I didn't quite understand—

Mr. Colin Carrie: I'm sorry for interrupting you, but maybe I can clarify with regard to our criteria. You mentioned that genetic testing is a key issue, for example, and for our criteria, the government developed the criteria before the results of the 2014 WHO meeting that you of course were part of. For example, for our witnesses here, nobody really contacted them and had an in-person interview or did a physical examination. Should we be adding these things? If the minister makes the decision to revisit this, what other things should we put into that criteria, perhaps, that are not in there now?

Dr. Ivor Ralph Edwards: I would go for genetic testing, but certainly physical examination. I don't see how you can reject someone without a physical examination.

The one key factor, though, is going to be what are the conditions that have been reported in some of the thalidomide victims, such as ventricular septal defect in the heart, the so-called hole in the heart. That is very common in society in general, but it does occur in these people exposed to thalidomide, so what are you going to say? If you compensated everyone who had a VSD, you'd have a huge number of people coming to you. That, I think, is the difficulty.

● (1200)

Mr. Colin Carrie: I agree.

How am I doing for time, Mr. Chair?

The Chair: You have six seconds.

Mr. Colin Carrie: Six seconds? Maybe next time.... Thank you.

The Chair: Mr. Ayoub.

[*Translation*]

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

Like everyone here, I thank you for your testimony, gentlemen. Thank you for joining us.

I am deeply touched by the situation you experience on a daily basis.

Allow me to establish a parallel with the Canadian justice system, which considers an accused person innocent until they are found guilty. So they are considered innocent until proven otherwise. With this in mind, the last time the committee met, I suggested that the burden of proof be reversed, so that it would rest with the government instead of with victims. So the onus would be on the government to prove the fact behind its decision to compensate someone or not.

At the very least, I prefer for someone who is not a direct victim of thalidomide to be compensated, rather than to have a situation where thalidomide victims fall through the cracks and cannot obtain financial compensation because they do not meet silly and mean criteria. Those criteria don't always take into account the situation your family and you go through every day.

I was wondering what you thought about that proposed change to the way it is decided whether compensation would be provided or not. I think that a similar change should have been made a long time ago, but when compensation is involved, a government will often consider the budget aspect. It has to establish budgets and set certain limits.

Time is running out when it comes to this issue; the facts can go back 50 or 60 years. As we were told earlier, some people may have suffered the effects of thalidomide and were never compensated, but they are no longer among us. There are fewer and fewer victims. I think that we should make a significant change to the compensation process.

I would like to know what you think about that suggestion to compensate survivors of thalidomide.

[*English*]

Mr. Terry Bolton: I'm not sure if anybody has changed the criteria yet. I would like to see the genetic testing included, and I would also insist on a physical examination, because you can't diagnose something from a piece of paper.

[*Translation*]

Mr. Ramez Ayoub: Have you suggested those types of criteria changes in the past, be it to Crawford & Company Canada or to the Department of Health? If so, when did you do it?

[*English*]

Mr. Terry Bolton: Well, I have suggested it to Crawford, to which they just basically said that “this is what the government gave us, this is what we've got to stick to, and we ain't changing it”.

Mr. Ramez Ayoub: When did you ask them?

Mr. Terry Bolton: It was right after I received my rejection letter.

Mr. Ramez Ayoub: When did you receive your rejection letter?

Mr. Terry Bolton: It would have been in approximately mid-June of last year, 2016.

[*Translation*]

Mr. Ramez Ayoub: In your particular case, why did you not apply or were slow to apply for compensation? Compensation was first provided in 1991. You talked about it, but I would like you to elaborate.

[*English*]

Mr. Terry Bolton: As I said before, in 1991, I was made aware of this thalidomide program. To be honest with you, at the time I didn't even know what thalidomide was. I went to my mother and asked her, and she said, “Terry, I told you that when you were born, you were born that way, and you were a gift from God.” I didn't argue with my mother.

Mr. Ramez Ayoub: Is it the same thing for you, Mr. Levesque?

● (1205)

Mr. Douglas Levesque: It was the same thing for me. I never pursued this until I was told by a naturopath that they couldn't do anything for me. In any testing they did with me, they got the opposite results. When I mentioned to them that my mom did take a pill in her first trimester on a couple of occasions, they said that was probably my problem. I've been travelling about an hour and a half to see a naturopath, because the one expert in Sudbury that everybody goes to see can't do anything for me.

The Chair: The time is up.

Mr. Ramez Ayoub: Thank you very much for the testimony.

The Chair: Dr. Carrie.

Mr. Colin Carrie: Thank you, Mr. Chair.

Doug, I want to ask a bit about when you were rejected. They gave you 60 days to resubmit. Did you do that? What happened? Did anyone contact you, interview you, or meet with you in person?

I am also going to ask whether you were offered a judicial review. My understanding is that this is one of the things they.... Were they supposed to offer that type of thing? Do you know?

Mr. Douglas Levesque: They never mentioned anything about judicial reviews. After I submitted originally, they gave me 60 days. I scrambled, looking high and low for more evidence to meet the three criteria. I had nothing else but what I had given them initially. In their rejection letter, they said, “Our decision is deemed final”. There was no appeal process. There was nothing, they said, that could be done.

Mr. Colin Carrie: I'm not sure whether you were asked this already. I know that Gord asked Terry about it, but did you get a genetic test done? Is it something you would submit to?

Mr. Douglas Levesque: I have been involved in genetic research testing through CHEO. They have a department called CARE for RARE. It's currently wrapped up now, but I'm sure they might be willing to open it up to people who were undocumented and people who are thalidomide victims as well. I'm sure that if we contacted them, something probably could be done. Their testing, with their research, is more in depth than standard genetic testing.

Mr. Colin Carrie: From the important testimony that you and our other witnesses have brought forth, I think everybody can see that there is definitely a lot of political goodwill around the table. I want to thank my colleagues, especially those on the government side, for allowing us to come forward with this study.

Doug, if you could give advice to the minister, what would you be asking her if you had her in front of you?

Mr. Douglas Levesque: For me, my main question, not to be greedy or anything, is that in 1991 there were four criteria and now there are three, so if I had submitted an affidavit from my mother in 1991, I would have been accepted. In terms of today, that wasn't part of the criteria. I didn't know about any of this in 1991. It has only come to light in the last four or five years.

Mr. Colin Carrie: I think we've gotten a good overview, because when you're looking at it with the best science.... Science always evolves. We had this meeting in 2014, and even though we can't prove negatives, by taking a look at things.... That's why we deal with null hypotheses in things like this, and with probabilities. I want to thank you for that.

In my last minute or so, I know that Ms. Harder had a question that she wanted to ask the witnesses as well.

The Chair: You have 46 seconds.

Ms. Rachael Harder (Lethbridge, CPC): All right.

I was wondering if, for the record, each of you could give a brief description of the impact that this has had on your daily life.

Mr. Terry Bolton: Are you referring to this recently...? Or do you mean what we've had to deal with all our lives?

Ms. Rachael Harder: Exactly.

Mr. Terry Bolton: All our lives, we've been left out.

We've been denied organized sports, because the people who run those sorts of things were afraid we'd get hurt if we played. In terms of jobs, I'm not bragging or anything, but I have quite an education, and I have gone for jobs that I know I was more than qualified for. They would basically tell me that I seemed to be the right candidate, and then I'd never hear from them again. I know it's discrimination, but you cannot prove it unless they come right out and say it.

● (1210)

Mr. Douglas Levesque: Over the years, I've been left out of sports and left out of functions, even weddings. I couldn't stand at weddings because I walk with two canes.

I have an employer who is very sympathetic. Over the last 26 years, I've missed between a year and a half and two years of work. In a lot of places, that would be frowned upon. I'm going to be missing another three or four months starting in July because I'm getting my knee replaced.

It goes on and on. It would be nice to have this settled for retirement.

Ms. Rachael Harder: Thank you very much.

The Chair: Thank you.

Ms. Sidhu.

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

Thanks to all our witnesses.

Mr. Bolton, my question is for you. You mentioned that TVAC has a list of conditions that they align with exposure to thalidomide. Were these ever submitted to Health Canada or presented to Health Canada when the 2015 program criteria were being developed?

Mr. Terry Bolton: I'm not sure if Health Canada has been made aware of them, but these are all things that are listed in medical journals, one published in 1963, I believe, that stated a lot of the different conditions that can occur with thalidomide. However, in 1963, when they did this, that was apparently when they took this government list as well, to find out.... I was an infant, maybe a couple of weeks old, when this was done.

A lot of us were missed. In 1962, they thought they would take the drug off the shelves. Well, in small towns like the one I grew up in, I can go and get a loaf of bread that's probably been on the shelf for two years. Things don't happen that quickly in small towns. A lot of us were born after it was pulled from the shelves.

Ms. Sonia Sidhu: Mr. Levesque, in an earlier committee meeting, we heard that applicants whose claims were denied had 60 days to resubmit their applications. Do you think that is enough time for you to resubmit your application?

Mr. Douglas Levesque: Well, with the stringent criteria, whether it was 30 days, 60 days, or six months, there's nothing to be found for the criteria that we have. We can't jump through hoops when our stuff was destroyed in floods or fires and when there's only a 10-year retention on medical records.

Mind you, I still have all my records from when I was at Sick Kids hospital, from when I was 18 months old until I had my last surgery there when I was 23 years old. I was an exception in this case. I was treated by Dr. Hoffman, who was a world-renowned neurosurgeon. After I left his realm, I went to see Dr. Moulton, who operated on me at St. Michael's Hospital. Three years ago, I was operated on here in Ottawa, again by Dr. Moulton. There are only certain doctors who I would let touch me, because in small towns, as Terry said, we don't have the expertise, and the knowledge isn't there.

Ms. Sonia Sidhu: Dr. Edwards, even the WHO states that approximately half of all birth defects cannot be linked to a specific cause. You mentioned the ventricular septal defect, the hole in the heart, and other things. What do you think about how these symptoms are related? Without documented proof, what are your thoughts about that?

Dr. Ivor Ralph Edwards: On symptoms, I'm always bothered by that question. As a human being, I want to give the benefit of the doubt to my patients. As a scientist, though, I have to say that if you don't know, for instance, whether or not someone has taken a particular drug, I don't see how you should ever say, “Well, this is caused by the drug.” It is opening a loophole in logic and science that you would never be able to justify, I don't think, not scientifically, anyway. That, I think, is the problem.

In countries like Taiwan and Japan that run a so-called drug relief system, if someone has an adverse effect from drug and it's reported, they decide whether that person should be given any special aid. I rather like that scheme. It's a no-fault compensation scheme...well, it isn't a compensation scheme: it just makes sure that the kinds of disasters that our two witnesses talk about in their lives are remedied as far as is possible.

● (1215)

The Chair: Your time is up.

Mr. Davies, do you have a final question?

Mr. Don Davies: Thank you.

Dr. Edwards, to make sure I understand, is there a genetic test that can exclude thalidomide embryopathy?

Dr. Ivor Ralph Edwards: No. [*Technical difficulty—Editor*] as I've said before, the competing probabilities in any causality statement that you make. What you can do is to do a genetic test so that you know that this gene causes this kind of problem, and then look at the family history and see whether this has occurred before in the family. Then you're on as a solid ground as you can be to say that the genetic thing was the cause, not the drug.

Mr. Don Davies: Can it be said, Doctor, that there is a consensus of diagnostic criteria for thalidomide embryopathy?

Dr. Ivor Ralph Edwards: We have that. It's in the meeting document and, as I say, a little amplified by our work, which is.... Yes, we have that, but the thing is that it's there to be as sure as possible. We can give the probabilities of other things being included, but you would never be sure that they were due to thalidomide.

Mr. Don Davies: Well, fortunately or unfortunately, we're not scientists at this table. We're policy-makers, and I think the task before us is to try to provide good public policy to determine which Canadians are entitled to compensation. It seems to me that.... Just in this meeting, I've written down a number of symptoms that are associated with thalidomide embryopathy: extra digits, webbing, cysts or ganglia, shortened limbs, inflammation, bowel or bladder issues, gastrointestinal issues, certain cardiac issues, hearing loss, small jaw....

If we're trying to figure out if it's likely that someone was a victim of thalidomide, would it not make sense that if they were born in a place in Canada at a time when thalidomide was being dispensed, if they're in a region where it was being dispensed, if they present to a doctor with not just a hole in the heart—your example is well taken—but a cluster of symptoms, and if they have a number of the symptoms in this cluster, we can be reasonably sure that cluster was likely caused by thalidomide and then qualify them for compensation? If you add in the genetic testing, wouldn't that be a reasonable approach, perhaps not with scientific certainty, but as a policy-maker?

Dr. Ivor Ralph Edwards: I have every human sympathy with it. I listened to the two witnesses, and I have a lot of sympathy, but you will open the floodgates. You will have lots and lots.... One of the things, for example, that has been found in the experimental work is that thalidomide causes an increase in clubfoot in animals—now, that's in animals.

If you were to say that every person with a clubfoot should be compensated, you will cost the health care—

● (1220)

Mr. Don Davies: But I'm not, Doctor. I'm talking about having a preponderance of.... I listed off a dozen things, and these witnesses have a number of them. If a person has extra digits, and webbing, and a small jaw, and hearing problems, and cardiac problems, and they were born at the time when thalidomide was.... That's the kind of thinking I'm having.

Dr. Ivor Ralph Edwards: We could work out the probabilities of that and therefore have a rational basis for compensation. I'm not saying it would be easy. The rarity of all of this makes scientific work very difficult.

Mr. Don Davies: Thank you, Doctor.

The Chair: Your time is up.

That concludes our 54th meeting and our questions and testimony from our witnesses.

I want to thank all of you for taking the time to do this. It's been very enlightening for all of us. I'm not sure where we'll go from here, but as a committee we will analyze all the information, and we'll write a report and make some recommendations, if that's the conclusion of the committee.

I especially want to thank Professor Edwards for taking the time to do this from Sweden.

We want to thank the technicians who have so successfully communicated with us and have made the communications available, which have been very good.

With that, I will conclude our meeting on thalidomide. We'll go into committee business for a minute, but we'll take a second and let the witnesses pack up. I believe Mr. Webber has an issue he wants to raise, and we'll do that.

Again, thanks very much. The meeting is suspended.

● (1220)

(Pause)

● (1225)

The Chair: We will come back to order.

I want to make sure everybody knows that we're going to do drafting instructions for this thalidomide study. If anybody has recommendations on changes or recommendations that we want in the report, we should have them prepared for May 18. That's a week from today. We're also going to do clause-by-clause on Bill C-211 that day. We're going to have witnesses for Bill C-211 on Tuesday.

That's it, but again, if you have some thoughts on this issue, we'd sure like to have them.

Mr. Webber, I understand you have a motion.

Mr. Len Webber (Calgary Confederation, CPC): I do, Mr. Chair.

I would like to present the following motion, which was submitted in advance, of course, as per the committee requirements. The motion reads as follows:

> That the final framework on Lyme disease not be tabled until the Standing Committee on Health has had the opportunity to review the draft work which should aim to (a) establish proper guidelines regarding the prevention, identification, treatment and management of Lyme disease and the sharing of best practices throughout Canada, and (b) ensure the creation and distribution of standardized educational materials related to Lyme disease for use by any public health care provider within Canada designed to increase national awareness about the disease and enhance its prevention, identification, treatment and management.

I table this motion because a year ago, almost to the day, there was a clear sense of hope in the Lyme disease community. A federally funded Lyme disease conference was held right here in Ottawa in May of 2016. There was a sense that finally experts in the field of Lyme disease would be engaged in the drafting of the federal framework outlined in Bill C-442, MP Elizabeth May's bill.

The Federal Framework on Lyme Disease Act was passed on June 11, 2016. The MPs and senators who passed this bill into law passed it with the understanding that it was to be consultative. But that sense of hope has faded. This federal framework on Lyme disease is being written behind closed doors. It is to be released later this month.

A draft framework was released in February of this year, and the reaction to it was fierce. Dr. Melanie Wills, director of the Canadian Lyme Science Alliance and a professor of molecular and cellular biology at the University of Guelph, said the following:

> As a researcher in the field of Lyme disease biology, I am dismayed by the lack of scientific rigor, collaboration, and leadership demonstrated in this document. The Framework does not provide a balanced or holistic portrayal of the biomedical literature, nor does it capture the experiences and needs of Canadians who are suffering from Lyme disease. The CLSA strongly advocates a thorough, inclusive, critical, and transparent evaluation of all available meritorious scientific evidence, as well as meaningful integration of input from diverse stakeholders. We can, and must, do better.

Dr. Liz Zubek, a family physician who specializes in the treatment of Lyme disease, said the following:

> This draft Framework tells me to follow outdated guidelines that haven't been revised in over 10 years. There has been an explosion of research in the past decade and newer guidelines exist that include patient input. This draft Framework also suggests that, as a doctor, I should be satisfied with our inadequate Canadian tests for now, and that maybe in the future we will find improvements. This is, frankly, ridiculous.
>
> I urge the Minister of Health to reject the Draft Framework and insist on a real Canadian action plan for Lyme disease. This needs to be created in partnership with people affected by Lyme and those researchers and doctors who are actively attempting to treat them.

Finally, these are the words of Rossana Magnotta, a director of the Canadian Lyme Disease Foundation:

> We call on the Minister of Health to intervene and insist on patient experts being involved in the writing of the framework, even if that means delaying the report to parliament. This is the correct and ethical thing to do.

Mr. Chair and colleagues, 38,000 Canadians have signed a petition clearly denouncing Canada's draft action plan on Lyme disease. The draft proposal ignores science and many major concerns that were raised at the conference. Major concerns include poor diagnosis, treatment plans that fail, human-to-human transmission, and blood bank contamination—yes, blood bank contamination.

● (1230)

You can see that there are some serious concerns by both professionals and patients within the Lyme disease community that this framework may lack some key items. I would like to give the Lyme disease community reassurance that they are included in the drafting of this framework. I am aware, colleagues, that this committee has no more days or time available in the near future to undertake any more studies. I'm aware of that, and I'm also aware that Health Canada intends to release this framework on Lyme disease at the end of the month.

Therefore, this motion I put forward proposes that, through the clerk, of course, we receive a copy of the framework in advance of the final copy being generated so that we can add our constructive input. I'm suggesting that we can review it independently, on our own time, as our meeting schedule is already full.

In the end, it will be we MPs who will have to answer to this framework, and it sure would help if any questions we have could be resolved ahead of the drafting of the framework. I think our input would be most valuable if it is contributed before the document is finalized, because once this framework is written, it's basically written in stone. It would be difficult to change.

Ideally, I would imagine that we could have a draft framework document for about a week to provide our input before it goes to final print, and if this proves to be a successful approach, it may help this committee in future issues.

I conclude with this question: do we all agree that having our input would be a valuable contribution to the process of developing an action plan framework on Lyme disease?

Thank you, Mr. Chair.

The Chair: Thank you very much. I think a lot of us have questions about Lyme disease.

I've looked at your motion, as I discussed with you earlier. The House of Commons instructed the minister to develop a framework, and we can't overrule that. It's out of our scope. It's out of our mandate. We can't do that. The motion you've submitted is out of our scope. It's out of order, because we just can't overrule the House of Commons. To do that, we'd have to go back to the House of Commons and move a motion there, but we can't overrule the instructions of the House to the minister to produce the framework.

Just as an aside, my understanding is that it has been changed. It has been amended and several things have been added to it. I don't know what they are.

Anyway, I'm ruling the motion as presented out of order.

Mr. Len Webber: Mr. Chair, I'd like to respond to that.

The Chair: Sure.

Mr. Len Webber: First of all, I think it would be helpful to the Department of Health to have our input and to have the input of our constituents who are suffering from Lyme disease. I assume all of you have met with the Lyme disease community. They have been on Parliament Hill numerous times to meet with MPs to talk about the serious issues that were not included in the draft framework.

You say to me, Mr. Chair, that perhaps the items that were not included in the draft framework are now in the final framework. I would like to see that before it is released, so that there are assurances in the community that this is a quality document.

The Chair: Dr. Carrie.

● (1235)

Mr. Colin Carrie: Thank you, Mr. Chair.

I would like to take just a moment here. I worked with Ms. May when we brought this forward. Again, there was a certain intent to come up with a framework that would be making a difference. The reality for all of us around the table is that we have not seen the final draft. You've heard.... I do appreciate your input in saying that it has been changed, but I have been meeting with Lyme disease advocates and patients who have Lyme disease, and there is a significant concern.

I think my colleague's intent here.... Maybe there are procedural things that we could do if we were to get unanimous consent or agreement in certain areas to make things move forward because, just as we saw with this study we're doing on thalidomide, sometimes you have a certain intent and if you get it in advance, maybe there's a way you could have improved outcomes....

I was wondering if my colleague would consider a friendly amendment. I would say that at the front of his motion, we would put “That the Standing Committee on Health request that...”. We would see if that is something that you would be able to take a look at without ruling it out of order. I realize that the House of Commons—

The Chair: I've ruled that it's out of order. The clerk advises me that it ends that issue.

Mr. Colin Carrie: Oh, it does, does it?

The Chair: I think many of us are interested.

To me, it's a very confusing subject, and there are so many different points of view and perspectives, but this motion I have to rule out of order because it overrules the House of Commons.

Mr. Oliver.

Mr. John Oliver: I share the concerns of my colleagues across the table. In my community, there's a very active group of people who are suffering from Lyme disease and some of the chronic conditions of Lyme disease, and they were in to see me after they had reviewed the draft report, indicating their concern with the draft report. It seemed to come down to this: was all the scientific evidence reviewed and were different weightings given to it?

I've heard very clearly from the Lyme disease community. I haven't heard from the Department of Health. I'm wondering whether the motion might be that we ask the department—I'm not sure who we're asking, but it would be whoever is involved with drafting the report—to come to the committee to talk about the work they've done and the preparation of the material. I don't think we can do a full study on Lyme disease and tear apart a report that Health Canada has put together, but I think we could hear from them and ask questions about the process of developing the report and how they've dealt with the concerns that have come from it.

It's difficult to see the affected community so disenfranchised with the report coming from Health Canada. There's a gap here somehow. Maybe we could help with that ongoing relationship if we heard from Health Canada about how they prepared it, what evidence they looked at, and how they were dealing with the concerns coming from the Lyme disease community, the people suffering with this.

The Chair: I'm going to hear from Mr. Davies and then Dr. Carrie. If it's okay, I'm then going to ask Mr. Oliver if he'd present a motion. If we all agree to it, we don't need advance notice.

Mr. Len Webber: On this point, though, Mr. Chair, Mr. Oliver's point about—

The Chair: We have a list.

Mr. Len Webber: Even though it's on this point? Okay.

The Chair: Mr. Davies.

Mr. Don Davies: Thanks, Mr. Chair.

If I understand your ruling correctly, Mr. Chair, the problematic part of the motion is that we can't prevent the final framework on Lyme disease from being tabled until we do something, because the House of Commons has ruled that it be tabled. I'm wondering if we can amend the motion to simply say "that the Standing Committee on Health review the framework on Lyme disease". That would certainly be in order. We can study whatever we want. That way, we're not holding up the framework. The framework will be tabled.

Mr. Webber, if the purpose of it is to get the framework before this committee and let the Lyme disease community come to have their say, it would at least be instructive for our committee. Then, of course, at our convenience, we can forward that report to the minister, and the minister could potentially make changes to the framework thereafter as she sees fit.

Am I right? Is that the problem with the motion as it stands?

The Chair: That is the problem. We can't overrule the House of Commons.

Mr. Don Davies: We can't hold them up.

● (1240)

The Chair: We all voted for this, and the House of Commons voted in favour of the framework. We can't say no.

Mr. Don Davies: I will move, then, Mr. Chair, that—

The Chair: The only way we can continue with this or amend it is if you overrule my decision, but that's not to say that we can't come up with a new—

Mr. Don Davies: Then I'll move a new motion. It will be exactly the words that are in the present motion, except for the words "not be tabled until the", which are to be replaced with "be referred", so that in the first sentence, taking out the words "has had the opportunity", it would say: "That the final framework on Lyme disease be referred to the Standing Committee on Health to review the draft framework", and then the rest follows.

The Chair: You're proposing that we have it come to the committee at some time in the future—

Mr. Don Davies: Yes, exactly.

The Chair: —as opposed to a briefing now.

Mr. Don Davies: Yes. If we can't hold it up—I respect your ruling, and I think you're right—then I think the purpose of Mr. Webber is to get the framework before this committee, albeit that it may happen after.

That's my motion.

The Chair: Mr. Davies, you're talking about this coming to the committee when we can put it in our schedule, not necessarily before it's tabled?

Mr. Don Davies: I think it's impractical before it's tabled, because I think it's going to be tabled next week. Isn't there a one-year deadline on it? Maybe the analysts or the clerk can help us. I think it has to be tabled next week.

A voice: It's by the end of the month, yes.

Mr. Don Davies: Do we have a month?

A voice: Well, it's the end of May....

Mr. Don Davies: I'm in my colleagues' hands on that.

The Chair: We have two proposals. I didn't allow Mr. Oliver to make it a motion because I thought I would want to hear from everybody.

You're getting your motion kind of unofficially, and I didn't give Mr. Oliver the chance to make a motion, so could we just hold that up?

Mr. Don Davies: I would be happy to stand down my motion until we hear from Mr. Oliver.

The Chair: Also, let's hear from Dr. Carrie and Mr. Webber. Then we'll decide what we want to do.

Mr. John Oliver: I think we're all chasing the same thing. We're just trying to figure out the best way to facilitate it.

I'm not sure that getting the framework and us doing a study on the framework would be as helpful as having Health Canada come in, present the framework to us once it's it been submitted, and talk about the evidence they reviewed and the work they did with the people who are suffering from Lyme disease, and why in that community, in their view, there is such a disconnect. We've all heard very clearly from people suffering from Lyme disease that they weren't happy with the framework.

I don't think we can stop it. I think that if we had Health Canada come in to talk to us right now, they probably couldn't say much, because it's in a confidential space right now. Once it's been tabled, I think it would be good to get them in and have a meeting with them. We've only heard one side of the story. I do think we should hear the Health Canada perspective and then make some decisions on whether we want to open up the whole framework as a committee.

The Chair: Okay.

I want to hear from Dr. Carrie and then Mr. Webber. Then we'll decide what we're going to do in the way of a motion.

Mr. Colin Carrie: Thank you very much, Mr. Chair, for allowing it to move forward like this.

I would mention to my colleague Mr. Oliver that they're not just tabling the report. They would be doing the final framework. I think all of us have met with the Lyme disease community. What they were really concerned about is that they saw the draft. We know that's not the final, and maybe the final has changed significantly. They were really concerned because a lot of their testimony was not reflected in that draft. My worry is that if the minister does table the final framework, it might be significantly difficult to change it once it's there.

If there were a way that we could, as a committee, get a copy of this maybe in advance or something along those lines so that we can see if that remains the problem, perhaps—and you said quite correctly that the House of Commons voted—there would be goodwill in the House of Commons to unanimously give the minister a little more time before she had to table the final framework.

I know that Ms. May worked extremely hard on this. I spent a lot of time with her initially. Again, the idea was to do something good and to come up with something that is workable for the community. I think we have to keep that in perspective, because this is not just a report. This is a final framework. If we put together and table a final framework, we may not be able to easily change that.

I'll defer to my colleague. I know that he has some comments.

● (1245)

The Chair: Go ahead.

Mr. Len Webber: I think you've pretty much said what I was going to say as well. Once this framework is presented, it's pretty much written in stone.

If there were perhaps a tabling in the House of Commons to postpone the release of the framework, perhaps we could have the House of Commons make that decision, then, on delaying the release of the report.

Here in this committee right now, I guess you've ruled out my motion, and Mr. Davies does have a new motion on the floor. I would like to hear the wording on that, but I would like to add “prior to the release of the report” in your motion, Mr. Davies. If you have the wording for that, I would like to make an amendment to your motion.

The Chair: You didn't actually move the motion. You suggested the motion. Then you thought we would talk about it, and I hope we can do that a bit.

Mr. Don Davies: I did move it, but—I don't think there's such a thing as standing it down—I'm happy to just have a conversation. I think the point is that we want to get that framework before this committee.

I would say to Mr. Oliver that, to be honest, I think the health department has spoken. They've spoken because they've drafted the framework, and I do think they should be here, absolutely, but I also think it's very important that we have members of the Lyme community here to tell all of us.... Yes, I've spoken with a few of them, but this is a very important issue on which we're all getting a lot of contact. I'm happy with Mr. Webber's suggestion. If we can possibly sneak in a meeting or two before the framework is tabled, that would be fine.

With respect to Colin's suggestion, I don't think that even with unanimous consent we should prevent the tabling, because my recollection is that the bill was passed. I mean, it's the law. There is a provision of a law validly passed that says it has to be tabled. I don't think we can do anything about that. The framework will be tabled in the House.

It would be nice to have a meeting. I'm even wondering if it could be one of those two meetings in June that we have scheduled to start on antimicrobial resistance, because those are not particularly time sensitive, but I think Lyme is, particularly with summer coming up. It would probably gain us a lot of goodwill as a committee to at least have one meeting, or even two, maybe in June, just to hear from the community, to review the framework, to hear from the health department, and to hear from some of the critics.

The Chair: I'm going to make a proposal that the committee consider asking the minister to come next week, with officials, to outline the process, somewhat along the lines of what Mr. Oliver suggested: the process they used, the information they took, etc. This is prior to the tabling of it. If the entire committee were unanimous in asking her, she might consider coming. Is that a legitimate request?

It's a concern to everybody, I think. The material I got from Elizabeth May is really confusing, and as you know, some people say there is no such thing as chronic Lyme disease, while some people say there is, and these are professionals. Some people say it can be diagnosed, and some people say it can't. Some people say there is no diagnosis for Lyme disease. Some say there is. To me, this is a very confusing issue, but the people who are suffering are really suffering. There's no confusion about that.

Mr. Oliver, would you help us out here?

Oh, I'm sorry. Mr. Ayoub, please.

[*Translation*]

Mr. Ramez Ayoub: I just want to make sure that I understand and that we have the right information.

The drafting of the federal framework on Lyme disease was undertaken a year ago. The final framework is now being prepared. But people are worried about what they saw in the draft report. I can understand that concern, but, at the same time, I feel that people are judging the content of a report that does not reflect the final framework. People are asking that the process be delayed, so that we can get involved in the drafting of the report. Yet who are we to do that? I personally don't feel in the least like an expert on Lyme disease. However, people are already judging that report. I think it is somewhat presumptuous for our committee to want to get involved in the process to influence the content of a report that has not yet even been made public. Never mind the fact that the House of Commons unanimously passed the resolution to develop that federal framework within a set time frame and that, currently, not only are we at the eleventh hour, but we have almost exceeded the time frame.

However, nothing prevents us from carrying out a study on Lyme disease afterwards, in response to the so-called final consultation report, even though I feel that nothing in life is ever final. We are seeing that in the thalidomide case. We want to review the contribution program for thalidomide survivors. The committee will probably make suggestions for changes to be made to the existing criteria. We will see where our discussion will take us. I believe we should do the same with the report on Lyme disease.

Thank you.

● (1250)

[*English*]

The Chair: Mr. Oliver.

Mr. John Oliver: Thanks.

Building on what Ramez has said, first of all, I think that because this is going to Parliament there is an issue of parliamentary privilege in asking to see things in advance. I think Parliament gets to see it first, so I don't think we can intercept it. I think that's the way I'd put it.

Second, it's a framework. This isn't a binding act. It's a recommended framework that can be.... I read through the draft framework and a lot of it was indicating the need for more research and for additional study. It isn't a binding piece of legislation, if I can put it that way. It's a framework to approach a problem.

I do think there is time for us to consider it after it has been tabled. I think getting on with it indicates an interest in it. I think that would be beneficial, so I support what Mr. Davies said. Maybe we should substitute it for the research on antimicrobial resistance and have a couple of days dedicated to it.

I have a concern about this sense of how the health department has been portrayed, as sort of masking and hiding.... I just don't like that. I think it should be a very open and transparent process in engaging with the people who are suffering from Lyme disease. I think it would be worthwhile to hear from them and also to hear from the community, and I think it would be better to have it after.... The other reason why I think it's better to have the framework tabled is that if the health department has listened and has built in the changes and concerns that were identified, I would sooner have the discussion with the final document than with one based on our knowledge from the framework document.

The Chair: Are you suggesting Mr. Davies' motion...?

Mr. John Oliver: Yes, if his motion is that we dedicate two days to it, that on our schedule we substitute for the antimicrobial resistance a review of the Lyme disease framework after it has been tabled, and that we hear from Health Canada and from the Lyme disease community about the final version, so that we actually know what we're talking about.

Ms. Rachael Harder: Are you moving a motion?

Mr. John Oliver: I think it's already there. If that's what's in it, I'm happy with that.

The Chair: Is that good?

You're on the list for speaking, Rachael.

Ms. Rachael Harder: I agree with this motion, very much so, and in the interests of time, I think we should vote.

The Chair: Is there any more debate?

All in favour of the motion of Mr. Davies, as seconded by Mr. Oliver?

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

The Chair: All right. The motion has carried, so we're going to replace our antimicrobial meetings with meetings on Lyme disease. Now we need a witness list, and we need really good witnesses for this.

Mr. Len Webber: There's just one point I want to bring up. I want to thank Mr. Davies for his motion and for bringing this up and, as well, I thank the committee for allowing this to occur. I think it's very timely.

Thank you.

The Chair: Well, you stirred it up, so we want to thank you.

Mr. Davies.

● (1255)

Mr. Don Davies: Well, right back at you, Mr. Webber. You brought it up, so thank you for that.

I noticed those two meetings in June. I believe there will be two meetings after that.

Some hon. members: Oh, oh!

Mr. Don Davies: There are some who hope we don't have two more meetings after that, but if we do, in fairness to the clerk, who is probably in the process of trying to set up witnesses for the antimicrobial resistance meetings, can we not at least pencil in the beginning of the antimicrobial resistance study for those two meetings the following week?

It gives you more time....

The Chair: You're aware that the House could rise, and things are going so fast in the House....

Some hon. members: Oh, oh!

Mr. Don Davies: What is that week?

The Chair: That is the week of June 11. It would be the 13th and the 15th.

Mr. Don Davies: Personally, I think we'll be here.

The Chair: Yes, it looks to me like we'll be here too, so—

Mr. Don Davies: Wouldn't it be better to at least plan for that? If we're not here, we can cancel, but if we don't set some agenda for those two days....

The Chair: Yes, we'll do that. We'll pencil those in, so June 6 and 8 will be for Lyme disease and then the 13th and 15th will be on antimicrobial resistance—or home. Hopefully, it's home.

Thank you very much, everybody. The meeting is adjourned.