HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

# Standing Committee on Health

HESA • NUMBER 053 • 1st SESSION • 42nd PARLIAMENT

**EVIDENCE**

## Tuesday, May 9, 2017

## Chair

**Mr. Bill Casey**

# Standing Committee on Health

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● (1135)

[*English*]

**The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)):** I call the meeting to order. This is our very first meeting on thalidomide.

We welcome our guests. We apologize for being late, especially to our guests on teleconference. You're looking very bright. We are glad you're with us. I'm sure we'll learn a lot about this issue today.

From Crawford, our guests today are Mr. Michael Mooney, vice-president, Class Action Services, and Brenda Weiss, project manager, thalidomide survivor compensation program.

From the Department of Health, we have Cindy Moriarty, executive director of health programs and strategic initiatives, and Theressa Bagnall, senior manager of program development at the office of grants and contributions services and innovation.

As individuals, by video conference, we have Dr. Martin Johnson, former director of the United Kingdom Thalidomide Trust, and Dr. Neil Vargesson, senior lecturer at the school of medicine, medical sciences and nutrition, in the institute of medical sciences, University of Aberdeen.

We're going to open with 10-minute remarks by each witness: Crawford, then the Department of Health, and then the individuals.

Mr. Mooney, you have 10 minutes.

**Mr. Michael Mooney (Vice-President, Class Action Services, Crawford):** Thank you.

I am happy to speak briefly on behalf of Crawford Class Action Services.

First of all, I would like to say thank you for the opportunity to appear. We are always pleased to be involved and to participate in the process, especially when the work we are doing involves providing important benefits and consideration to people who are entitled to receive them pursuant to either a litigation settlement, or in this instance, a program.

Crawford Class Action Services has been operating since about 1999. We've conducted somewhere between 90 and 100 legal settlements pursuant to class-proceeding litigation, or government subsidy or other benefit programs where a third party administrator was desired to be engaged.

We've had the pleasure of being involved in such important cases as the Indian residential school settlement, the hepatitis C tainted blood transfusion cases, the Walkerton water crisis in Ontario, and numerous other cases involving medical devices, food-borne illnesses, fraud against the markets, anti-trust or anti-combines settlements—pretty much anything—and of course institutional duty-of-care cases for situations where unfortunate incidents of abuse or interference with people's rights have taken place.

We are pleased to be involved working with Health Canada on the thalidomide compensation program. We began our work in October 2015. We are in place as a third party administrator to execute the program as designed by Health Canada and delivered to us. Within that capacity, we've worked to follow the process that was outlined and to provide service to the survivors and to potential new members of the class who are seeking to be considered in the program as well.

I think that's the extent of our opening comments. I don't really have a lot to add beyond that, except that we are happy to do our very best to answer any questions that may be put our way about our involvement in the administration of the program.

We look forward to the mutually shared learning opportunity that all of us will have from being involved in this process today.

**The Chair:** Thanks very much.

Now we move on to the Department of Health. Ms. Moriarty, go ahead.

**Ms. Cindy Moriarty (Executive Director, Health Programs and Strategic Initiatives, Strategic Policy Branch, Department of Health):** Good morning. Thank you for the opportunity to provide information on the government's support for Canadian thalidomide survivors. Most of my remarks will be in English.

[*Translation*]

I can also respond in French.

[*English*]

I would be happy to take questions in either language.

In my current position at Health Canada, I am responsible for the oversight of a number of funding programs, including the thalidomide survivors contribution program.

I'd like to provide you with a brief history leading up to the establishment of the program, as well as some information about the program's design and implementation. Some of this you may have already received from a letter from the Honourable Jane Philpott, Minister of Health.

I'll start with the history. In the late 1950s and early 1960s, thalidomide was used as a sedative. It was also found to be effective in treating symptoms associated with morning sickness. Thalidomide became available in sample tablet form on July 17, 1959, and was licensed for prescription use by the Department of National Health and Welfare, now Health Canada, on April 1, 1961. It remained legally available until March 2, 1962, when it was removed from the market. Thus, the earliest full-term births to be affected by thalidomide would have been after April 1960.

● (1140)

[*Translation*]

In 1991, the Government of Canada created the $8.5 million extraordinary assistance plan for people born with disabilities caused by thalidomide. The funds were distributed in the early 1990s, then the program ended.

To date, 97 known Canadian survivors have received compensation through the plan. Many years later, on December 1, 2014, the House of Commons unanimously passed a motion to provide support for Canadian survivors. In spring 2015, the government announced a set of federal support measures for survivors. These measures are provided by the Thalidomide Survivors Contribution Program.

[*English*]

The purpose of the program is to contribute to meeting the needs of thalidomide survivors for the remainder of their lives so that they can age with dignity. The program also provided an opportunity and a process to assess individuals who had not already been identified in 1991 to determine if they were Canadian thalidomide survivors.

Each year a certain number of children are born with spontaneous or otherwise unaccountable malformations. In the absence of any definitive scientific test, it is difficult to distinguish between conditions caused by thalidomide and those caused by other factors.

It was, therefore, important to ensure the program was founded on objective and verifiable criteria. Thus it was decided and subsequently announced on May 22, 2015, that the program eligibility criteria would be determined based on the 1991 criteria, as follows: that there be verifiable information of the receipt of a settlement from a drug company; documentary proof, for example medical or pharmacy records, of the maternal use of thalidomide—brand names known to be Kevadon and Talimol—in Canada during the first trimester of pregnancy; and listing on an existing government registry of thalidomide victims.

This approach provided an objective process to assess unconfirmed individuals to determine if they were thalidomide survivors. It also provided consistency between the 1991 extraordinary assistance plan criteria and the criteria used to assess new applicants.

I'd like to note that the absence of time parameters in the eligibility criteria allows for the possibility that a person might submit proof from outside the time period of thalidomide distribution in Canada. The criteria also did not preclude the person whose mother ingested thalidomide after its withdrawal from the market.

Next, a few words about program implementation.

Following a competitive process, Health Canada selected Crawford & Company (Canada) Inc., an experienced and well-established provider of claims services, to act as the independent third party administrator of the thalidomide survivors contribution program. In addition to administering the ongoing support payments and the extraordinary medical assistance fund, Crawford is responsible for assessing the eligibility of all new claimants.

The administrator's discretion in implementing the program was intentionally limited. Crawford was to strictly adhere to the program parameters, including the eligibility criteria.

Crawford has confirmed 25 new survivors, in addition to the 97 survivors who had been identified in the early 1990s. This brings the total number of confirmed living survivors to 122. Of the 25 new individuals confirmed, 16 submitted documentary proof of maternal ingestion. That is the second of the three criteria that I just listed.

Four individuals have filed requests for judicial review of the administrator's decision. Last week, on May 2, a decision was rendered in the first of these cases. The decision reflected that the court does not have jurisdiction to review the crown's prerogative power nor to reformulate or add eligibility criteria, and it found that the administrator's decision was procedurally fair.

In closing, thank you for your time today. As Michael said, I think we all have something to learn from today's exchange in going forward. I hope the information has been helpful to you.

● (1145)

[*Translation*]

I'm happy to answer your questions.

[*English*]

**The Chair:** Thank you very much.

Now we will go to our friends in the United Kingdom.

Dr. Martin Johnson, do you have an opening statement to provide us with a little background?

**Dr. Martin Johnson (Former Director of the United Kingdom Thalidomide Trust, As an Individual):** The background is that I was the director of Thalidomide Trust from July 2000 to May 2014. Up until the end the 2006, we accepted as new beneficiaries to the trust only those individuals who had achieved a settlement in respect of their thalidomide damage with Diageo plc, as the heirs and successors to Distillers Co. (Biochemicals) Ltd.

The process they employed involved two U.K. experts, Professor Richard Smithells and Dr. Claus Newman, who had separately specialized in the care of thalidomide children in the 1960s and were co-authors of the paper “Recognition of Thalidomide Defects” in the *Journal of Medical Genetics*, October 1992.

This was a normal adversarial process. Following the death of Professor Smithells in 2002, the lawyers acting for Diageo were left with about 12 unresolved claims where Professor Smithells and Dr. Newman had been in disagreement over diagnosis. I assisted them in finding experts they had not used before, namely Dr. Hans-Georg Willert from Göttingen University and Dr. Janet McCredie of Sydney.

As a result, they were able to resolve these remaining cases. It was largely a result of this experience that led Diageo to announce they were going to discontinue their *ex gratia* scheme from the end of 2006, with 12 months' warning given by advertisements in the national press.

Dr. Willert died in September 2006, and the only other remaining thalidomide diagnostic experts in Europe other than Dr. Newman were Professor Marquardt of Heidelberg, who was very frail and elderly; Dr. Jürgen Graf of Nuremberg, whom Marquardt had trained; and Dr. Peter Kohler in Stockholm, who also retired not long afterwards.

Against this background, the trustees of the Thalidomide Trust decided they had to be able to consider applications to the trust directly from potential thalidomide victims affected by the Distillers' product.

From the beginning of January 2007 until my retirement at the end of May 2014, we were contacted by more than 600 applicants, of whom fewer than 30 met our criteria. Only three of these were able to produce documentary evidence of their mothers having been prescribed the drug.

We were aware that probably 50% of the original cases in the 1968 and 1973 settlements, where thalidomide exposure was agreed a virtual certainty, had no documentary evidence. This was because of the very widespread and casual distribution of the drug from hospitals to dental surgeries and as free samples to general practitioners. I heard there had been one case where the mother had been given the tablets by her veterinarian surgeon.

From the outset, it was known that this standard of evidence could not be insisted on in every case. We were also aware from epidemiological studies that the number of people born with non-thalidomide dysmelic conditions during the years 1959 to 1962 was likely to exceed the number of thalidomide survivors by between two and three to one, so we expected to see several cases not conforming to the typical thalidomide damage patterns.

My role was first to screen out those applicants who were born either before the availability thalidomide or after its withdrawal, allowing for the appropriate gestational timings. People born after the withdrawal date were advised that the case could only be considered if contemporary documentary evidence of late ingestion of the drug by their mother could be produced.

Second, we checked the location of the mother at the appropriate time to assess whether or not she was in a territory where we had known Distillers' thalidomide to be available. We were aware that thalidomide had travelled with medical practitioners to some unexpected places, but if a claim was made concerning a territory where we had no record of distribution, then we would require documentary evidence showing that the Distillers version of the drug had actually been present in that location before taking the case further. This was not produced in any case I know of.

● (1150)

The third stage of screening was for atypical conditions, specifically unilateral and transverse reductions. People with such conditions were also informed that we could only proceed if contemporary documentary evidence was produced that their mother had received the drug. I had been trained by most of the experts mentioned above in this subject, and by 2007 had met several hundred thalidomiders in various countries, so my trustees considered my knowledge adequate for this purpose.

People who passed these three stages of screening then had their cases presented to a committee of our trustees, which always included medical and legal experts. The decision almost invariably was then to commission an expert medical report from Dr. Newman. I can think of no subsequent case where Dr. Newman's recommendation was not followed. We did have one case of a person who'd moved to Australia as a child, and we arranged for that person to be examined by Dr. McCredie. Then her report, including X-rays, was reviewed by Dr. Newman for the trustees.

The trustee chair of our claims committee, as we called it, was always a very experienced High Court judge, and the standard of proof required for a decision was on the balance of probabilities.

In parallel with this, we began work to transfer and update Dr. Newman's knowledge, particularly to encompass what had been learned over the years about various genetic conditions. This was the background to the WHO meeting in Geneva, where the work of the genetics teams was considered by a gathering of global experts on the subject. It was hoped that an algorithm could be developed to facilitate screening. I do not know how far this has developed, but it should be easy to find out. I've been making efforts on this topic since Friday afternoon, when I was contacted about this, but I don't have an answer. I do know that the algorithm is not in use yet.

While our medical experts would always say that there was no aspect of thalidomide damage that had not been reported prior to the arrival of thalidomide, there were distinct patterns to typical thalidomide damage, and phocomelia was foremost among these. In a paper in the 1960s, one German doctor, reporting on many cases he'd dealt with, wrote that before thalidomide he had seen more babies with two heads than with phocomelia. All the work by Smithells, Newman, McCredie, Willert, Marquardt, etc., was based on extensive reporting from Germany of cases where there was no doubt that thalidomide had been involved.

The WHO meeting, in essence, endorsed the results of all the German early research that had been studied and acquired around the world in subsequent years. Theories have been advanced, such as that thalidomide operated primarily by restricting the growth of blood vessels. That theory was rejected on the basis of the known damage timeline, which mostly fell before the development of the circulatory system, and the abundant contemporary evidence showing that ingestion of the drug by mothers after the sensitive period, 20 to 42 days from conception, caused no detectable damage to the baby.

We did deal with a few claims pushed by law firms in the U.K. that were mainly concerning atypical cases, but the whole point, as seen by our board, was that atypical cases required a higher burden of proof in the form of contemporary documentation before they could be accepted. To my knowledge, this was produced in only one instance, and that was an exceptionally rare disorder called RBS. Typical cases presented no problem for acceptance.

From the notes that I was sent on Friday, I understand that you are trying to find out whether there are ways to assess thalidomide damage. The answer has to be yes because we did it. It is possible to assess thalidomide damage with a high degree of confidence. It's a medical-legal issue. I gather that Dr. Newman, in his middle eighties, is still performing this function for the Thalidomide Trust, but he's now being supported by Professor Sahar Mansour of St. George's University Hospitals, London. I note also that Professor Schuler-Faccini of Brazil is still in the saddle and operating in this role. She reported at Geneva that she'd been studying cases born as late as 2010.

● (1155)

I recommend that you read the Geneva report. It refers to an appendix 3, which is a technical appendix and which has still not been appended to it. I think it is probably available if you are able to make contact with the St. George's University team, or possibly the Thalidomide Trust. The WHO report says that theories of mechanism of causation are not actually of help with the diagnostic problem, but they're very keen that research is continued into these subjects, because one day it might add an awful lot to the sum of human knowledge.

In summary, no, we don't know how the drug does what it does to the babies, but we do know what it does and we know the times in the gestation pattern when it happens. On that basis, we were confident to take the decisions that we did.

I hope this is of service to you.

**The Chair:** Thank you very much.

That is very helpful, and we look forward to having questions and answers with you.

Now we go to Dr. Vargesson for 10 minutes.

**Dr. Neil Vargesson (Senior Lecturer, Institute of Medical Sciences, School of Medicine, Medical Sciences and Nutrition, University of Aberdeen, As an Individual):** Thank you.

I'm a developmental biologist. I'm a scientist, not a clinician. I've been studying how thalidomide acts on the embryo for the last 15 years.

The drug itself is quite complicated. It exists as enantiomer, which means it can exist in two different forms in the body. One form is believed to be positive. That's what gives us its good benefits, its anti-inflammatory actions. The other side is supposed to be its teratogenic side effects, and that's damage to the embryo.

I've been interested in how the drug works. I got interested in this some time ago. Janet McCredie's work from the 1970s suggested that the nerves were targeted by the drug to cause the various birth defects. I've always been interested in that work and interested in how a drug like thalidomide could cause such massive damage. This drug, in just a short time period, affects almost every tissue in the body apart from the brain and the central nervous system. How it can do that is just amazing.

As Dr. Johnson just alluded, in the report from Smithells and Newman in 1992, they talk about just one tablet being enough to cause damage to an embryo. If you took more than one tablet, you would get lots more damage.

We took apart the drug. We made different versions of it, broke it down, and asked the question, what does the drug do in an embryo? We used chicken embryos and zebra fish embryos because they develop in very similar ways to early humans. They have similar genetic and molecular makeups to us. They're simple to use. You can put drops on them and see what they do. We found that, if you make versions of the drug, you can change the molecular structure. You can find versions of the drug that affect blood vessels. You can find versions of the drug that affect the inflammatory system and the immune system.

This is what the drug does normally. If you take a tablet of the drug, it's useful to treat cancers because it destroys blood vessels. It's useful to treat conditions like leprosy and multiple myeloma because it's anti-inflammatory.

We found that the drug's anti-angiogenic actions are what causes its effects on the embryo, and the anti-inflammatory actions don't seem to do much to it. We're now looking at molecular targets of that action, and if we can understand molecular targets, you could perhaps, possibly, identify or have a tool to identify who might be at risk.

We're also now looking at drug safety. Dr. Johnson also mentioned that there is a new generation of thalidomide babies in Brazil, and I would strongly recommend that you contact Lavinia Schuler-Faccini in Brazil because she is leading all the diagnostics there. In Brazil they have a leprosy problem, and thalidomide is very useful to treat leprosy. It's very effective, but the side effect is that they have a new population of babies with thalidomide-like damage.

We've been trying to make forms of thalidomide that don't cause birth defects. We're looking for versions that are not anti-angiogenic —that is, don't affect the blood vessels—and that are purely anti-inflammatory. We have identified some of those, and we're now trying to use those in other inflammatory conditions to see if we can use them as an alternative to thalidomide.

That's my expertise. I'm not a clinician, but I would say that, from the animal evidence from the 1960s through to recent years, if you look at particularly the primate studies—that's the studies in monkeys—this drug causes an amazing range of damage. If you look at monkeys, you have four or five embryos per litter, and each embryo is different. Each embryo is affected differently by the drug. You can have some that have phocomelia, as Dr. Johnson mentioned, where they have the digits sticking out of the top of the shoulders, and some that have almost no damage at all.

How the drug can do that, how the drug can affect one pregnancy and affect each embryo in such a different way, we still don't understand, but the fact is that in animal evidence the drug affects each embryo differently.

I think Dr. Johnson can confirm this or disagree, but I think each individual thalidomide survivor has a different range of damage as well. This is one of the reasons it's been so difficult to understand how the drug acts and how it causes its problems, because each person seems to have a different amount of damage. This is one of the problems we have in science, trying to understand how the drug acts.

● (1200)

Thank you for your time. I hope that was helpful.

**The Chair:** It was very helpful. It just tells us how big this question is.

We're going to start our questioning now with Dr. Eyolfson. We have seven minutes.

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

Thank you all for coming. It was very interesting testimony.

Dr. Johnson, I'd like to start with you. You've been talking about the patterns of abnormalities that we see. Of course, that's one of the questions we're really thinking about because the challenge is that we have so many people who have to provide documentary evidence, and after so many years, it is just not available.

In broad terms, is there a pattern of abnormalities you can see that would give you a very high likelihood that a person was injured by thalidomide?

**Dr. Martin Johnson:** Yes. They had an ear deformity pattern that was very definite. The bilateral radial aplasia, the arm reductions with the radial club-hands, is very rare outside thalidomide. The balance of probability is that, if somebody is born in a period when thalidomide is available and presents with one of these typical conditions, it is more likely that these problems will have been caused by thalidomide than that they will be random occurrences.

**Mr. Doug Eyolfson:** This is probably difficult, but could you give us a ballpark number for probability? Are we talking a likelihood of greater than 50%, greater than 75%?

**Dr. Martin Johnson:** I must caution you that I'm not a medical doctor and that I'm doing it from observation, not from clinical expertise. Of the candidates we saw, the 600 that I mentioned, latecomers, and from various parts of the world, not just U.K., all thinking they might have a chance at a claim, there were only maybe 20 or fewer with radial aplasia and born in the right place and right time for it to be possible for their mothers to have been exposed to thalidomide. The quote from the German study struck me years ago. This man said he'd seen more babies with two heads than with phocomelia. Phocomelia is a description of fairly extreme bilateral arm reduction and radial aplasia.

To get into percentages, I would rather defer to one of the scientific diagnostic experts, such as Dr. Newman. But if you were to find somebody with one of the couple of conditions that I mentioned, from the right period, and presenting without any other inconsistencies—and now it's possible to eliminate genetic phenotypes in a way that wasn't possible up until the last maybe 10 years—your probability is going to be very high. It would be above 75%, I would suggest.

We were working on the civil law basis, obviously, with eminent High Court judges in charge. They would say we just have to be at 51% to decide to accept. I would say that, in most of our acceptance decisions, we took none as marginal as that. The feeling was that it was between 80% and 90%, every case we looked at, if not higher.

● (1205)

**Mr. Doug Eyolfson:** You would be confident—and again, this is guesswork and I understand we're not nailing down numbers—that if someone presented with phocomelia, with the ear abnormalities that you mentioned as well, despite not having any records but being of the appropriate age, you'd say it's extremely likely that this person's problems are due to thalidomide.

**Dr. Martin Johnson:** Yes.

Dr. Newman had a kind of scale with something like 25 points. Most of the ones that he recommended would be well over 20 out of 25 on that scale. The challenge comes, though, that there are always other possibilities. There was one person born in the middle 1970s who was strongly believed to have been exposed to thalidomide but with no documentary evidence, who came in at about 24 out of 25 on Dr. Newman's score, but we couldn't accept because there was no evidence of probability of exposure. It's a combination of the availability of the drug plus the damage pattern.

**Mr. Doug Eyolfson:** All right, thank you. I still have a couple of minutes here.

Dr. Vargesson, you had said that much of the damage takes place during embryogenesis. Has anyone found, so far, any actual genetic consistent abnormality with it, some changes at the DNA level?

**Dr. Neil Vargesson:** I'll answer that a different way. There are phenocopies of thalidomide embryopathy, so there are genetic conditions that look very similar to thalidomide embryopathy, such as Holt-Oram syndrome, and Okihiro syndrome. We can now genetically test for those, so we can now discount that they're thalidomide. There's a possibility that, in the past, some people may have had those conditions and it had been thought to have been thalidomide. There has been a lot of research looking at the mechanisms of thalidomide, and there are a couple of genetic targets. There's a gene called cereblon, which is ubiquitin ligase, that takes away gene function in cells. That's been show to be—

**Mr. Doug Eyolfson:** Sorry to interrupt, but I'm running out of time.

If you had, theoretically, someone who is presenting with abnormalities, because there are some of these phenotypes that someone might have, and you say you have some of these genetic tests, if you tested it and they did not have that genetic phenotype but had the anatomic abnormalities that you've seen in some of these thalidomide victims, might that be a useful rule-out test? That is, you've ruled out a natural genetic abnormality and can say with certainty that this would be thalidomide damage?

**Dr. Neil Vargesson:** Yes.

**Mr. Doug Eyolfson:** All right. Thank you.

**Dr. Neil Vargesson:** There's a group in Brazil, Lavinia Schuler-Faccini's lab, and she's actually looking at thalidomide survivors—adult and youth patients. Right now, they're doing genetic screening in those patients to try to identify which genes may be affected in thalidomide survivors. Hopefully, her work will answer your question fully, because you might be able to actually identify genetics, or gene changes in individuals with thalidomide damage.

**Mr. Doug Eyolfson:** Thank you.

**The Chair:** Thanks very much.

Dr. Carrie, I understand you're going to split your time with Mr. Brown?

**Mr. Colin Carrie (Oshawa, CPC):** No. He can have the full time.

**The Chair:** That's nice and simple.

Mr. Brown, welcome to our committee.

**Mr. Gordon Brown (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC):** Thank you very much, Mr. Chairman. I want to thank you for your efforts on this important issue. I want to thank the committee for finally undertaking this study of the thalidomide survivors contribution program, and thank the witnesses for coming today.

As you all know, I brought this issue forward on behalf of a constituent of mine, Mr. Terry Bolton, who will appearing on Thursday here at the committee. When I brought that forward, you all know we discussed the history of this issue. We don't need to go over that tragedy that happened about 55 years ago. What we want, and what I have asked for a number of times and pushed the minister on, is to give those forgotten thalidomide survivor victims an in-person interview.

My first question is to Mr. Mooney from Crawford. About how many people were rejected from the program who had made applications under the thalidomide survivors contribution program? How many people received rejection letters who had applied to be compensated?

● (1210)

**Mr. Michael Mooney:** I thank you for the question. I'm going to defer you to my colleague Brenda Weiss, who is the senior project manager and who's actually dealing with the day-to-day operation of the project.

**Ms. Brenda Weiss (Project Manager, Thalidomide Survivor Compensation Program, Crawford):** There were 167 individuals who received decisions that they did not meet the eligibility criteria. Those were for individuals who submitted applications prior to May 31, 2016, which was the deadline to submit the application.

**Mr. Gordon Brown:** I understand that your team—and we've already heard this—is following the guidelines set by Health Canada. Quickly, because I don't want to use up all of my time, I have a number of questions, could you please explain the scope and the extent of the medical assessment that had been done on those rejected claims?

**Ms. Brenda Weiss:** With the criteria we were provided, each individual claim went through three different tiers of analysis. We had someone at our level at Crawford review the person's presentation to see whether or not they presented proof to meet any of the three eligible criteria. If they presented medical documentation, we then forwarded their claim to a medical professional, and they also reviewed the claim to see whether or not the individual provided proof of one of the three criteria. They would provide that report back to Crawford, the administrator. Then I would make the final review, along with my colleagues, and verify whether or not the proof was provided. Then the ultimate decision was delivered to the claimant.

**Mr. Gordon Brown:** Part of that criteria included producing documentation, a prescription for thalidomide at that time, or a doctor testifying to that effect. I know in the case of Mr. Bolton, because it's so many years ago, he does not have the ability to get a prescription because the doctor has long passed away. There were fires at the various pharmacies in Gananoque, his hometown, so there is no record of these.

What we've been asking for is an in-person interview. I do not believe that an in-person interview was part of that process because we've already heard today from Mr. Johnson that there is a high degree of confidence that if a person was born in that period of time, and thalidomide was available, and if they have phocomelia, their mothers were in fact likely to have taken thalidomide, whether it be a sample drug or other case where there's an inability to produce those prescriptions.

Why has there not been an in-person interview to see if those people who have been denied compensation could have met that criteria if they were able to produce those documents? Obviously, it's going to be impossible. These people have lived a lifetime, really, of discrimination, of pain and suffering, yet because they can't produce a prescription they're not going to be compensated.

Why has there not been an in-person interview of those people?

**Ms. Cindy Moriarty:** I don't know if that's a fair question for Crawford as they're administering the existing criteria. All I can say is that decisions were made by the government to establish the program with the criteria that we have, which doesn't include in-person interviews. It just includes the three criteria that I outlined.

All we can talk about today is how that program is implemented. We're not in a position to talk about what it could have been or might have been, and Crawford is just implementing our direction.

● (1215)

**Mr. Gordon Brown:** If the minister were to direct Crawford to do an in-person interview, then could that happen? My question is to Ms. Moriarty.

**Ms. Cindy Moriarty:** That would be possible through a policy process. It might require a cabinet decision. I don't want to commit the minister to anything, but—

**Mr. Gordon Brown:** Obviously, you can't commit the minister to that, but the minister could do that. The minister could direct Crawford, through Health Canada, to give these forgotten thalidomide survivors an in-person interview, because that's what they've been asking for.

We've heard from Mr. Johnson that there's a very real likelihood, and he puts it at a high number, a high probability, that the mothers of these people who have phocomelia ingested thalidomide, and if they fit the period of time....

It is really up to the minister. That's my question to Ms. Moriarty.

**Ms. Cindy Moriarty:** I can't answer on behalf of the minister.

**Mr. Gordon Brown:** But the minister could direct Health Canada to—

**Ms. Cindy Moriarty:** You're asking a hypothetical....

**Mr. Gordon Brown:** The minister could direct Health Canada to make that decision.

**Ms. Cindy Moriarty:** Not that linearly, but it's possible, yes.

**Mr. Gordon Brown:** Thank you.

**The Chair:** Thank you very much.

Mr. Nantel.

[*Translation*]

**Mr. Pierre Nantel (Longueuil—Saint-Hubert, NDP):** Thank you, Mr. Chair.

I'm replacing my colleague Don Davies here. I'm very pleased to do so, because I narrowly avoided the illness, in the sense that I'm exactly the same age as the people affected. I was quite well acquainted with two people affected. You should have seen the emotion expressed by these people when, after my colleague Libby Davies tabled the motion, the House acknowledged them. The NDP has been working on this case for a long time. We must acknowledge the work of Libby Davies, who was a health critic for this topic in particular, and of Don Davies, who took over. Coincidentally, they have the same last name.

I'm not an expert in the field, so I'm pleased to see English experts among us. When a problem seems unsolvable, we usually look at what has happened and at the expertise acquired elsewhere.

How do the developments in the thalidomide victims' cases in Canada compare with the developments in other countries? My question is for the two British experts, who are speaking today by videoconference.

Ms. Moriarty, since you are the one asking the people from Crawford to administer the program, I'll also ask you the question. What are the best practices?

As my colleague Mr. Brown said, the people affected by this drug face unspeakable difficulties in life that any normal person wouldn't have to endure. The compensation for these people doesn't involve huge amounts for a government, especially since, in this case, everyone clearly failed at their job. This includes the pharmaceutical company and the various governments that approved the drug.

Ms. Moriarty, what expertise has been acquired worldwide on how to manage this situation and compensate victims over the long term? A few years ago, when we tabled our motion, we argued that, although the people affected had been compensated and had received support, their disabilities or defects had resulted in wear and tear and premature aging. This was specific to each case.

From this perspective, what are the best practices worldwide?

**Ms. Cindy Moriarty:** Thank you for your question.

I want to respond to the best of my ability. However, you'll understand that I'm limited in what I can say or hypothesize regarding the existing program and its management.

● (1220)

**Mr. Pierre Nantel:** I want to congratulate the committee for inviting witnesses from both sides of the fence.

**Ms. Cindy Moriarty:** Exactly.

I can assure you that, before establishing the program, we tried to find out how other countries handled this matter. The experiences are quite varied. We looked closely at the United Kingdom's model. Finally, we decided that we needed to meet the same criteria implemented by Canada in 1991.

There's no ideal solution. Even with the scientific advances, there's no diagnosis or definitive test. Even though we can deduce certain things and identify some possibilities, we can't be 100% certain that thalidomide caused the condition of the people affected. In the establishment of objective evidence, all international experiences are a mix of objective criteria and probabilities.

Dr. Johnson has just explained—

[*English*]

I feel bad for speaking in French. I don't know whether you're following me, when I'm talking about you.

**Mr. Pierre Nantel:** Actually, I thought they had translation. If they don't, please speak in English.

**Ms. Cindy Moriarty:** Okay. I want to respect you, since you asked the question—

**Mr. Pierre Nantel:** That's very nice, but we—

**Ms. Cindy Moriarty:** In terms of the U.K. model, I was just going to say that it's a mix of probabilities and objective evidence, so there are a number of tiers that they go through. It's not a pure probability model. I think you'll find across the world that there are variations in that regard.

In Canada, we have the model that we do and it's managed the way that it is.

**Mr. Pierre Nantel:** Before going to our international witnesses, according to your knowledge, where have the thalidomide syndrome or effects been diagnosed across the world and in how many countries?

**Ms. Cindy Moriarty:** Thalidomide was distributed in more than 46 countries worldwide. It was developed in Germany and they did testing in 1953-54. To the best of my knowledge, the drug became available in 1957—which is the year I was born, just FYI, so I'm in the same generation. It came to Canada in 1959, but it was variable in Europe and other countries in the late fifties and early sixties.

**Mr. Pierre Nantel:** Thank you, Mrs. Moriarty.

Mr. Johnson, do you have complementary answers to my question? Maybe he didn't get it at all. Did you get translation on the other end?

Actually, they don't hear me at all and I don't know sign language.

**The Chair:** Dr. Johnson, can you hear us?

**Dr. Martin Johnson:** Yes, I can, but you've gone fairly quiet at this end. I don't know what's happened with the audio, but the audio level seems to have dropped.

**The Chair:** Generally speaking, we're not a quiet group.

Could you repeat, Mr. Nantel?

**Mr. Pierre Nantel:** Thank you.

Dr. Johnson, I'm no specialist in health issues like this, but after six years of being in Parliament, one of the most immediate solutions that comes to mind is to ask what other countries done. I was asking Ms. Moriarty about what she referred to as other countries' actions. What have other countries done to solve the issue and help these patients?

**Dr. Martin Johnson:** To the best of my knowledge, they have all found a clinical medical expert with long experience in the particular subject. Austria has recently established a scheme, with a government panel advised by a professor of genetics, and the Germans have their Contergan Foundation, which uses Dr. Jurgen Graf. We consulted Dr. Graf, but he doesn't like delivering legal documents in English because it's a little bit outside his language skills. However, he gives his expertise.

In their recent settlements, the Australians used Professor Janet McCredie, with one other, I think.

Brazilians have a government panel set up, advised by Professor Lavinia Schuler-Faccini. Their situation is different, since thalidomide is still available in Brazil and there are still babies being born. I think the most recent that I heard of was in 2012. She described it to the WHO meeting, about trekking through the jungle to identify cases to track down the prescription and where the drug had come from.

[*Translation*]

**Mr. Pierre Nantel:** Come on!

[*English*]

**Dr. Martin Johnson:** Around the world, there is still a lot of current experience. What's happening, as in the U.K., is that the long-established expert is transferring the knowledge and training up an apprentice. However, to be an apprentice in this, you seem to be a professor of genetics to start with, or something of that order.

I think there is a trend towards bringing in the geneticists now, rather than the orthopaedic specialists, because there are, as Dr. Vargesson said, a number of genetic phenocopies of thalidomide—that is, genetic disorders that produce the same results. In saying that, most of what we dealt with were inquiries from people whose condition was very different from the normal thalidomide pattern. Our usual response to those people was that if they could produce evidence of their mother ingesting the drug, we would look at it. However, we're referring back to all the old reports from where it was known that mothers had taken the drug—that was definitely evidenced—and how their babies came out. None of those would have had transverse or unilateral reductions.

There are patterns, so you need a clinician with expertise, and that's what's happening in the different countries around the world.

● (1225)

**Mr. Pierre Nantel:** Professor Vargesson—

**Dr. Martin Johnson:** I think the person who you took on in the late sixties and early seventies who advised on a lot of Canadian cases was Dr. Newman. He told me he had spent time in Canada looking at your cases for you. I don't know how many, but he has certainly been around.

**The Chair:** Thank you very much.

Now we go to Mr. Ayoub.

[*Translation*]

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

I want to thank the witnesses for their presentations.

Regarding the Thalidomide Survivors Contribution Program, there are still 167 individuals whose applications were rejected because they didn't meet the eligibility criteria. What are the chances that there are thalidomide victims among those 167 individuals? Do you have any idea?

[*English*]

**Mr. Michael Mooney:** We're not qualified to make a determination like that. That's not our role in the process. Also, similar to what other people have said, I'm neither a medical doctor, a scientist, nor an expert in this field so it would be—

[*Translation*]

**Mr. Ramez Ayoub:** You determine whether the applicant meets the three criteria. If so, you consider the applicant a victim, and the applicant can obtain compensation. However, if the person doesn't meet the three criteria, the person's application is rejected and you don't ask further questions.

Is that how Crawford administers the program?

[*English*]

**Ms. Brenda Weiss:** When people submitted their applications, we would write to them if the proof was not sufficient as defined in the program. Sometimes we would speak with them and review the material they presented, and try to help them think of other avenues they could pursue to try to help them meet the criteria. Ultimately, the criteria were defined and—

[*Translation*]

**Mr. Ramez Ayoub:** From what I understand, you provide some guidance. There are still 167 individuals who don't meet the criteria.

Since thalidomide, have other drugs or medications had similar effects, according to the research conducted by your company?

I'll also ask Health Canada to answer this question. Do you know of other drugs that had similar effects and that were removed from the market?

● (1230)

[*English*]

**Mr. Michael Mooney:** On behalf of Crawford, we have no knowledge of that.

[*Translation*]

**Mr. Ramez Ayoub:** What about Health Canada?

**Ms. Cindy Moriarty:** I don't have any specific knowledge. It's outside my area of expertise.

I know other drugs were used to treat nausea in pregnant women, but they didn't necessarily have the same effects.

**Mr. Ramez Ayoub:** If you can't answer me right now, I would appreciate an answer later, if possible. You can ask your Health Canada colleagues.

Since the thalidomide case, has Health Canada changed the way drugs are approved for Canadians?

**Ms. Cindy Moriarty:** Yes.

**Mr. Ramez Ayoub:** I imagine so.

**Ms. Cindy Moriarty:** Absolutely.

To my knowledge, thalidomide was, as we say in English, a watershed moment for drug approval.

All regulations, the drug approval process and the clinical trials—

Sorry. I don't know the specific French vocabulary.

[*English*]

**Mr. Ramez Ayoub:** You can continue in English. That's okay by me.

**Ms. Cindy Moriarty:** I feel bad for our guests.

It was definitely one, if not the one, of the watershed moments in terms of clinical trials, and regulation of samples, distribution of drugs, and approval of drugs. For sure there have been significant changes since those days.

[*Translation*]

**Mr. Ramez Ayoub:** Do you see the link I'm trying to make when I ask whether there have been other drugs of this type or whether there have been changes in the way drugs are approved before they're made available?

I'm wondering about something. I want your opinion, as an expert at Crawford. I also want Health Canada's opinion, and maybe our external experts' opinion.

I realize that, until now, the victims have needed to provide proof of their condition. The victims must show that drugs were indeed taken, obviously by their mother in the case of thalidomide.

According to the Canadian justice system, we're innocent until proven guilty. However, in this case, the victims bear the onus of proof. Isn't there another way to support them, up to a certain point, and help them meet the criteria, as I heard Ms. Weiss say? Isn't there a way to reverse the onus of proof and put the onus back on pharmaceutical companies, and likely on Health Canada, which approved the drug initially? This would give Crawford another type of mandate, which would be issued by ministerial order, or by Health Canada.

I don't have much time left, but I want your opinion on the matter.

**Ms. Cindy Moriarty:** I'm trying to decide who will answer you.

**Ms. Theressa Bagnall (Senior Manager, Program Development, Office of Grants and Contributions Services and Innovation, Health Programs and Strategic Initiatives, Strategic Policy Branch, Department of Health):** Do you want me to respond?

**Ms. Cindy Moriarty:** Okay, go ahead.

**Ms. Theressa Bagnall:** It's a major challenge. Based on today's presentations and on our other information, we know there are different ways to provide evidence.

It would be difficult to reverse the onus of proof because we know that various conditions are very similar to the condition caused by thalidomide. Even today, birth defects occur regularly within the general population. The program was established to support thalidomide victims. The challenge is to determine the difference between the actual victims and the others.

**Mr. Ramez Ayoub:** Could the three criteria be included in the new process to ensure greater eligibility and to avoid making victims responsible for defending themselves and providing evidence?

There are 167 individuals who are left over and who don't seem to meet the criteria. However, they may still be among the victims. Today, nobody can say that none of those 167 individuals suffer from a condition related to thalidomide and that none of them are denied compensation. If nobody can say so, the system may need a review. That's what I think.

● (1235)

**Ms. Theressa Bagnall:** The government must make the decision.

**Mr. Ramez Ayoub:** The government receives advice. No decision is purely political. Experts help make the decisions.

[*English*]

**The Chair:** Your time is over. That completes our seven-minute round.

Mr. Mooney, you said you referred the file to a medical professional. I think you said that.

**Mr. Michael Mooney:** Yes. It was my colleague who said that, but yes, that's correct.

**The Chair:** Why do you do that? What is that medical professional expected to do with the file?

**Ms. Brenda Weiss:** The reason we did that is that we are not medical professionals. We wanted to make sure we had not missed anything, so we turned it over to someone who was more qualified to double-check to make sure nothing had been missed.

**The Chair:** What were they checking?

**Ms. Brenda Weiss:** If medical documentation was submitted, they would review all of the medical documents to see if any of the three criteria were met with the submission of that medical documentation.

**Mr. Michael Mooney:** Medical documentation is often replete with acronyms, codes, or language of people in the profession that, unless you are involved in that, isn't necessarily in your direct knowledge. It was done as a secondary way of making sure that medical documents that were provided were reviewed by people with the best likelihood of knowledge or understanding of interpreting the documents to determine eligibility.

**The Chair:** I just think of my own doctor. He wouldn't diagnose anything without an examination. I don't know any doctor who would.

Anyway, moving on, we'll go to Dr. Carrie.

**Mr. Colin Carrie:** Thank you very much, Mr. Chair.

I want to thank all the witnesses but also my colleagues around the table for allowing us to look at this, because I think that at the end of the day the purpose of this was to compensate people who were horribly damaged by this drug.

I want to talk to Health Canada first.

I understand you did your research and helped design and regulate the requirements for eligibility, the criteria for the compensation package. My understanding is that in its report in 2014, the WHO's meeting of experts on thalidomide embryopathy recommended that genetic testing and clinical genetic evaluations be done to help diagnose thalidomide embryopathy where possible.

I know the timeline. That was in 2014. You were well into your work. Did you take those recommendations into account when you were coming up with the criteria that you gave to Crawford?

**Ms. Cindy Moriarty:** I'm trying to recall the timeline, quite frankly, concerning when the actual report was published, because the event was in 2014, which is around the same time as the parliamentary motion. I wasn't personally involved in the design of the program, but I know that at the time of doing so it is typical to do as much research and international scanning as possible, and then at the end of the day a decision is made.

We have looked at that report since. I think I may not be up to date, after hearing Dr. Vargesson today—there are constantly more developments—but to my understanding there are about 13 or 14 conditions that present in similar ways to thalidomide and can't be ruled out through genetic testing.

We are keeping an eye on this as well. We have had recent discussions with the U.K.'s Thalidomide Trust—just as recently as last week, actually—and they confirmed that the algorithm hasn't been proven or verified yet. They're very hopeful. It still is just a probability, not a definitive test, but we constantly keep our eyes open for emerging science.

**Mr. Colin Carrie:** I'm really glad to hear that. In view of the fact that many claimants have been rejected without a medical examination that would include this genetic testing, how would you change the criteria today, considering this new medical testing that's available, such as genetic testing?

**Ms. Cindy Moriarty:** With all respect, I'm not really in a position to answer that question by speculating on changes. What I can do today is explain how the program is run and answer questions about the existing program.

**Mr. Colin Carrie:** I can understand that, but maybe I'll ask the same question to Crawford & Company. In your opinion, given the information that we're getting today plus the fact that in 2014 the WHO actually recommended that genetic testing and clinical genetic evaluations be done to help diagnose thalidomide embryopathy where possible, if you were going to look at the criteria, given this information, what could be done better to assess the rejected claimants?

● (1240)

**Mr. Michael Mooney:** With all due respect to the same caveat my friend gave, we're not really in a position to comment about how this may change. It involves expertise and understanding of the disease and of the arising science in a much more comprehensive manner than I could profess to understand and, therefore, modify a program based upon it.

Again, our role is limited to executing the program as designed and delivered to us as a third party administrator, not to sit and ask what about this and what about that, unless doing so is contemplated in the engagement from the outset.

**Mr. Colin Carrie:** I understand. It's a difficult question to ask, and there may have to be a political decision moving forward. Because neither of you feels you have the expertise to answer this, I'll ask Dr. Vargesson.

You have a paper titled, “Thalidomide-induced teratogenesis: history and mechanisms”. You state, “Thalidomide embryopathy is a severe condition and affects many tissues, all of which can occur independently in humans but rarely together.” Does that mean that if a patient presented with a number of such conditions, the assumption should be thalidomide?

Also, from what you've heard today concerning the Canadian system criteria, would you recommend to our colleagues down at the end of the table that perhaps the criteria could be changed?

**Dr. Neil Vargesson:** Claus Newman, one of the doctors who is working with the Thalidomide Trust, classified thalidomide embryopathy as a syndrome, a collection of conditions that are independently seen. If you see a combination of those conditions and the patient is of the right age and has had some sort of exposure past, then yes, you would want to expand your criteria to cover all bases. Isn't that right?

You get various damage. There's nervous system damage. There's eyes, ears, internal organs, genitalia, limbs, gastro-intestinal tract. Each of those tissues or systems can be affected independently of every other. If you see a combination of those conditions, you would say there's a possibility, yes, but you would need to see a clinician to get a proper diagnosis.

**The Chair:** The time is up.

**Mr. Colin Carrie:** Thank you for your advice.

**The Chair:** Go ahead, Mr. Kang.

**Mr. Darshan Singh Kang (Calgary Skyview, Lib.):** Thanks to all the witnesses. The more questions we ask, the more questions are raised.

In 1991 when the government established an actual extraordinary assistance plan, there were only 97 living thalidomide survivors, and in 2015 when the government came out with the thalidomide survivors contribution program, it opened it up to more survivors who could have been affected by thalidomide.

When we recognized there were only 97, what was the reason behind opening it up so more survivors could come forward? Why were they overlooked, or why were they not included in the first list of those 97 survivors?

**Ms. Cindy Moriarty:** The program in 1991 goes back to a registry that was created when the federal government worked with provincial and territorial governments back in the early sixties when the thalidomide crisis broke, to identify babies born with thalidomide and put their names on a registry. That registry was safeguarded, so there was a number of names that the government had available. In 1991 when the decision was made to do this one-time extraordinary assistance plan, efforts were made to find people on the registry.

I believe in 1991 there were 109 individuals. There are 97 of those individuals who are currently living. Some have since deceased. That was back in 1991.

The current program was established in 2015, and the decision was made to use the same criteria that were used in 1991 and apply them now. In 1991 it was a one-time payment. The intention of this program is to provide financial support and medical and health support for the rest of their lives.

Those who qualified in 1991 were automatically admitted into the program. They didn't have to go through another application process. It was decided that we should give an opportunity to those who might not have been identified back at the time for various reasons. A number of individuals came forward, and of those, 25 new individuals have been accepted into the program, for a total of 122.

It's much easier to do these numbers in English than in French.

Do you want to add something to that?

● (1245)

**Ms. Theressa Bagnall:** I could add that in 1991 the criteria were developed through a process that involved the War Amps society as well as the newly emerged Thalidomide Victims Association of Canada. They were representing approximately 400 people who believed themselves to be thalidomide survivors. That's where those criteria came from. It was through that consultation process.

The other reason the program was opened up in 2015 to individuals was that there was no social media in 1991 to help with awareness of the extraordinary assistance plan, and perhaps people were missed, so there was an acknowledgement of that. Opening up the program in 2015 allowed the basket to be recast again to collect those people.

I am also aware of one individual, in 1991, who had received a settlement through a drug company and felt fairly comfortable. That individual voluntarily declined the settlement in 1991 because it was a fixed amount of money to be distributed among all of the identified survivors. That individual voluntarily excluded him or herself from the program, which meant that he or she would not have been eligible for the program in 2015; hence, another reason the program was expanded.

**Mr. Darshan Singh Kang:** My concern is that it's 24 years later and they still have to meet those three eligibility requirements. How is it going to help those people who came forward 24 years later? That's what concerns me. We should probably have broadened the eligibility requirements a bit so those people could qualify for the compensation and that's where my concern is. They couldn't qualify in 1991, and why did we open it up? How many people came forward after that who were left out? That's what my concern is.

Please reply very quickly, please.

**Ms. Theressa Bagnall:** Not all of the individuals who applied in 2015 applied in 1991, so we have new individuals applying this time around.

**Mr. Darshan Singh Kang:** My concern is that it took 24 years for the bulk of those people to know there was some kind of compensation program. There was no education or outreach to those people when they came forward before, so that's where my concern is.

Thank you.

Dr. Johnson—

**The Chair:** Sorry, your time is up.

I have a blank page here. Is it Mr. Webber or Dr. Carrie?

**Mr. Len Webber (Calgary Confederation, CPC):** I have a very quick question and then I'll pass it on to Rachael Harder.

**The Chair:** All right.

**Mr. Len Webber:** This is directed to Martin Johnson. Mr. Johnson, you talked about cases of late ingestion of thalidomide that occurred in the U.K. How did you deal with that? It was late ingestion after the thalidomide warning was out.

**Dr. Martin Johnson:** It was dealt with before my time, but there were, I think, 12 cases of children born in 1963, so there were pharmacists, and so on, who hadn't cleared the drugs out when they were supposed to.

**Mr. Len Webber:** Okay.

**Dr. Martin Johnson:** There were two cases of those born in 1965 that we class as “bathroom cabinet accidents”, where people had not realized that the bottle of tablets that said “to be taken as advised” was actually thalidomide. In each of those cases, I'm assured, the actual tablets were produced. Out of over 500 claims on the British system you have 14, maybe 15 cases where it was settled on that basis early on and the tangible evidence was available.

**Mr. Len Webber:** All right.

I have a quick question. In Canada's case, how many do we have making claims who have had late ingestion of thalidomide?

● (1250)

**Ms. Cindy Moriarty:** I'm not sure if I have the number handy of how many, but I think the latest birthdate we have in terms of a confirmed survivor is 1964. So we have accepted people who were born after the drug was withdrawn.

**Mr. Len Webber:** I see.

I'll pass it on to Ms. Harder.

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

My question is for Mr. Vargesson. Mr. Vargesson, you've talked a bit about genetics and the fact that it can actually go a long way to disprove other causes, and that looking at other offspring or siblings can also be used in order to see the impact that thalidomide may have had on a victim. Given these statements, can you conclude that extensive testing and observation can all but disprove other causes in the case of thalidomide victims, let's say, someone with multiple issues, a genetic test, and normal children, for example?

**Dr. Neil Vargesson:** I'm not sure what the question is. Are you asking if we can rule out thalidomide embryopathy or if we can rule it in?

**Ms. Rachael Harder:** I guess you can consider both angles.

**Dr. Neil Vargesson:** The genetic testing that's available right now is for only a few conditions, and these are phenocopies of thalidomide, such as how arms intergrow, and a few others. These are limb reduction deformities, and you can use those definitely to say, “Yes, this is not thalidomide.” If a patient has a family history of abnormalities, then it's probably genetic; it's not thalidomide. If they don't have that and they have a collection of problems, then, yes, you have to consider there's a possibility.

**Ms. Rachael Harder:** Thank you.

I have a question for Health Canada. Now that we've gone through the majority of cases—and obviously there are these four more that are in discussion right now—if you were to look at the criteria that exist today, would you suggest that any changes be made to these criteria in terms of being able to come to conclusions with regard to whether or not thalidomide was in fact used?

**Ms. Cindy Moriarty:** I think I would respond similarly to how I did previously on that. I'm not in a position to speculate on what the program could be or what a different program might look like.

**Ms. Rachael Harder:** I'm not asking you to speculate, but there are always lessons learned along the way. If there's a lessoned learned, what is it? Or is there one? Maybe it was done perfectly.

**Ms. Cindy Moriarty:** Nothing is done perfectly, certainly not at my hands.

None of us had a great knowledge or expertise about thalidomide when we took on this program. It's been quite eye-opening. The only lesson learned that I have had, frankly, is how uncertain we still are, 60 years later, about a number of factors, and that we have choices in the way decisions are made to identify thalidomide victims either based on objective criteria or based on probability and supposition. There are two directions to go, and within those two directions there are various kinds of options.

Canada opted to go along the objective criteria route. Other countries have opted to go on the basis of probability or a combination of those two. In either case it's not perfect. I don't think any of us who have been managing any of the programs internationally can say with 100% certainty that every individual who has been admitted and identified is in fact a thalidomide survivor, and I don't think we can say with certainty that every single individual who has been denied internationally is not. The bottom line and the lesson learned is that we don't know, and we don't know in every single case. Sometimes we know more than in other cases. All I would say in terms of a lesson learned is that we really need to pay attention to the science and the research and the development.

Is the commitment for this program something that will continue over the lifetime of the thalidomide survivors? It will be evaluated. It will have its moments to reconsider and review whether or not there are changes needed. I just can't speak to those more specifically today.

● (1255)

**The Chair:** Time is up.

Ms. Sidhu.

**Ms. Sonia Sidhu (Brampton South, Lib.):** Thank you to all the presenters.

My question is for Mr. Johnson. It is very helpful for the committee to hear an international perspective.

Did the United Kingdom use any third party adjudicator, as we did in Canada?

**Dr. Martin Johnson:** I'm sorry, I'm not sure of your terminology.

We had a committee led by a High Court judge that included patient advocates, legal experts, and medical experts evaluating the medical report, having already passed through a process of increasing the probability of the individual's being thalidomide. By the time we would get to our committee process, we already had a high probability that the person's mother was in a place in which it was likely that thalidomide would have been available and prescribed to her and that the damage could have been caused by it.

We're then looking for the diagnostic issue, which is, as one of your colleagues said earlier, that such things as genetic testing come in to show what is not thalidomide. There is no genetic test to show that somebody is thalidomide-damaged, but genetic testing eliminates people who might otherwise look as if they are.

**Ms. Sonia Sidhu:** Okay.

Have the children of thalidomide survivors ever appeared to inherit the abnormalities of their parents?

**Dr. Martin Johnson:** No. There were a couple of claims in the 1990s that this had happened, but what it really pointed to was the defects of the original diagnosis, whereby people with genetic phenocopy patterns that looked like thalidomide effects but were not went on to have children, basically proving that the parent's damage was not thalidomide also.

**Ms. Sonia Sidhu:** My next question is to Dr. Vargesson.

Can you describe what research is necessary to better understand the impact of thalidomide on the human body? How would this support better diagnosis of thalidomide embryopathy?

Both of you can give me the answer.

**Dr. Neil Vargesson:** At the present time, the funding into research on thalidomide embryopathy and the way the drug acts on the embryo is pretty much at zero. There's very little interest in doing that research, because the drug is no longer, in our countries anyway, used in situations that might cause those problems.

Where the funding goes is based on drug safety and how you can make the drug safer. That's the research area in which we're going to find out how this drug acted and understand a bit more about diagnostic tools that we could probably use from it.

That's what I'm doing right now. It's what a few other labs around the world are doing. The best animal model would be primates, monkeys, but there are ethical reasons we can't use those, which is why we use chickens, fish, and mice, and ultimately clinical trials.

It's going to take some time to understand the exact mechanisms, because the funding is just not there at the moment.

**Ms. Sonia Sidhu:** Okay.

My next question is to the Crawford company, Mr. Mooney.

Does the application review process involve a medical interview on any assessment of the applicant? Is any interview required or is there any medical assessment when you select an applicant?

**Mr. Michael Mooney:** Do we perform or solicit or conduct a medical review of the person, in person?

**Ms. Sonia Sidhu:** So any requirement, do you have that?

**Mr. Michael Mooney:** No.

**Ms. Sonia Sidhu:** Okay.

What kinds of challenges are your organization facing in reviewing the applications?

**Ms. Brenda Weiss:** In terms of our challenges, I think it's more the challenges of the persons who are presenting their applications. As many have already mentioned, those who have not been able to meet the criteria have expressed that it's very difficult for them to find documentary proof because so much time has passed. For us, we try to help find ways to help them find that proof. It could perhaps be through discussion, so if, say, they spoke about perhaps someone who had direct knowledge we would ask them if they could go get an affidavit from that person who can provide the details of the ingestion.

I think the challenges were more from their perspective in trying to meet the criteria. For us, the challenge was trying to help the people meet the criteria.

● (1300)

**The Chair:** Time's up.

Mr. Nantel, you have three minutes.

**Mr. Pierre Nantel:** Thank you very much.

[*Translation*]

My first question is for Mr. Vargesson.

Mr. Johnson said earlier that certain genetic tests help determine whether the patients' symptoms are caused by something other than the thalidomide taken by their mother. However, there's no genetic test that proves the condition is caused by thalidomide.

I want to hear your comments on the matter. Do you share this view? I think so.

[*English*]

**Dr. Neil Vargesson:** Yes. There is no genetic test to say you are definitely. There are tests that could rule out other conditions that are phenocopies of thalidomide, but there's no test that says you are definitively thalidomide.

**Mr. Pierre Nantel:** I know, for example, that some patients came to Health Canada saying that they had tests demonstrating that it could not be anything else other than thalidomide, but there is no test that could prove it was thalidomide. If that's the case, I think we are quite close to some sort of certainty. It can't be anything else but you cannot demonstrate that it is, so we're very close. It's a question of semantics, if I'm not mistaken here.

I'll forward the question to the Health Canada people. How many cases of that nature, of that close proximity to a diagnosis, have you had to decline?

**Ms. Cindy Moriarty:** I wouldn't know specifically. We don't see each case. That's Crawford's role. I am personally aware because individuals will then sometimes write to Health Canada to appeal their case and they have included letters from geneticists. I think there's one, perhaps two, where what I have seen is that the geneticists said, “In my opinion it could be, it is possible, it is likely.” I have never seen a geneticist's report that says, “Yes, it is.” I would look to the experts here perhaps to help, but to my knowledge, there are 13 or 14 conditions that present similarly to thalidomide for which there is not genetic testing.

It's not like we can rule out 99.9% of everything and that leaves us with only the possibility of thalidomide. We can rule out a number of things and that leaves us with a smaller list including thalidomide. But I'm not 100%.... Dr. Vargesson is nodding, but I'll let him speak for himself.

**Mr. Pierre Nantel:** Before I go back to Mr. Johnson and Mr. Vargesson, I'll ask Mr. Mooney from the company to answer precisely how many have been declined with such results coming from geneticists.

**Ms. Brenda Weiss:** I am aware that there are people who submitted the reports, but I don't have the number off the top of my head. Sorry.

**Mr. Pierre Nantel:** You may want to transmit this to the committee because if we're talking about two, three, four, or five, I can't believe we would say no with such close proximity for such small amounts of money, which would change the lives of these people, but I'll let Mr. Johnson speak.

**Dr. Martin Johnson:** It is a very tough business dealing with applications from people who believe their disability, their damage, is caused by thalidomide, and I, unfortunately, have had to say no to almost 600 such people. But in none of those cases did I think there was any room for doubt that thalidomide was not the cause, for the various reasons I gave earlier.

I would be very surprised if there were any medical expert in North America who could say confidently, “This can only be thalidomide; we can rule out all the other possible causes”, because the causes of the majority of defects, particularly limb reduction defects, are still unknown. Some limb reduction defects may be genetic. Some may be, as we know, thalidomide. Some may be some other environmental factors as yet undiscovered, as Janet McCredie demonstrated. She found three children with thalidomide phenocopy damage who could not have been thalidomide children, and she tracked back to the probable exposure date of the mother and found three different farming chemicals, insecticides, that had been ingested by the mother that had caused damage that looked like thalidomide damage.

It would be a very unwise doctor who would say that there can't be any other possible cause.

● (1305)

**Mr. Pierre Nantel:** Mr. Vargesson, do you want to complete?

**Dr. Neil Vargesson:** I would agree with Dr. Johnson. It is difficult. There are so many other factors involved. We know 13 or 14 different conditions that are very similar to thalidomide, and you can genetically test for some of those, but not all of them. We don't know. Embryonically, we're still unsure how the embryo forms from a single cell to a fully formed organism, so to understand all of these different things that can go wrong is still unknown.

I think common sense is needed, yes. You could look at the probabilities and say they were born in the right era, they may have had some exposure, and they have some conditions that appear to be thalidomide, but that's as far as you can go, that there's a possibility.

[*Translation*]

**Mr. Pierre Nantel:** Thank you.

[*English*]

**The Chair:** Okay, the time is up.

That completes our session for this morning. I want to thank all of our witnesses for your answers on a difficult issue and a troublesome subject really. I want to thank our U.K. presenters especially because you're taking the time out of your day to do this for us. It is very helpful.

I want to thank the technicians who did this. We have better video conferencing than CBC news has, I think. They have done a great job of connecting us.

Thanks very much, everybody, and we're going to take just a quick break and then we have a little committee business. I have to talk about witnesses for our next presentation, and I think Mr. Webber might have a motion, so let's just take a minute while our guests pack up and leave.

● (1305)

(Pause)

● (1305)

**The Chair:** The clerk sent around a list of proposed witnesses this morning for Bill C-211 and needs our approval of the witness list, so that we can make sure they're invited and they get here on time.

Is the list all right with everybody, or does anybody have a question or want to make a change on it? The witnesses are all based on recommendations from the committee members. This is for meeting two on May 16.

Do we have the approval of the committee?

**Some hon. members:** Agreed.

**The Chair:** That is carried, so there's your mission.

Mr. Webber, do you want to discuss your motion or leave it for another time?

Okay, Mr. Webber doesn't want to discuss his motion, so that being heard, the meeting is adjourned.