



HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

Standing Committee on Justice and Human Rights

JUST • NUMBER 034 • 1st SESSION • 42nd PARLIAMENT

EVIDENCE

Tuesday, November 15, 2016

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Chair

Mr. Anthony Housefather

Standing Committee on Justice and Human Rights

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• (1130)

[English]

The Chair (Mr. Anthony Housefather (Mount Royal, Lib.)): Ladies and gentlemen, we're all here.

[Translation]

The meeting is called to order.

[English]

It's a great pleasure to welcome all of you to this meeting of the Standing Committee on Justice and Human Rights, where we will be commencing our study on Bill S-201, an act to prohibit and prevent genetic discrimination.

It is a great pleasure to welcome the Senate sponsor of the bill, Senator James Cowan.

Welcome, Senator Cowan.

The House sponsor of the bill is Robert Oliphant.

Welcome, Mr. Oliphant.

We've also had the kind agreement of all the members of the panel to appear together to allow the committee to pose more questions to all of them.

I'd also like to welcome, from the Canadian Human Rights Commission, Marie-Claude Landry, the chief commissioner.

[Translation]

Welcome, Ms. Landry. It is a great pleasure to welcome you here today.

[English]

Welcome also to Fiona Keith, counsel, human rights protection branch, and Marcella Daye, senior policy adviser, human rights promotion branch.

Thank you so much to all of you for appearing.

I'm going to turn the floor over to Mr. Oliphant and Senator Cowan, whoever wishes to go first.

Mr. Oliphant.

[Translation]

Mr. Robert Oliphant (Don Valley West, Lib.): Thank you, Mr. Chair. I will begin the presentation.

[English]

Thank you, Mr. Chair and all the members of the committee, for this opportunity to appear before you along with my friend and colleague Senator Cowan, the sponsor of the bill in the Senate.

It's funny to be sitting at this end of the table. It's a great privilege, and I'm reminded, as the chair of another committee, of what a great opportunity it is to be a witness before a parliamentary committee, so thank you.

I was very pleased and a little surprised when the House of Commons voted unanimously in favour of Bill S-201 and to send it here for further study. I did expect it to pass, but I was particularly pleased to have support from all sides and all corners of the House, including members of every party and the independents, including the Bloc Québécois and the Green Party.

The fact that it passed unanimously in the House and Senate tells me that the groups, the individuals, the patients, and the geneticists, the people in Canadian society who have been arguing for this bill and for genetic protection, have made their case and have made it well, and senators and members of Parliament have had an education in that process, so I'm not going to dwell particularly today on all the policy issues, though we can get into some of that.

I particularly chose that this bill would come to this committee for a reason. I sensed that the health committee would understand very intuitively the importance of the bill and the way medicine is changing in the 21st century, and they would get that very quickly; however, this is a bill that does pass a law. It not only amends two laws but it creates a new act, and I think this is an appropriate committee to actually get into the nature of discrimination and into the nature of the way we develop laws in this House and in this country.

I want to take a moment to thank in particular Bev Heim-Myers from the Canadian Coalition for Genetic Fairness, who has the presidency of the Huntington Society of Canada, and her team, which has brought together a wide collection of health charities and patient groups, as well as others in civil society—the CIJA, for instance—and other groups that have come together to educate Canadians and to make sure this bill is passed.

This bill is about changing the way medicine is done in Canada. Twentieth-century medicine was a view that we had on the way we were doing both diagnostic and corrective medicine. In the 21st century, with the discovery of the human genome, we have a radically new way of having medicine that is very much targeted.

For example, this past summer, the gene for metastatic fast-moving prostate cancer in men was discovered in about 80% of the cases. My father died of prostate cancer after a 20-year journey. His friend and colleague died after 18 months. For a long time, researchers have been looking at different cancers and understanding it in that way. This summer, there was a radical shift in looking at cancer and understanding that the genetic makeup of one person is different from another person; it's not necessarily the cancers that were different. This hasn't explained it completely, and there's not 100% certainty about it, but it's an inkling for further research and for changing the way that each of us will have our own health taken care of, as well as what we can do for our constituents.

I don't, however, want to overestimate the genetic factors in disease. That would, I think, also be damaging to our shared understanding of the new world of 21st century medicine. There is mounting evidence that within biology and biochemical sciences, genetics is only predictive in about 5% of chronic illnesses or disease. In fact, 90% to 95% of illnesses are shaped by our environment and by our lifestyle and other things. For us to be moving the needle too far on this is also of concern, in that we don't want to say that because someone has a genetic makeup, they are certain of getting a disease. That's just not the case. It is a marker. It is a helper for a geneticist, a physician, or a clinician, but it is not the end of the story for anyone who has that marker. Some research by opponents of this bill, I think, have not understood that and not taken that into account in their tables.

• (1135)

[Translation]

Bill S-201 has three components, each of them essential to fight discrimination, similar to the legs of a stool that has just three legs. By order of importance, they are: the Genetic Non-Discrimination Act, which would prohibit all forms of genetic discrimination, whether based on DNA or RNA; amendments to the Canada Labour Code; and amendments to the Canadian Human Rights Act. Each component is essential. None of the three components can be removed from the bill, just as we cannot take away one or two legs of a stool and still be able to sit on it.

[English]

The first leg of that stool is the creation of a new statute, the genetic non-discrimination act. This act would make it a criminal offence for a service provider or anyone entering into a contract with a person to require or compel a person to take a genetic test or to disclose the results of a genetic test.

It would also make it a criminal offence for a service provider or anyone entering into a contract with a person to collect, use, or disclose a person's genetic test results without prior consent. There would be exceptions, of course, for health care practitioners and research.

The bill sets out criminal penalties that are, I would note, strong, but they are maximum, not minimum, sentences. This is a guideline. It stresses the importance of this as a human right.

[Translation]

The bill states in black and white that society condemns genetic discrimination. It is not acceptable and will not be tolerated. The

criminal sanctions in the bill are high in order to serve as an effective deterrent. The bill does not target any particular sector or industry. It focuses on reprehensible behaviour, which is specifically defines, and legally protects the public against it.

• (1140)

[English]

This new act would apply to everyone who commits a prohibited act.

The second part, the second leg of the stool, consists of changes to the Canada Labour Code. It sets up a complaint procedure for those employees who work in federally regulated industries. It's part of the change about government being a good employer.

The third, which I think is important but not as important as the first, is an amendment to the Canadian Human Rights Act, namely, the insertion of the words "genetic characteristics" into that act. Some have asked whether that alone would be sufficient, and I will argue that it would not be sufficient. I have been a member of a human rights commission. I have been a chair of a human rights commission. The onus in a human rights complaint is put on the complainant. It's on the patient, who may actually be struggling and may not have the financial resources. The act would ensure that the crown was acting on behalf of the population to ensure that we have strong deterrents to this form of discrimination, and it would make it fundamentally important for all Canadians to understand it.

You'll be hearing from groups in the insurance industry who are concerned about this. We will draw attention to the Privacy Commissioner's report that the insurance industry does not need to worry in the short or medium term. We understand that. I think we would be open to amendments at the committee if you wanted to put in some kind of a review over three years or five years, whatever is legislatively appropriate, to ensure that this won't in fact change the nature of the insurance industry.

We're of the strong belief that having the best human health information will safeguard Canadians' health, will encourage them in their lifestyle issues, in their environmental factors, and in co-determinants, to have the best health outcomes possible. In fact, we think this will help the insurance industry. People like you and me will pay our premiums for a longer period of time, and will ensure that we have the best health outcomes, and the insurance industry, like the other countries in the world that have this kind of protection, will not face an adverse reaction.

I look forward to your questions. I want to thank you for considering the bill, and also, in particular, end by thanking Senator Cowan, who is getting long in the tooth but is still eager, engaged, and really quite wonderful at this. When he started this process, there were just over 2,000 genetic tests, and in just a few years, there are now close to 38,000 genetic tests. He has shepherded this bill, brought it to different iterations, and has taken it through the Senate to get unanimous consent. He has offered it to me—I'm the custodial parent of this bill, and it's a great privilege to work with him in our adoptive procedure.

Thank you, Senator Cowan.

The Chair: Thank you very much, Mr. Oliphant.

Senator Cowan, please go ahead.

Hon. James S. Cowan (Senator, Lib., Senate): Thank you very much, Chair, and thank you, members of the committee, for allowing me to appear. I thank my friend, Rob, for most of what he said. The crack about being long in the tooth, I'd ask him to reconsider, but the rest of it, I appreciate.

I've circulated a statement that you can have a look at, at your leisure, so I won't cover all of it in the few minutes that are available today, but I would be happy to return to it in the question period. I want to get, really, to the essence of it. There are some concerns that have been expressed about the bill and I want to address those.

We know that this bill is strongly opposed by the insurance industry. They now have access to genetic test information and they, understandably, don't want to relinquish that access. They say terrible things will happen to the industry if this bill passes. I understand their concerns, but there are many countries around the world, as you know, which have prohibitions in place like those contained in Bill S-201, and the insurance industry in those countries continues and does just fine.

I hope you'll hear from the Privacy Commissioner of Canada. His office commissioned two studies, which concluded—and Rob alluded to this—“At the present time, and in the near future, the impact of a ban on the use of genetic information by the life and health insurance industry would not have a significant impact on insurers and the efficient operation of insurance markets.” Earlier this year, when the Privacy Commissioner appeared before the Senate in its study of this bill, he confirmed that his office stands by that conclusion.

While I understand the concerns of the insurance industry, I don't share them. When I balance the concerns of the insurance industry against the potential health benefits for Canadians of genetic testing without fear of discrimination, my choice is clear.

When Senator Ted Kennedy sponsored GINA, which is the American federal law against genetic discrimination, he hailed it as the first major new civil rights law of the new century. He said the bill recognizes that “discrimination based on a person's genetic identity is just as unacceptable as discrimination on the basis of race and religion.” I agree.

Bill S-201 says that it's not acceptable to put someone in a position where they must hand over their most personal information, information about their DNA. We have criminal penalties if someone steals a car, a computer, or a piece of jewellery. Six years ago, Parliament passed an anti-spam law, which imposed penalties of up to \$10 million for sending unwanted email. If we're prepared to legislate to prohibit sending unwanted emails, then I believe we should be prepared to prohibit unwanted access to one's genes.

I understand from the speeches at second reading and from my conversations with others that the government supports amendments to the Human Rights Act but opposes everything else in my bill; that, in fact, there is an intention to propose amendments to delete all of

the provisions relating to the Canada Labour Code and to the genetic non-discrimination act.

I am told that the concern is constitutional, that some lawyers believe that the provisions in the genetic non-discrimination act would fall within provincial, not federal, legislative authority. This issue was explored in detail when the bill was before the Senate. I know that you are planning to hear from a number of distinguished scholars, including Peter Hogg and Professor Bruce Ryder, who are pre-eminent constitutional authorities—and I am not one of those. Just let me say that I take issues of constitutionality very seriously. I'm satisfied, based upon discussions I've had with eminent constitutional authorities in this country, as well as our own Senate Law Clerk and Parliamentary Counsel, that Bill S-201, including the proposed genetic non-discrimination act, is constitutional as a valid exercise of the federal criminal law power and it, therefore, falls well within the legislative authority of our Parliament.

There's been a suggestion, as well, that before we proceed, the provinces and territories need to be consulted. In fact, all the provinces and territories have been consulted about this bill, not once, but twice. Last December and January, I wrote to all the ministers of health in the provinces and territories and then, in February, the Senate Human Rights Committee, which was the committee studying this bill, wrote to all the provincial and territorial ministers of justice.

● (1145)

In total, we received replies from nine provinces and territories. Not one raised any objection or problem with the bill, either from a policy aspect or from a constitutional or jurisdictional point of view. Indeed, several provinces expressed strong support for the bill. I have now met or spoken with cabinet ministers in three provinces. Not one has raised any constitutional or jurisdictional concerns or any policy concerns. My strong impression is that this is an area where the provinces recognize the need for a uniform, national regime in the form of national legislation.

There was a meeting, just last month, of federal, provincial, and territorial justice ministers in my home province of Nova Scotia. I spoke with the justice minister from Nova Scotia, who happened to be the chair of that meeting. She said that no one raised this bill—not the federal Minister of Justice, nor any provincial or territorial minister of justice. We've seen other situations, where provinces have come forward to express constitutional and policy concerns about federal legislation, including private members' bills. We know about Bill C-377, which would be repealed by Bill C-4, which is now before the Senate. Seven provinces, in that case, sent submissions to the Senate saying that the bill was unconstitutional. Provincial governments, I suggest to you, are not shy about expressing themselves about these matters, but I've heard nothing from any province or territory opposing Bill S-201. As far as I know, no one else has either.

That's not surprising. Canadians need a national solution. They need to know that if they have a genetic test at one point in their lives, they need not worry that at some later time they might move to another part of the country where the rules could be different. They need to know that they will be protected from coast to coast to coast, no matter where they live.

I also want to address the proposal that the bill be amended to delete everything but the changes to the Canadian Human Rights Act. As Rob said, the Human Rights Act is important, but it is a law of limited application, applying only to certain sectors. For example, it has no application to the insurance industry, because the insurance industry is regulated at a provincial level. This came up, as you might expect, during the Senate hearings on Bill S-201. Let me read to you from the hearing, when the then-acting Canadian Human Rights commissioner testified in response to a question from my colleague Senator Eggleton.

Senator Eggleton said:

[W]hat would you do if somebody came to you with a complaint of discrimination on the basis of insurance that was denied them, under the current law?

The acting commissioner said:

Under the current law we do not have jurisdiction over the insurance industry. It's federally regulated private sector companies, so as I say transportation, telecommunications, banking industry, but not insurance companies.

In other words, you would be protected as long as you experienced genetic discrimination from your bank or your airline, but that's all. The bottom line is that, if the bill only amends the Canadian Human Rights Act, none of us could responsibly tell Canadians they can feel free to have genetic testing without fear of genetic discrimination, because that would not be the case. We would not have prohibited and prevented genetic discrimination, as the title of the bill says. We would have said, genetic discrimination is unacceptable in certain situations, but perfectly acceptable in others.

No one knows where the future lies, and again, Rob refers to this. No one knows what they will be doing in a few years or even months. This kind of limited protection would not be real protection. Indeed, I would argue, and this has been said to me by representatives of health organizations, that passing such a bill would be dangerous, in that Canadians would think they are protected—after all, Parliament has passed a law against genetic discrimination—but if they did go out and have a genetic test, they, in fact, could well encounter genetic discrimination, and there would be nothing anyone could do about it.

• (1150)

Mr. Oliphant has eloquently described this bill as a three-legged stool. I agree with that analogy. I have every confidence that all three legs of that stool will remain standing, that the whole bill will be found to be a valid exercise of the federal criminal law power. As I've said, all the provinces and territories have known about this bill for some time, and no one, not one person, has raised an objection of any kind.

Will there be a constitutional challenge? Perhaps. We all know that the insurance industry, as I said at the beginning, strongly opposes this bill, and they have deep pockets to launch such a challenge. However, as Professor Ryder told the Senate committee, and probably will tell you as well, "There will always be legal debate—we don't work in the realm of certainty—but I think you can work within the realm of confidence here."

I'll conclude with a quote from Professor Ryder:

I am the sort of person who will say that it is one of your most important responsibilities to ensure that the legislation you vote in favour of is constitutional. I want to say, in this case, that I am very confident, and I believe it would be the consensus view of other constitutional experts, as well, that this bill is constitutional. ...I don't think you should be too concerned about the risk of unconstitutionality, because this seems to me to be very solidly within Parliament's jurisdiction.

I'll do my best to answer any questions in the course of the time that we have available.

Thank you very much for your attention.

• (1155)

The Chair: Thank you very much, Senator Cowan, and thank you for your considerable efforts to bring this bill forward.

[Translation]

We will now move on to Ms. Marie-Claude Landry, from the Canadian Human Rights Commission.

[English]

Ms. Marie-Claude Landry (Chief Commissioner, Canadian Human Rights Commission): *Merci*, Mr. Chair, honourable members.

[Translation]

Thank you for inviting the Canadian Human Rights Commission to speak before your committee on Bill S-201, an act to prohibit and prevent genetic discrimination.

[English]

I would like to introduce my colleagues, Fiona Keith, counsel for the commission and Marcella Daye, senior policy adviser. We would like to leave the committee with three main messages today.

First, we support Bill S-201 and we strongly support adding the ground of "genetic characteristics" to the Canadian Human Rights Act. Second, while the change to the CHRA would be a positive step, it cannot alone address all concerns surrounding the use of genetic information. Third, if Parliament adopts robust, comprehensive, and forward-thinking legislation to regulate the use of genetic information, it would make Canada a world leader in this emerging human rights issue. Before I elaborate on those three points, I'll speak briefly about the current context of genetic discrimination and human rights law in Canada.

Parliament designed the Canadian Human Rights Act in 1977 to promote equality and to protect Canadians from discrimination based on grounds such as sex, age, disability, and race. Canada's provinces and territories all have similar human rights laws. Through the years, our human rights laws have evolved to keep pace with social change and with technological advances. Genetic research holds great promise and is developing quickly. It has inspired new methods of diagnosis and treatment. Some believe it will revolutionize medicine and health. But as Parliament has been examining Bill S-201, we have learned that some individuals choose to avoid genetic testing out of fear. They fear that the very tests meant to help them may one day be used against them or their children.

People are afraid of discrimination by employers, by schools, or by insurance companies because of what their genes may say about them. In some cases, parents have to decide whether to test their child, knowing that the child's genetic information will follow them into adulthood, and could negatively affect them later in life. A test that could help save someone's life should not be a calculated risk. The scope of information that genetic testing can reveal about us now and in the future is extraordinary, and it goes well beyond our health information.

In the future, these tests could answer even more questions. What is my indigenous lineage? Do I have a genetic propensity to be anxious, a good athlete, or a natural leader? Without regulation the vast information contained in our genes could be used, shared, or accessed without our knowledge. The regulation of genetic information is an emerging area of law that remains virtually uncharted. Other jurisdictions like Ontario are considering legislation. But across Canada, jurisprudence in this area is almost non-existent. Our rights in this area are not clear.

Last February I gave my first parliamentary appearance as chief commissioner of the Canadian Human Rights Commission. I spoke on this very issue and this bill. At that time, I told the Senate committee that the commission supports adding the ground of "genetic characteristics" to the Canadian Human Rights Act. We see this legislative change as an important and positive step towards better protecting people in Canada from genetic discrimination.

• (1200)

As it stands today, the commission has the authority under our act to accept discrimination complaints regarding genetic characteristics only, and only if the complaint is linked to another ground such as disability.

Adding the ground of "genetic characteristics" to our act will allow people to file these complaints without having to link it to another ground. It will make it clear to people in Canada that they have a right to be treated equally regardless of their genetic characteristics and regardless of whether they choose to access genetic testing or share the results.

This brings me to my second point. While changing the Canadian Human Rights Act will be a positive step for human rights, it cannot address all the concerns surrounding genetic discrimination. Other stakeholders and experts from across Canada agree. There will still be a clear need to address the very real and the very serious fears of discrimination raised during the Senate debate on Bill S-201, fears about test results being used against us and fears for our children. We believe that in order to properly address these concerns it is going to take a concerted national approach.

This brings me to my third and final point. In order to prevent harm and keep people in Canada safe, robust, and forward thinking, comprehensive laws are necessary. Doing so will make Canada a world leader in this emerging issue. We encourage the federal government to take the lead, to pass robust national legislation, to meet with provincial and territorial governments to determine how best to implement nationwide protections against genetic discrimination, and to consult with stakeholder groups and human rights commissions across Canada. We believe this concerted national approach is the best way to ensure that Canada's human rights

protections against genetic discrimination are robust, forward thinking, and comprehensive.

To conclude, I believe genetic information and genetic tests are meant to help us. But without adequate human rights protections and regulation of this information, genetic information could actually do more harm than good. Taking a test that could help save one's life should not be a calculated risk.

[Translation]

To conclude, taking a test that could help save one's life should not in any way raise another risk. The analysis of genetic information is meant to help us and not hurt us.

[English]

I want to thank you very much, and with my colleague I'm available for questions.

[Translation]

The Chair: Thank you very much for your testimony, Ms. Landry.

We will now move on to the question and answer period.

[English]

We're going to start with Mr. Nicholson.

Hon. Rob Nicholson (Niagara Falls, CPC): Thank you very much, Mr. Chairman.

Congratulations to all of you who have been supportive of this. This is an excellent piece of legislation. In my comments when this was before the House with our colleague Mr. Oliphant, I said something like this is probably going to get more difficult to get passed with the proliferation of information and the expansion of technology, and so this is why I think it is so important that a piece of legislation like this comes forward.

As well, I agree with what our colleague from the House had to say with respect to our ability to create offences. I mean, this is something that the Parliament of Canada can do. It can take activity and, if we deem it to be criminal activity or offensive activity, that's within the jurisdiction of Parliament. I'll be interested to hear Peter Hogg, who I believe is coming before us here, but that being said, I think it's completely consistent.

Senator Cowan, congratulations again on bringing this forward. I think it's very important. You did make one comment that sort of alarmed me a little bit. You said that the government may want to not have this as part of the Criminal Code or they may want to have amendments on that. I wonder if you could expand on that, or perhaps it might be better directed towards monsieur Oliphant. He might be in a better position to know this, but what are you hearing with respect to this bill?

• (1205)

Hon. James S. Cowan: Thank you, Mr. Nicholson. Thank you very much for your support.

I'm obviously not speaking for the government, and I have no direct information at all. I'm simply hearing and interpreting. I think it is really what Mr. Casey said in his speech during the debate in the House of Commons. He alluded to the government supporting the principle of the bill, but having concerns about jurisdiction and the need to consult with the provinces.

I've asked to see proposed amendments, and I have not been provided with those amendments. I'm simply relying on what I'm hearing second- and third-hand, that the government may be looking to introduce amendments, presumably through a member of the this committee. I have no inside information and no further details.

The indication I had was that the only part of the bill they were prepared to support was the part that would amend the Human Rights Act. I think we're all agreed that that's simply not sufficient. I suggest, and health professionals have suggested to me, that this would be a dangerous signal to send because, as I explained, people might believe that there is a protection out there that really isn't there.

Hon. Rob Nicholson: We've had a couple of experts, with respect to the Canadian Human Rights Commission and human rights commissions in general. Madam Landry and our colleague Mr. Oliphant made it very clear that the Canadian Human Rights Act in and of itself, cannot address all the concerns. It can lead to a false sense of security for people, if they believe that it is only included in there. Having it as a type of criminal offence would add to the support of that belief.

Do you have a comment on that, Mr. Oliphant?

Mr. Robert Oliphant: I just want to add one correction to make it clear on the record. It is not a change to the Criminal Code.

Hon. Rob Nicholson: No, I appreciate that.

Mr. Robert Oliphant: It's an act that uses the federal government's powers against crime to do this stuff. That's just one thing I wanted to get on the record.

Hon. Rob Nicholson: Yes.

Mr. Robert Oliphant: The second thing is that I think it's absolutely appropriate that the federal government moves cautiously in areas that could have some shared jurisdiction. I don't disagree with checking out the provinces' attitudes and ideas about this kind of legislation.

There are murky areas in anything that deals with discrimination. I think, however, as Senator Cowan said, that we are not hearing that it's a problem. It was quite interesting for me to see the Bloc Québécois members of the House support this bill at second reading. They have finely tuned consciences on whether jurisdiction is federal or provincial. They voted for this bill, and the same evening they voted against another private member's bill because it trod on provincial jurisdiction.

I think that if you do talk to the provinces, you'll find that they're quite pleased with this piece of legislation. This actually is a robust piece of legislation that has robust powers to the point that I think it's deterrence potential is huge. I actually hope that this legislation will mean a lack of court cases and a lack of discrimination because then it will cause people to back off.

Hon. Rob Nicholson: I didn't mean to imply that, as an offence, it was going into the Criminal Code. I appreciate that it's not.

Madam Landry said that Canada would be a world leader if we got involved with this. But, Mr. Oliphant, you pointed out that there are a number of jurisdictions around the world that are already in this, and that they haven't seen the wipeout of the insurance industry.

Perhaps you or Senator Cowan could present that to us. I know that in the United States there are a number of jurisdictions looking at that. Could you give us a list of other countries that are doing that? That would be very helpful.

Mr. Robert Oliphant: He's the expert on this. What I would say is that there's a range of approaches, including voluntary agreements with insurance industries. In the U.K., this is now being tested as we speak. However, I read an article this week that said that it is already being looked at and that it probably doesn't work as a voluntary commitment.

Another approach can be seen in jurisdictions, like the U.S., that have a federal law and select state laws, so there are jurisdictional issues. There are other countries that you've studied.

● (1210)

Hon. James S. Cowan: I would be happy to provide to the committee a survey that my office has.... It is a sort of compilation of the various approaches that have been taken in various countries: the United Kingdom, the United States, Austria, Belgium, Denmark, Finland, France, Germany, Ireland, Israel, Luxembourg, the Netherlands, Norway, Portugal, Sweden, and Switzerland. UNESCO and other United Nations organizations have made some declarations from time to time.

The most recent one was in October of this year. The Council of Europe's Committee of Ministers issued recommendations to member states, and one of the recommendations was that predictive genetic tests not be carried out for insurance purposes. It said, "Existing predictive data resulting from genetic tests should not be processed for insurance purposes unless specifically authorised by law."

They are addressing this in a variety of ways, from strict legislation to moratoria. As I said in my remarks, there's no indication in any of those countries that the insurance industry has suffered in any way. In Britain, as an example, we have evidence that since their moratorium came into effect around 2000, insurance rates have in fact dropped. There's no suggestion that they dropped because of the moratorium, but they haven't gone up, because there is some protection in place.

Hon. Rob Nicholson: Thank you again.

Hon. James S. Cowan: I would be happy to provide that.

Hon. Rob Nicholson: I appreciate that. That would be very helpful.

The Chair: Thank you very much, Mr. Nicholson.

We're going to go now to Mr. McKinnon.

Mr. Ron McKinnon (Coquitlam—Port Coquitlam, Lib.): Thank you, Senator, and Mr. Oliphant, for bringing this to us.

Thank you, Senator, for all the many times you have done this.

You spoke at some length about the jurisdictional concerns, and Mr. Nicholson spoke to this as well. Since that seems to be the major thrust of the concerns, perhaps we'll stick with those. There's been concern that your attempt to change the law to provide criminal sanctions, which are under federal jurisdiction, is really a backdoor attempt to encroach on provincial jurisdiction over, say, private contracts. Will you please expound on that?

Hon. James S. Cowan: I will quickly confess that I am not a constitutional expert. I think that question should be addressed to Mr. Hogg and Professor Ryder when they're here. My understanding from my reading and my consultations with those and other officials and the Senate legal counsel is that—and Mr. Nicholson alluded to this—there is a federal power to legislate against bad behaviour. If Parliament decides that discrimination is something that it wishes to discourage or to prohibit, it can use the federal criminal law power to penalize.

As long as it is not identifying and targeting any particular segment, any particular industry, or any particular actor in society, then that is a legitimate use of the federal power. There are legion examples that can be provided to show where Parliament has done that, has stepped in to deem a particular type of behaviour to be unacceptable, and has used its power under the criminal law to legislate against that.

There is no mention of insurance at all in this bill. There was mention of it. In an earlier version of the bill, I had a provision that was intended to provide protection to the insurers who at that point were concerned that people would take genetic tests and then run out and get millions of dollars' worth of insurance, something that has not happened in any other jurisdiction around the world. For some reason they believed that might happen here in Canada.

We built a protection in to say that if the provinces, which have the responsibility to regulate the insurance industry, wished to provide this protection for high-end policies, they could ask for genetic information. It was intended to be a help to the insurance industry, and they turned it around and said it was all about them. As you'll note, that provision was taken out in the version that I tabled in the Senate after the last election, and it's the one before us now. There's no mention of insurance.

This bill does not target any particular actor, any particular player, or any particular industry. It targets unacceptable behaviour no matter who does it. It just happens that we know from the research and from the anecdotal evidence that we've heard—and that you will hear—that the biggest users and abusers of this information are the insurance companies and, to a less extent, employers. This is not and could not be about any particular sector. If it were, then it would cross that line. In my view and in my opinion, it does not cross the line.

• (1215)

Mr. Ron McKinnon: Thank you, Senator. That's my question.

I will share my time with Mr. Hussen.

Mr. Ahmed Hussen (York South—Weston, Lib.): Is there any time left?

The Chair: You have two minutes left.

Mr. Ahmed Hussen: Okay, wonderful.

I think, Mr. Oliphant, that you indicated there was no opposition from the provinces. I would like to explore that a little further.

Mr. Robert Oliphant: Sure.

Both Senator Cowan and the clerk of the committee at the Senate sent letters to the provinces and territories. I believe seven of the 10 jurisdictions actually responded, either strongly in favour or neutrally. No one had a negative or adverse response to it. Some chose not to say anything. That would be the first thing.

Moving on from that, in discussions with individual ministers of health in Ontario, Nova Scotia, and elsewhere, that has been reiterated.

One of the issues, I think, is that there is a kind of a wonderful flexibility in Canada in the way our Constitution works. I think it's partly because when I see unanimity, particularly in the House of Commons, that tells me there's an instinct in the House to use our power to do this. I can't know what's in the mind of every MP, but I think it was that this is important enough that we should act.

I think the provinces are going to end up saying—and we can't determine that for sure—that they're glad we acted, so they don't have to do all of that. They may have to do some particular things. I would like to see them insert those words in their human rights acts as well. I don't think that would be out of place either. It's a strong signal. We're saying it wouldn't be as necessary. Madam Landry may have a comment on that as well. We think there's a sentiment in both Houses that we want to do this as Canadians helping Canadians.

Hon. James S. Cowan: Might I add just one comment?

The Chair: Sure.

Hon. James S. Cowan: We'd be happy to provide copies of the materials—we provided this to the minister before of course, and it was provided to the Senate committee—and the sense you get from the letters is the provinces are looking at their human rights codes and their labour codes, assuming that this bill will pass, and they're seeing what changes they might need to make. We haven't suggested the changes to them, if any, that they need to make at the provincial level. That's not our responsibility. But there's no indication—and let me reinforce that—from any source, either written or oral or through the back door or under the table, that any province or territory has any concern and has any expectation other than we will do the right thing and pass this bill.

Mr. Ahmed Hussen: Thank you.

The Chair: Thanks very much, Senator Cowan. Our clerk will obtain from the clerk of the Senate the letters that were obtained by the Senate human rights committee.

Mr. MacGregor.

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): Senator Cowan, I'd like to open by congratulating you for getting to this stage. You've been working on this issue for a long time, going through the Senate. Last week I was talking to school groups in my riding and outlining the process, the very long route a bill must take before it reaches royal assent. I think we have to respect the version of the bill that we have before us because it has gone through all that scrutiny in the Senate, and you've had the witnesses at the human rights committee. I'm concerned, like my colleague Mr. Nicholson. We have started to hear rumours that the government may have reservations about this bill. In fact, hearing that gives me a sense of déjà vu with you two because of Bill C-14. It feels we are here again.

Senator Cowan, can you provide this committee with examples of where federal criminal law power is currently in statute, but may seem to be in provincial areas? I know there are examples where federal criminal law power is used extensively, and in some cases where it may seem to impinge on provincial jurisdiction, but has been accepted as constitutional.

• (1220)

Hon. James S. Cowan: Absolutely. I do have that information; I'm just looking for it.

Mr. Robert Oliphant: We have a list.

I just don't want to be inaccurate.

Mr. Alistair MacGregor: While he's looking for that, Mr. Oliphant, can you emphasize for the committee just how important that concept of the three-legged stool is, the fact that we may have Canadians feel they're under-protected, but if we get this bill and remove one of those legs they will not be.

Mr. Robert Oliphant: You're going to be hearing from geneticists. I've been working on this bill with the geneticists from SickKids hospital in Toronto, and they're talking about real cases, clinical experience, where you have a child presenting symptoms that could be one of two different diseases as its foundation, and a genetic test will make the difference. Parents have declined getting that test done half the time for fear of future discrimination that child may face. Even though they may have a 5% chance of getting that illness, they don't trust the system. If they sense possible discrimination, they won't get the test, and the child could die. That's the reality.

After the death of that child they would have to go to the Human Rights Commission in their province or territory and take a case forward to a commission after it's too late. We're trying to say it's very different. You got a letter from a Mr. Howard, that he copied me on. It was a stunning letter for me because he doesn't understand the differences. Rights are rights, but the experience and the truncation of those rights have a different effect in different ways. It's quite different on a life-and-death issue like this, where you can have a health impact that makes a difference.

The Chair: Senator Cowan, we get back to your half of the list.

Hon. James S. Cowan: Thank you.

I'm referring now to evidence that Professor Ryder gave to the Senate committee when he addressed this point.

By way of a preamble, he referred to section 91(27) of the Constitution, which confers on Parliament the exclusive jurisdiction to pass laws in relation to criminal law. The leading decision on that is the *Margarine Reference* in 1949, when Justice Rand held that a valid criminal law must have "as its dominant characteristic the putting in place of prohibitions, coupled with penalties", for "a typically criminal public purpose", such as the protection of public peace, order, security, health, and morality. That's the definition that's been used.

Then he goes on to talk about a wide range of statutes that have been upheld pursuant to that. These include the following: prohibitions on anti-competitive practices in combines legislation; the consumer protection provisions in the Food and Drugs Act; the now-defunct therapeutic abortion provisions in the Criminal Code; Tobacco Products Control Act, now the Tobacco Act; the Lord's Day Act; the Firearms Act; recent legislation repealing the long-gun registry; the Young Offenders Act, now the Youth Criminal Justice Act; the drug offences in the Controlled Drugs and Substances Act; the toxic substance provision in what is now part 5 of the Canadian Environmental Protection Act; the prohibition on issuing false prospectuses in what is now section 400 of the Criminal Code; and the prohibited activities provisions in section 5(1) of the Assisted Human Reproduction Act.

• (1225)

Mr. Alistair MacGregor: Thank you for that, Senator Cowan.

I think that's a great list to read into the record.

Quickly, because my time is almost up, for the benefit of the members of this committee, has the Canadian Medical Association taken a position on this bill, and what is it?

Hon. James S. Cowan: Yes, the Canadian Medical Association has taken a strong position in support of the letter of this bill. There was a letter submitted to the chair on November 1.

Mr. Chair, is that being circulated, or how is that handled with the committee?

The Chair: I imagine it's being translated right now, because I haven't seen it yet, but as soon as it's translated it will be circulated to members of the committee.

Hon. James S. Cowan: I could provide copies here, but the concluding sentence to the letter signed by the president of the Canadian Medical Association is, "To that end, the CMA urges the Standing Committee on Justice and Human Rights to support the enactment of Bill S-201 with no amendment."

Mr. Alistair MacGregor: Thank you very much.

The Chair: We'll now go to Mr. Bittle.

Mr. Chris Bittle (St. Catharines, Lib.): I want to, again, echo my colleagues and thank especially you, Senator Cowan, for your incredible work on this. To be at the forefront of an advancement in human rights is an exciting thing to be part of.

You touched on it briefly, Mr. Oliphant and Senator Cowan, but can you explain your motivation behind this bill and what drove you to sponsor it, to be a custodial parent, if you will, and to bring this forward to the Senate in Senator Cowan's case?

Mr. Robert Oliphant: When the people spoke in 2011 and sent me home to Toronto after a brief but very good time in the House of Commons, I was hired to be president and CEO of the Asthma Society of Canada, a small but mighty health charity.

I was fairly quickly elected to the governing council of the Health Charities Coalition of Canada. That is the group that the 30 or so health charities and patient groups in Canada are members of. We look at particular policy issues that are stumbling blocks or barriers for us to advancing the health of Canadians.

At our coalition, we made the decision to get into the area of genetic testing. With the discovery of the human genome, medicine was changing every day. Our old laws and old practices were not keeping up. Everything about our world in health care was changing.

They have not yet discovered the asthma gene; they've discovered biomarkers to recognize why different medications don't work. They used to do it by trial and error. Until a couple of years ago, everything was by trial and error in the area of asthma. We now have biomarkers that tell people why certain medications work.

In other diseases.... This year, for example, they discovered the gene for cystic fibrosis. A few years ago they discovered the genes that are related to breast cancer, ovarian cancer, cervical cancer, now prostate cancer, multiple sclerosis, Alzheimer's, and rapid onset and early advanced Alzheimer's. They now have a genetic component for that.

As a patient organization, we found that none of the governments in Canada was moving quickly on this. We looked at the American model; we looked at another model, in Europe, and said, let's do this. That's when Bev Heim-Myers, one of my colleagues, started working with Senator Cowan on this bill.

It seemed a natural fit for me to pick it up. I'm not a lawyer—there's a reason I'm not a lawyer, when I read that list of acts—however, I understood the bill from the health perspective. What I was hoping was that the lawyers would give us a break. That was my goal on this one, to say that the health impact of this is so important and that people's lives could be affected so positively that it's important.

One story I got was that companies were now looking at.... It wasn't so much life insurance that was the problem, but are you going to hire someone who carries a gene when someone else doesn't carry that gene, even though they might have a 5% chance of actually developing this disease because of all the other factors? We now have documented cases of employers choosing one person over another because of the experience of providing health care benefits or drug benefits.

That's not the way we work in Canada. We share risk, we work together on it, and that is pervasive. I would say that is a fundamental principle that we're trying to engage in.

● (1230)

Mr. Chris Bittle: I thought we would hear from you both.

Hon. James S. Cowan: Oh, he's handing it off to the long-in-the-tooth colleague.

Some hon. members: Oh, oh!

Hon. James S. Cowan: I think, Rob, that to come to the justice committee and say that you're glad you're not a lawyer is not a very goodwill way to state your case.

The Chair: I just want to say that age is a prohibited ground of discrimination under the Canadian Human Rights Act.

Hon. James S. Cowan: Exactly. I'm proud to be a lawyer, and I'm proud to be before the committee.

The Chair: Absolutely. Obviously we need to add lawyers as a ground of discrimination, too, at some point.

Hon. James S. Cowan: Seriously, I first was aware of this issue in 2011, when Barbara Kagedan, who's with me now and is really the godmother of this—if he's the adoptive father, Barbara is the godmother of this case—drew it to my attention. I was astounded. I couldn't believe that we wouldn't have protection in Canada for this kind of thing.

As I looked into it and began to talk to folks, I had the same experience Rob had. The more you talk about it, the more you hear. Every time I speak about this, somebody will call me and say, let me tell you my story. I'm sure you'll find, as you are identified with this issue over the next few weeks, that people will start to call you and tell you their stories as well.

It was those personal stories, I think, that really motivated me, that drove me to do what we've done over the last few years.

The Chair: We'll hear a final short question from Mr. Bittle.

Mr. Chris Bittle: You mentioned that you heard from the provinces. In their responses, did they highlight their own current or anticipated regulation of insurance contracts?

Hon. James S. Cowan: I would say that generally what they were saying is they appreciated it. They were aware of it in many cases, and they appreciated being advised. If they were not aware, they were talking to their human rights commissions. They were talking to their labour folks to see what changed. The sense seemed to be that we're looking at it to see what changes we need to make at the provincial level to complement what's being done at the federal level.

As you know, there was a bill presented in the Ontario legislature within the last month, and it was made very clear at that time by the sponsor of the bill that the purpose of the bill was to bring the Ontario Human Rights Code in line with the anticipated changes to the federal act.

I would think that the underlying tone of the correspondence that we received—both I received and the committee received—and the conversations that I've had and others have had with provincial authorities is that they're looking to tweak their provincial legislation to complement what I hope we will be doing at the federal level.

The Chair: Thank you very much.

We're going to now go to a second round of questions.

We're going to start with Mr. Fraser.

Mr. Colin Fraser (West Nova, Lib.): Thank you, Mr. Chair.

I would like to echo the comments from all sides.

Senator Cowan, thank you for all of your work on this important bill and for bringing it forward to this stage.

Mr. Oliphant, thank you very much for bringing it forward to the House and getting it to this stage so that we can study it. I appreciate that.

My first question is for you, Madam Landry, with regard to a point made earlier by Senator Cowan about only changing the Canadian Human Rights Act with regards to genetic discrimination. If we only change that element, it may give some Canadians false confidence that their rights would be protected. I know you mentioned that. It's only one act that could be changed, the Canadian Human Rights Act, and there are other elements that we would need to look at.

Would you worry as well that there could be ramifications of false confidence that Canadians may have in genetic testing if only that part was changed?

Ms. Marie-Claude Landry: It could be, for sure. I would say that, and I said that before the Senate committee. Canada is actually far behind in terms of protecting the discrimination about genetic discrimination. We should not think that it's just about discrimination. It's about health and security for persons. We need to have, as I mentioned in my speech before, a robust bill to make sure that protection will be there.

When I mentioned that Canada could be a leader, we actually have the chance to have a big transformation in this country and have a bill that will address what we call *multiples facettes* of this situation, and have a comprehensive bill about genetic discrimination and protecting genetic discrimination.

Marcella, do you want to add something?

● (1235)

Ms. Marcella Daye (Senior Policy Advisor, Human Rights Promotion Branch, Canadian Human Rights Commission): Was there a follow-up question?

Mr. Colin Fraser: No.

Ms. Marcella Daye: I could just add that human rights law in Canada is shared jurisdiction. Therefore, whatever change is made to our act cannot affect those elements that are regulated provincially. It cannot have that reach, whereas the other powers that are envisioned in the first part of this act, this bill before you, can indeed have that reach across the country.

We certainly encourage, regardless of what act is changed, an examination of human rights codes across the country and the

addition of genetic characteristics to all human rights codes, and we believe that will flow as part of the normal course of action, as we're already seeing in Ontario.

Mr. Colin Fraser: Thank you very much. That's a helpful answer.

Senator Cowan, I'd like to drill down a little bit more into the elements of the bill that deal with the criminal law power, in particular, the proposed offences and punishment.

It mentions that it's a hybrid offence, that an indictable offence would have a maximum, and you correctly identified that it only outlines, of course, maximums, the worst offenders and the worst circumstances: a \$1-million fine and/or five years' imprisonment on summary conviction and a \$300,000 fine maximum and/or 12 months' imprisonment. Of course one of the key fundamental principles of criminal law is deterrence, both specific and general, in order to deter people from committing offences.

I'm wondering if these are similar punishments to other countries that have this sort of prohibition and how those punishments were arrived at. What thought was given in arriving at those offences for indictable or summary?

Hon. James S. Cowan: I would say, first of all, that it is a question of deterrence, as Rob said earlier. That's what we're trying to do. It's not so much collecting the fines, or putting people in jail, as it is deterring people from what I think we all agree is unacceptable behaviour.

I think we did look more at Canadian comparables in what was happening here. We could certainly provide you with the comparables, but take, for instance—I think I mentioned this in my opening part—in 2010, we passed Bill C-28, which was the anti-spam legislation. It imposed penalties of \$1 million for an individual or \$10 million for a corporation, and here the maximum is \$1 million. We felt that it has to be large enough so it's significant, but yet comparable.

For the imprisonment, there is a whole range of sections in the Criminal Code that provide for sentences up to five years. I'll just give you a smattering of them. Section 338 is defacing a brand or a mark on cattle, section 394 is unlawfully buying or selling valuable minerals, and section 397 is falsifying a book or document. There are eight or nine of them there. Then there are a number that are higher. For instance, you can get 14 years if you counterfeit or mutilate a postage stamp, 10 years for insider trading, 10 years for the fraudulent manipulation of stock exchange transactions, and 10 years for stealing or forging a credit card.

We looked at it and said, this is serious. We think it's very serious, so we wanted to make the maximum terms of imprisonment and the maximum fines significant, but we did have regard to what is already in those kinds of communications.

Mr. Colin Fraser: I suppose, with regard to specific deterrents, having a maximum of that nature would allow repeat offenders, in order to punish them and make sure that they don't keep doing it, to have an adequate deterrent for that specific offence.

Hon. James S. Cowan: Yes.

Mr. Colin Fraser: There's no minimum penalty here.

Hon. James S. Cowan: Right.

Mr. Colin Fraser: Thank you.

The Chair: Thank you very much, Mr. Fraser.

Thank you very much, Senator Cowan, for being the first to mention cattle at one of our meetings. It's very much appreciated. I know many of our western colleagues will be very happy about that.

Mr. Falk.

• (1240)

Mr. Ted Falk (Provencher, CPC): Thank you to all of the witnesses here at committee today. I found your testimony and your comments very interesting and enlightening.

Of course, on the Conservative side, we voted in favour of the legislation not only just to bring it to committee and study it, but in principle we're in favour of it, as well.

As technology advances, and as there's progress made on lots of different fronts, different people want to use the benefit of that technology for different purposes, and I think when that happens, we have to also create the proper safeguards that prevent its abuse. We want to be able to use that technology for good purposes, and I think this piece of legislation seeks to address the potential abuses.

I am a bit intrigued with something Mr. Fraser brought up, which is that the punishment seems to be a little industry specific. You mentioned anti-spam legislation and the monetary penalties there, specifically targeting Internet companies and companies that would use that medium as a source of advertising, and that seems to be drawn there, too.

I'm wondering, from an industry perspective, though, do you see any benefit at all for genetic testing that could be an advantage to people?

Hon. James S. Cowan: Thank you, that's an excellent question. Where do I begin?

At the root of it, I think that's the motivation behind this, because we see this genetic testing as key to the personalized medicine or precision medicine that is recognized by health care professionals as the future of medical care.

Let's put it this way, when you go to your doctor and you are diagnosed with a condition or an illness, then the doctor will prescribe a medication that is for the average person. That happens to be the average male with that condition, because that's the way they test it, whereas if the medical professional were to have access to your precise genetic information, then the doctor prescribing could know which medications are most likely to succeed and just as importantly which medications are almost sure to fail.

Here's a startling statistic that I heard a couple of weeks ago in Vancouver. I am told that there are between 10,000 and 20,000 Canadians who die every year because of adverse drug reactions. That's an astounding figure. What happens is that many people are prescribed drugs based upon the general information, and they react adversely.

There's a syndrome called the long QT syndrome. It's a mutation that appears in the general population, in one in 2,500.

Mr. Ted Falk: Can I thank you for that and ask you another question, which I also want to get in?

Hon. James S. Cowan: May I add one thing?

Mr. Ted Falk: You can add just one thing.

Hon. James S. Cowan: I'll provide the information to you.

Mr. Ted Falk: When I go to purchase insurance these days, they do a variety of medical tests on me. They do an EKG and they do a blood sample. What would be the difference, in your mind, between that and a genetic test affecting their risk rating?

Hon. James S. Cowan: From the point of view of public policy, where I would draw the line is the point at which the insurance companies have access to information about your current situation. They ask you about your historical medical information. They ask you about your current information; what hospitalizations you've had, what drugs are you taking now, whether you drink or smoke, they weigh you, they do all those kinds of things.

The difference between that and the results of genetic testing is that those results indicate, to a greater or lesser extent and with greater or lesser accuracy, what might happen in the future. As public policy-makers, I think if we are to draw a line between what is reasonable to provide to somebody who is assessing risk and what is across the line, I think the proper place is there.

Mr. Ted Falk: I'm not entirely disagreeing with you, but I'm subjected to blood tests, and EKGs, and chest compression dimensions. These are all kinds of things already that help them rate my risks under these current conditions. They check my pulse, and my blood pressure, and all these kinds of things. I'm just wondering why you see that as being significantly different from doing a genetic test.

• (1245)

Hon. James S. Cowan: I think the difference is that what that blood test will give you is an indication as to your current situation. Are there elements that are out of whack in your blood count? I'm really going beyond my ken here, but they'll assess your current state and they also have access to what's happened in the past. A genetic test is a predictor, with a greater or lesser accuracy, about what might happen in the future. That's the difference.

Mr. Robert Oliphant: I really want to emphasize that part. Because of the predictive nature— When the insurance industry was opposing this, some of the actuarial studies that were done did not take into account behavioural changes that could improve a person's health if they had the genetic test.

Mr. Ted Falk: Sure.

Mr. Robert Oliphant: I was a pastor for 25 years. One of my jobs was to encourage people to go to the doctor, because they didn't want to get bad news. I was saying that we need to lower the barrier that is a human instinct to avoid getting bad news. That's what we all have at a base level. If we also have a potential discrimination in another way, like you can't get a job, it's another thing.

The Chair: Go ahead, Mr. Falk.

Mr. Ted Falk: Thank you very much, Mr. Chair, and I recognize you're extending me some grace here.

Madam Landry, thank you for coming. Thank you for your testimony. Have there been any current complaints about discrimination based on genetic testing?

Ms. Marie-Claude Landry: Sorry, can you repeat that?

Mr. Ted Falk: I can't talk French, but I'll talk slower.

Are there any current complaints made to the Canadian Human Rights Commission on genetic discrimination? Have you had any cases?

Ms. Marie-Claude Landry: As I mentioned in my speech, in fact, people can complain about the situation if it's linked to something else as a disability. We have around 20 file inquiries or complaints about genetic discrimination, but they are related to something else also; disability, race, or—

The Chair: I think what Mr. Falk is asking is this. Have you had to reject complaints because they didn't tie to another prohibited ground?

Ms. Marie-Claude Landry: If it didn't relate to another ground, for sure.

Mr. Ted Falk: You can answer in French, if it helps.

The Chair: Have you had ones you've had to throw out? That's what he's saying. They've come to you, but you said you can't deal with it because.... That's what he's trying to ask you.

Ms. Marie-Claude Landry: The answer is yes. If it doesn't link to something else, such as disability or race, yes.

Mr. Ted Falk: And it has happened?

A voice: Yes.

The Chair: *Merci beaucoup.*

Now we're going to go to Ms. Khalid.

Ms. Iqra Khalid (Mississauga—Erin Mills, Lib.): Did you want to add something?

Ms. Marcella Daye: Thank you. I can just add a bit more detail to that.

Since genetic characteristics are not an enumerated ground in our legislation, individuals do not file complaints on that basis alone. Therefore, the complaints and inquiries that have come to us are almost always linked to another ground because people recognize those other grounds on the face of the act and genetic characteristics then become a complementary piece for that. People are saying, "I have the genes for this race," or, "It was discovered I have the genetic marker for this disease". They have been connected to other grounds in our act, but I cannot say that there has been one that we have rejected specifically because it was only based on genetic characteristics. As the chief commissioner mentioned, if a complaint were to come to us that only cited that ground unrelated to any of the other grounds, we would have to reject it as the law stands today.

The Chair: Thank you.

Ms. Kahlid.

Ms. Iqra Khalid: Thank you, ladies and gentlemen, for coming in. I have two questions—basic ones, I hope.

The current Bill S-201 doesn't define what genetic discrimination is. It's my understanding that a previous version of the bill did define

it and that the Human Rights Commission had recommended that the definition be removed and that it be left to the tribunal and to the courts to decide how to interpret it.

My question is, why is that? Secondly, would it be beneficial at all or would it be detrimental if parliamentarians were to set a baseline from which courts, tribunals, and in reality our provinces could work with respect to determining what genetic discrimination means?

• (1250)

Ms. Marcella Daye: Overall, and through the period in which we have been asked to comment on our act, we have remained steadfast that we do not recommend that definitions be included in the Canadian Human Rights Act. One reason for this is that Canadian human rights legislation, like all human rights legislation, needs to be interpreted broadly in order to give effect to the underlying purpose of the act, and that definitions are often limited by the time in which they are prepared. Especially on a topic such as genetic characteristics, which is very rapidly evolving, that rationale becomes more important. We would not want to freeze a definition in time when the science and technology are developing.

Doing as suggested also allows judges to bring the judicial interpretive principle into play when individual cases arise. We very rarely—in fact, I can't recall a time—recommend that a definition be added, but that does not mean that we cannot offer guidance and clarity on the concepts that are covered under our act. In fact, in the legislation you have before you there has been a section that deems discrimination based on a genetic test to be discrimination based on genetic characteristics. Those kinds of clarifications can assist in interpreting our acts.

I hope that's helpful.

Ms. Iqra Khalid: Thank you.

Most forms of discrimination are protected within our Canadian Human Rights Act as well as within various other statutes. The courts have said that these various statutes are given quasi-constitutional status. This bill creates a specific act for a specific form of discrimination, with its own set of penalties.

Do you have any concerns about elevating one specific type of discrimination over others?

Ms. Marcella Daye: We are not unfamiliar with legislation that has both criminal sanctions attached to it and similar protections under human rights law. For example, sexual harassment is an issue that can be complained about to the Canadian Human Rights Commission, but if the same incidents also make up a sexual assault, then a criminal action can be made on those same incidents. That kind of complementary legislation is not unfamiliar.

We're always concerned with hierarchy of grounds under the Canadian Human Rights Act. We don't want one ground under our act to be subject to different rules from those for any other ground, but because this legislation creates a separate process, under the Canadian Human Rights Act it may not have that same effect.

We are open to further examination of those issues and hope that the committee would look at them, as they do at other issues under the act. The very fact of there being a multiplicity of venues, including the Canadian Human Rights Act, is not unusual wherever Parliament has esteemed that a certain type of behaviour that is more precise needs to be raised to a level of protection of health, safety, or security of the person that provides a need for criminal sanctions.

Ms. Iqra Khalid: Thank you very much for that.

Mr. Oliphant, Senator Cowan, did some provinces or territories highlight the need to coordinate with federal efforts with respect to this specific type of discrimination?

Mr. Robert Oliphant: No.

I think we should promote its happening for complementary.... A member of provincial parliament in Ontario has his private member's bill, which he has said complements ours, but right now, that is accidental. We're hoping it isn't accidental, that we do it more intentionally, but right now, I think it is also to respect the provinces, that desire not to do it.

We can't have it both ways; we can't be doing something that some people say is provincial and then tell them to do something. This is a modelling exercise, since we hope to model good behaviour at the federal government level, and other provinces and territories might see it as something they can do as well.

The Chair: Ms. Khalid.

Ms. Iqra Khalid: Thank you, that's it. I have no more questions.

The Chair: Mr. Cooper.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Mr. Chair.

Thank you to the witnesses. In particular it's great to see Mr. Oliphant and Senator Cowan. We spent so much time on Bill C-14.

I want to commend you, Senator Cowan and Mr. Oliphant, for putting forward this legislation. It is a fact that Canada is the only jurisdiction in the G7 without legislation to protect individuals against genetic discrimination. Certainly this will go a long way to closing that gap.

I would like to follow up on Mr. Falk's question. Looking at the Canadian Human Rights Act, I am a little unclear as to whether cases have been dismissed. I know, for example, if you look at the Canadian Human Rights Act one of the prohibitive grounds of discrimination is disability. Has disability been interpreted in the context of genetic discrimination, and if so, what have the outcomes of those cases been?

• (1255)

Ms. Fiona Keith (Counsel, Human Rights Protection Branch, Canadian Human Rights Commission): No cases have been decided on this issue under the Canadian Human Rights Act. A case originating in Quebec went to the Supreme Court of Canada where

an issue related to genetic characteristics was recognized by the court and linked to discrimination on the basis of disability, so that has been recognized in the jurisprudence.

To go back to your initial question, which was whether or not the commission has dismissed a complaint or decided not to deal with a complaint on the basis of genetic characteristics, as my colleagues explained earlier, the act currently does not list genetic characteristics as a prohibited ground of discrimination. We do not collect statistics on that particular form of discrimination.

If a complaint comes to us and names a ground of discrimination that's already in the legislation, for example, disability, we would deal with it on that basis. But if a complaint comes to us solely on the basis of genetic characteristics we would not deal with it and we would not report it.

Mr. Robert Oliphant: Could I add to that?

Because I have a very low level of experience of working in an office with human rights complaints, what typically happened in the Yukon was that a phone call would come in and the receptionist started doing triage and screening. It might get to an investigator but if it wasn't on the list of prohibited grounds it got logged as a call but it didn't get analyzed, so we don't have that data. We would like to have it but that's the way the human rights system....

Because I have very low level experience and they have a high level of experience, I even know what it's like to answer the phone.

Mr. Michael Cooper: The case that you're referring to, Ms. Keith, was on the basis of the Quebec charter. Is that correct?

Ms. Fiona Keith: That's correct.

Mr. Michael Cooper: I think the Quebec charter and the court ruled on the basis of a handicap.

Ms. Fiona Keith: I believe that's the language in that legislation.

Mr. Michael Cooper: Yes.

One of the things that is troubling is that in Canada today people are penalized for proactively undertaking testing that could be very beneficial to them over the long term.

Mr. Oliphant, you had referred to the fact that not only are people being penalized, but in many cases they are frankly afraid of seeking this testing for fear of discrimination. I think you referred to something at SickKids hospital in Toronto. Would you care to elaborate a little?

And Ms. Landry, you might want to add to it because I know you alluded to that.

The Chair: I have to ask for a brief answer from Mr. Oliphant because we have to get to Mr. MacGregor. We're going to be kicked out of the room shortly.

If it's okay with you, Mr. Cooper, I'd like Mr. Oliphant to answer.

Mr. Robert Oliphant: I think Dr. Ronald Cohn is one of your witnesses.

The Chair: Yes, he is.

Mr. Robert Oliphant: I think so, and I think you'll get a better answer from Dr. Cohn than from me because he'll have exact.... I've met with him now five or six times about this issue, and I think he can give you exact scenarios of the way that plays out in both his research work, where people don't even want to get into research projects for drug tests because it now involves those kinds of tests.

We won't have new drugs coming onto the market because people don't want to do that. Then we have a physician in a clinical practice who is arguing with parents to ask them to get the tests so he can do his job, and they step back.

I want to get on the record that the other thing in Canada is that not only is this about the health of Canadians—and that's my primary thing—but biotech industries are emerging that Canada can be a leader in.

I talked to people from two companies. One is Sequence Bio in Newfoundland, which is a world leader on biotech information, and they're going to do a survey of 100,000 Canadians. They are desperate to have this information so they can do that testing. They feel they won't get a sample size big enough if they don't do it. In Quebec BiogeniQ is another company. These are jobs, and these are important issues that we also need to address.

● (1300)

The Chair: Thanks.

Just because of time, we'll go to Mr. MacGregor.

Mr. Alistair MacGregor: I have a very quick question, Senator Cowan.

I have read the Senate transcripts as your bill made its way through there and you certainly encountered a fair number of your colleagues who were skeptics on its constitutionality. May I have your thoughts on what it was you think led them to overcome those doubts and stand with you to send that bill to this House?

Hon. James S. Cowan: I always hesitate to speak for others, but my sense would be that we provided to the Senate, as we will provide to your committee, strong evidence from eminent constitutional scholars that this is a legitimate exercise of the federal power. I think the responses from the provinces, both to my enquiries and

from the committee, indicated that the provinces are not concerned either from a jurisdictional or a policy point of view. They're looking to examine their own codes and legislation to make it complementary, but they're not saying, "Hold on, we need to act first." They're waiting for federal action, in my view, and I think that's my responsibility.

The Chair: Technically, you have two more minutes.

Mr. Alistair MacGregor: Okay.

The other point I wanted to get across follows up on Mr. Falk's question. Nothing in this bill is going to prevent or hamper the provinces from legislating contractual law with insurance companies if they so wish. I would venture that both of you would agree with that. There is also the fact that in this new era of medicine—we really are on the dawn of a new age of personalized medicine—it may be that if we take away the fear people have of getting a genetic test we may actually encourage more healthy lifestyles, people taking control of their own destinies, so to speak. It may, in the long run save our health system thousands if not millions of dollars. In fact, it may even save the insurance companies some money as well. Would you agree with that?

Mr. Robert Oliphant: Absolutely. The thing about targeted...and I have avoided the words "personalized medicine" because it kind of sounds like a high-end store. It's targeted medicine, so you don't waste time doing trial and error to get to better health outcomes. You actually give information so that people can change their lives.

The famous case is Angelina Jolie, the famous case of a person who dropped her risk from over 90% down to 5% of developing breast cancer. That gives her the opportunity to live a full life, pay more insurance premiums, do all the things that she is going to do. For normal, average, non-star people as well, it can have that impact. It's hugely important that we drop any barrier because it is so human to not want to do that. If there's something artificial or legal in the way, let's get the barrier down.

The Chair: Thank you so much.

I just want to thank all of the witnesses for coming forward today. Your testimony was greatly helpful to our committee. Since there's another committee coming in, I would ask everyone to clear out as quickly as possible.

The meeting is adjourned.

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