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# Standing Committee on Justice and Human Rights

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## EVIDENCE

## Thursday, November 17, 2016

## Chair

**Mr. Anthony Housefather**

# Standing Committee on Justice and Human Rights

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● (1100)

[*English*]

**The Chair (Mr. Anthony Housefather (Mount Royal, Lib.)):** I'd like to bring this meeting of the Standing Committee on Justice and Human Rights to order as we recommence our study on Bill S-201, an act to prohibit and prevent genetic discrimination.

I'd like to welcome today, as our witnesses from the Department of Justice, Laurie Wright, who is the assistant deputy minister, and Laurie Sargent, who is the deputy director general and general counsel, in the human rights law sector, public law and legislative services sector.

Welcome. By the way, I'm always so impressed by this title. It is the longest title I have ever seen.

**Voices:** Oh, oh!

**Ms. Laurie Sargent (Deputy Director General and General Counsel, Human Rights Law Sector, Public Law and Legislative Services Sector, Department of Justice):** I do my best.

**The Chair:** We welcome you.

Ladies, as I understand it, you do not have a statement in advance of questions.

**Ms. Laurie Wright (Assistant Deputy Minister, Department of Justice):** That is correct. I understand that you may have something from the minister by way of a statement.

**The Chair:** Perfect.

Members of the committee, we're going to be interrupted by bells at a certain point. I'm wondering if members would agree to give unanimous consent at the 30-minute bells to go for 15 minutes and then stop after 15 minutes so that we can go to vote. Is that okay with everyone on the committee? Do we have unanimous consent so that we won't interrupt?

**Some hon. members:** Agreed.

**The Chair:** Given that, we'll move to questions for witnesses, starting with the Conservatives. Who will be going first?

Mr. Nicholson.

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

Thank you very much for your appearance here today.

The bill describes “genetic characteristics”. Do you have any issue with that definition perhaps being too broad? Do you have any thoughts on that at all?

**Ms. Laurie Sargent:** Thank you very much.

As you know, we're here to provide the technical views. From our perspective, we're not going to speak to the term “genetic characteristics” as it is used in relation to the genetic non-discrimination act. We're going to leave the statement to speak to that.

As we understand it, from the perspective of the Canadian Human Rights Act, that definition won't be imported into the CHRA, so, as with so many other grounds in the CHRA, the terms will be left to be defined by the Canadian Human Rights Commission and others as they interpret the legislation.

That would be our understanding of the bill, anyway. Thank you.

**Hon. Rob Nicholson:** All right. That's fair enough.

Let me ask you questions with respect to the fines and penalties here. This is not part of the Criminal Code, but it creates an offence. That being said, how do you think the penalties, the fines, or the prison time line up? Do you find this pretty well in line with others? Do you find it consistent, or above, or below? What are your thoughts on that?

**Ms. Laurie Wright:** Certainly, the act stipulates that a prison term of up to 12 months could be imposed on summary conviction. By way of general reference, the Criminal Code for summary conviction offences has a maximum term not exceeding six months.

Also, with respect to both the possible term of imprisonment and the fines that are available under the genetic non-discrimination act, they would line up with much more serious penalties that you would see for offences in the Criminal Code, such as counterfeiting or those kinds of things. They're certainly on the high end.

● (1105)

**Hon. Rob Nicholson:** Are you able to give any opinion with respect to the constitutionality? This is an issue that has come up on a number of occasions. I expressed my own opinion yesterday that creating an offence of actions that we find intolerable or wrong is within the federal jurisdiction, but nonetheless, we're going to be hearing more about this. You may or may not want to comment on it, but I thought I would raise it with you.

**Ms. Laurie Wright:** Thank you very much.

As you know, Mr. Chair, we're here to provide technical comments on the bill, not to provide advice to the committee.

Thank you.

**Hon. Rob Nicholson:** Thank you very much.

Those are my questions, Mr. Chairman.

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

You still have more time in the block if Mr. Falk or Mr. Cooper wants to ask any questions. No?

All right. We're going to move to Ms. Khalid.

**Ms. Iqra Khalid (Mississauga—Erin Mills, Lib.):** Thank you very much, Chair.

Thank you, ladies, for coming in today to answer questions on the technical aspects.

As you may know, we will be having some lawyers coming here and presenting testimony on the constitutionality of the bill, among other things, so I'm sure Mr. Nicholson will really look forward to that.

**Voices:** Oh, oh!

**Ms. Iqra Khalid:** I do want to ask some technical questions. If you can, as a beginning, please talk about how each section of the bill affects the respective codes that are being amended. For example, what is the effect on the Labour Code? What is the effect on the Criminal Code and on the Human Rights Act as well, please?

**Ms. Laurie Wright:** Maybe I'll ask Laurie to address the Canadian Human Rights Act first, and then I can follow up from there.

**Ms. Laurie Sargent:** With respect to the Canadian Human Rights Act, the key piece will be that it's adding a new prohibited ground of discrimination to the CHRA: the ground of genetic characteristics. We were just been here on Bill C-16, which was also adding a new ground of gender identity and expression. This bill will provide explicit protection against discrimination on the basis of genetic characteristics.

From the Department of Justice's perspective, there already is some protection in the CHRA under the ground of disability for anyone who has a predisposition, as we would call it, to a disability that might be revealed through any number of means, including a genetic test. That has been established in the case law by the Supreme Court, in the case of Quebec v. Boisbriand (City) and Quebec v. Montreal (City). This is taking that, in a way, one step further to make it clear that discrimination is prohibited whenever someone has a genetic characteristic that may predispose them to particular abilities or not, or illness or not, and clear that this is obviously a prohibited basis on which employers and service providers who are regulated by the federal jurisdiction can make decisions.

**Ms. Laurie Wright:** With respect to the Canada Labour Code, in terms of the detailed interaction between the two, I would refer you to the possibility of speaking to labour officials about the details of the Canada Labour Code. I can say generally that the concurrent changes to the Canadian Human Rights Act and to the Canada Labour Code do appear to create two systems that would operate to effectively be looking at the same kinds of complaints and issues at the same time.

With respect to the Criminal Code portion, the criminal nature of the genetic non-discrimination act, I think it would be solely, as another honourable member already mentioned, a question of whether the types of penalties match up with those for offences of a similar kind of gravity that are already in the Criminal Code.

● (1110)

**Ms. Iqra Khalid:** Okay. Thank you.

I understand that we are talking only about the technical terms here. What arguments can be made against the constitutionality of this bill with respect to jurisdiction? I'm not talking about your position. I'm talking about what arguments can be made. If possible, can you cite some cases that we could refer to in preparation for our questioning of the lawyers who will be attending?

**Ms. Laurie Wright:** I'm not in a position necessarily to put specific arguments on the table. I can tell you that there is a long history, both in the judicial committee of the Privy Council and in the Supreme Court, of looking at various times when Parliament has brought forward legislation that purported to apply to insurance companies, and it has been rejected on numerous occasions.

**Ms. Iqra Khalid:** To flip that, can you then give arguments that can be made for the constitutionality of this proposed legislation? If you can, then we'd really appreciate you citing some cases.

**Ms. Laurie Wright:** I'm not going to be able to go into that level of detail. I do understand, for example, that Professor Ryder testified in the other place with respect to his views on how to support the constitutionality of the bill, so I could refer you to that.

**Ms. Iqra Khalid:** Okay, can you please?

That's it.

**The Chair:** He will be here on Tuesday, so he can speak to us as well.

**Ms. Iqra Khalid:** Thank you.

**The Chair:** Are there any other questions, Ms. Khalid? You have another half minute.

**Ms. Iqra Khalid:** I think I'm just going to say thank you, and that's it.

I think Mr. Bittle has a question.

**Mr. Chris Bittle (St. Catharines, Lib.):** I'll try to approach it in a different way, as we're all coming at this.

Based on your knowledge, has the Department of Justice heard from any province or territory expressing concerns about the constitutionality of this bill?

**Ms. Laurie Sargent:** On that point, obviously Senator Cowan and others have reached out, and the responses received to date have not indicated any significant concerns on their part.

Officials at the Department of Justice reached out in September to start discussions with them with respect to Bill S-201 and its various elements in a little bit more detail. We have not yet received responses.

I want to note, however, that it was clear from discussion that provinces and territories were very interested in the legislation. They could see that it had potential implications for their own human rights legislation, for their own regulation of the insurance industries, and of course for health care. While we weren't necessarily talking about concerns at that time, it seems very important that we speak with officials and ministers to ensure that everyone fully understands some of the implications of this legislation.

**Mr. Chris Bittle:** Here is just a quick—

**The Chair:** Maybe do that in the next segment, if it's okay, because we're seven minutes in. I'll start the next Liberal segment with you.

**Mr. Chris Bittle:** Thank you.

**The Chair:** Mr. MacGregor.

**Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP):** Thank you, Mr. Chair. I really appreciate the appearance of both witnesses today. I will try to keep this as technical as possible.

I want to go on to the subject of federal criminal law power. We know that criminal law's main purpose is to look at a supposed evil, which may be directed at any kind of form, against any person or organization. If we enact legislation with the purpose of protecting vital public interests, an argument could be made that doing so falls within the jurisdiction of criminal law power.

If we look technically at the bill before us, Bill S-201, and examine the relevant clauses, are you able to tell this committee how federal criminal law power could technically fit within the direct prohibitions that exist in these clauses? It seems to me that a behaviour is being targeted and not really a direct contract. A contract could exist in any kind of business, but this seems to me to be the action and not the end result.

● (1115)

**Ms. Laurie Wright:** I think we're probably straying into the realm of more detailed legal advice, as much as you have tried to structure it as a technical question.

What I can say is that throughout the history of the jurisprudence on the criminal law, the Supreme Court has been quite clear that it's a power that needs to be circumscribed in order that it not spill over and start to take up too much of an area of provincial jurisdiction. You therefore have examples of such cases as the reference on the Assisted Human Reproduction Act, which struck out several provisions from that legislation because they were overly concerned with matters to do with regulation of a profession and a business in a province.

**The Chair:** Okay. But the provisions leaving it criminal remained in the act. Those were not struck down.

**Ms. Laurie Wright:** The provisions that were struck down were the ones that were geared towards putting certain restrictions on how the medical profession carried out its business in the area.

**The Chair:** Yes. I just wanted to clarify that.

Go ahead, Mr. MacGregor.

**Mr. Alistair MacGregor:** Suppose Bill S-201 is passed in its present form—and we've already had some indications from the provinces that they seem at most ambivalent about it—if you were tasked by the Department of Justice, by the federal government, to defend this bill against a provincial challenge, how would the Department of Justice defend the specific provisions in the first clauses?

**Ms. Laurie Wright:** I think again we're probably getting into the realm of something that's more specific than what I am here for, which is to talk about the substance of the bill in technical terms. It would certainly be at the discretion of the minister and Attorney General of Canada to determine the way forward in consultation with her cabinet colleagues.

**Mr. Alistair MacGregor:** Then I'll move to the later clauses of the bill, the ones that specifically deal with the changes to the Canadian Human Rights Act.

Does the department feel that the clauses within this part of the bill are enough to give people who may have concerns peace of mind that they will not be discriminated against? Looking at those clauses —because we've heard about a three-legged stool—do you feel that if we're going to remove the other two and just leave this one, technically those protections specified in this bill will stand up against a challenge? Will people still be discriminated against? I want to know whether technically it will stand up against discrimination.

**Ms. Laurie Sargent:** Thanks.

Of course, we're not able to express an opinion on that particular topic. I would say that, within the realm of what the Canadian Human Rights Act regulates, which is employment within the federal public service and also within the federally regulated sector —banks, aviation, etc.—this will provide explicit protections. This will provide protections against discrimination in employment in relation to any person who feels they have an allegation and a claim that their employer has either asked them to undergo a genetic test and/or made a decision, a hiring decision, or some other decision, in a discriminatory fashion based on the results of a genetic test.

**Mr. Alistair MacGregor:** Does this final section of the bill place the onus on the individual who feels they have been discriminated against to then take action?

**Ms. Laurie Sargent:** Within the human rights system that's generally how things work in terms of an actual individual complaints process. The Human Rights Act itself sets out norms that employers and service providers must be aware of, so it also has a role to play in regulating the conduct of businesses and employers. However, you're absolutely right that when an individual seeks to bring a complaint, they have to do so. They come before the commission. The commission has its own powers and abilities to investigate the alleged discrimination. It's a relatively informal process, but again, the burden, as with all discrimination complaints, would rest on the individual bringing it forward in the event they felt that discrimination had occurred.

**Mr. Alistair MacGregor:** Thank you.

● (1120)

**The Chair:** The floor is yours, Mr. Bittle.

**Mr. Chris Bittle:** Just as a very brief follow-up to my last round of questions, as Mr. MacGregor put it, there seems to be at best a level of ambivalence from the provinces. In your experience at the Department of Justice, have provinces been shy about expressing constitutional concerns with proposed legislation in the past?

**Ms. Laurie Wright:** It tends to be extremely context-specific. As my colleague mentioned, from our perspective, it was only early this fall that we started our outreach to talk specifically about the content of the bill with colleagues at our level in other jurisdictions.

**Mr. Chris Bittle:** I'm going back to past legislation. I believe you both have been with the department for quite some time. Even without the department reaching out, provinces generally aren't shy, wouldn't you agree, about advising the Department of Justice that they have concerns with particular legislation, especially if they believe it might interfere with provincial responsibility or jurisdiction?

**Ms. Laurie Wright:** The normal process for the development of policy across government that results in legislation would include within it outreach and consultations with provinces and territories as well as with stakeholders, civil society, and others. In the normal course of development of government legislation, there would certainly be opportunities for those kinds of considerations to be taken into account.

**Mr. Chris Bittle:** Thank you.

**The Chair:** I believe Mr. Fraser has a question.

**Mr. Colin Fraser (West Nova, Lib.):** Yes.

Thank you very much, ladies, for being here.

I have a quick question with regard to the statement of the government's position on this that we were handed. The briefing reads, “Canada does not generally use criminal law-type prosecutions and penalties to address discrimination.”

I'd like to hear your comment on the fact that generally they are not used. Can you give examples of where the criminal law-type prosecutions and penalties are used to address discrimination? What examples are there in our law?

**Ms. Laurie Wright:** The closest analogy I can come up with are the provisions in the Criminal Code that are not based on penalizing discrimination but are the hate crimes and hate speech provisions. These are also geared toward preventing very serious activity that would be based on similar grounds that you would normally see in an anti-discrimination statute, but where the types of actions have risen to the level that they go beyond what's appropriate for that framework in terms of being addressed more under the criminal law.

**Mr. Colin Fraser:** Thank you. That's it.

**The Chair:** Does anyone else on that side have any questions?

During their testimony, the sponsors of the bill made an analogy with respect to the anti-spam law, noting that heavy fines were levied for companies that created spam. Can you distinguish that law from this proposed law?

**Ms. Laurie Wright:** As I understand it, the anti-spam legislation is not perceived as a criminal law power. It is a trade and commerce-based statute. It is based on compliance and heavy fines intended to stop deep pockets from carrying out certain kinds of activities.

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

We've done one round and now the bells are ringing, but if we're going until 15 minutes before, then we have 11 more minutes.

Members of the committee, do you have any other questions for this witness? We'll just go to anybody who has questions.

Mr. Falk?

**Mr. Ted Falk (Provencher, CPC):** Yes.

Could you expand just a little more on whether the fines that are being proposed in this bill are consistent with other fines within the Canadian Human Rights Act? How much of a variance is there?

**Ms. Laurie Sargent:** Obviously, it would be impossible to do a comprehensive survey of all the different penalties in the Criminal Code and in other criminal-based legislation. One thing that does jump out is that even on a summary conviction, the proposed fine of, I think, $300,000 and potential imprisonment of up to 12 months is higher than pretty much anywhere else, based on the survey we did. Fines usually tend to be below the $100,000 range, but it varies of course, and imprisonment tends to be up to six months. They are of course higher than those that, on average, would be found in the Criminal Code.

Picking up on your question, I want to add one piece, which is that when one looks at Criminal Code provisions, generally they are more focused on intentional actions or intentional harm being committed, usually resulting in some form of physical or “security of the person” impact or economic harm.

It's helpful to think about what different types of activities are being criminalized and what the commensurate penalties are. Again, though, I'm not in a position to provide a comprehensive overview of the different penalties provided for.

● (1125)

**Mr. Ted Falk:** Would you please expand as well, Ms. Wright?

**Ms. Laurie Wright:** I just want to add that normally the purpose of the human rights anti-discrimination legislation is remedial, so it's primarily focused on the kinds of remedies that bring the parties together and reconcile them in terms of what the action was as opposed to being a penal kind of legislation that has huge fines and penalties. There is a possibility, under the Canadian Human Rights Act, for some penal action to be taken against those who have committed discrimination, but the primary purpose is remedial.

**Mr. Ted Falk:** Okay, thank you.

Thank you, Mr. Chairman.

**The Chair:** Does anyone else have any questions?

Mr. MacGregor.

**Mr. Sean Casey (Charlottetown, Lib.):** Mr. Chair, if I'm not cutting into anyone's time, may I have permission to ask a question?

**The Chair:** Mr. MacGregor had his hand up first, and then, Mr. Casey, if there is no objection, we'll let you ask.

Mr. MacGregor.

**Mr. Alistair MacGregor:** I'll make it quick.

I just want to do some comparison here. Part X of the Criminal Code deals with specific prohibited activities that relate to contracts. It prohibits certain types of behaviours and actions relating specifically to contracts. Technically, how do the prohibitions in this bill with respect to contracts differ from what is already prohibited in the Criminal Code?

**Ms. Laurie Wright:** I'll say first that I'm not a criminal law expert, so I am here largely to address some of the other elements of the bill.

Second, on principle, it would be necessary to look at the kind of behaviour and the severity of the action that's being taken with respect to the contract. For example, fraud would be one of those kinds of things. That would be the way I would approach the question.

**Mr. Alistair MacGregor:** Okay, thank you.

**The Chair:** Does the committee agree that Mr. Casey can ask a short question?

**Some hon. members:** Agreed.

**The Chair:** Mr. Casey.

**Mr. Sean Casey:** Thank you very much, colleagues and Mr. Chair.

I know that you can't comment on the constitutionality, but I would ask for your comments as lawyers within the Department of Justice.

We know from Senator Cowan's testimony and from the letter that has just been distributed that the view of the government and of the department is that this is provincial jurisdiction. We know that you're not here to comment on that.

If the bill is passed as it presently stands, without amendment, we heard from Senator Cowan—and I believe it's true—that it is inevitable that there will be a constitutional challenge launched by the insurance industry, and the Department of Justice will be in the uncomfortable situation of appearing in court to defend a bill that it doesn't support.

As a Department of Justice lawyer, with those lawyers reporting to you, do you have any comment on the situation that we will be put into in the event that a bill that the government doesn't support ends up being passed and then you have to defend it in that situation in court?

**Ms. Laurie Wright:** I would begin by saying that, as you know, Mr. Chair, it's not my personal view or the view of any of those who report to me with respect to the legal analysis that may have been applied or that will be relevant to the question of moving forward to defend a piece of legislation that has been challenged. Certainly it is within the discretion of the minister and the Attorney General to make her decisions and instructions to counsel with respect to moving forward.

It is an important fundamental principle that a sovereign Parliament that has enacted a law is due its day in court. It is thus not unusual for the department and the Attorney General to be in a situation of defending those laws in court, and we do it to the best of our professional ability.

**The Chair:** I imagine that would happen any time there's a change of government, when one government disagrees with the position of the previous government but a law has been adopted.

If colleagues would allow, I'll ask one short question.

In response to Ms. Khalid's excellent question before, and then in terms of Mr. MacGregor's question, you talked about referring us to cases that might lead us to believe that the law might be unconstitutional. You referred us to a flurry of cases in which it had occurred at the Privy Council and then at the Supreme Court related to the insurance industry.

The current bill, as opposed to its predecessor version, no longer makes exemptions for insurance contracts of large amounts, so it removes any reference to the insurance industry. Are you aware of any case of a law being struck down when it made no specific reference to the insurance industry?

● (1130)

**Ms. Laurie Wright:** Certainly in the long history of jurisprudence on who has jurisdiction over certain matters—because, as we know, there are no bright lines drawn in sections 91 and 92 of the 1867 Constitution Act—there has been a predominant theme of recognizing, as the words of the Constitution put forward, that matters of property and civil rights and matters of a purely local and private nature are within the jurisdiction of the provinces. There has been a series of cases on other areas—around, for example, regulations of professions and the attempt to regulate particular industries—that would follow the same theme.

**The Chair:** Does anyone else have any questions for these witnesses?

If not, Ms. Wright and Ms. Sargent, thank you again for your wonderful testimony today. We really appreciated it.

**Ms. Laurie Wright:** Thank you very much.

**The Chair:** Colleagues, we still have a couple of minutes before we have to leave.

Could we get a motion to approve the travel budget for the conference we had previously passed a motion to attend?

Mr. Nicholson moves acceptance.

(Motion agreed to)

**The Chair:** Colleagues, I guess we should take a break and come back after the vote. Is everybody good with that?

**Some hon. members:** Agreed.

**The Chair:** The meeting is suspended until after the vote.

● (1130)

(Pause)

● (1205)

**The Chair:** We are going to reconvene the meeting of the Standing Committee on Justice and Human Rights studying Bill S-201, an act to prohibit and prevent genetic discrimination.

I'd like to welcome this group of witnesses to the committee. From the Canadian Coalition for Genetic Fairness, we have Bev Heim-Myers, who is the chair.

Welcome.

**Ms. Bev Heim-Myers (Chair, Canadian Coalition for Genetic Fairness):** Thank you.

**The Chair:** From the Centre for Israel and Jewish Affairs, we have Noah Shack, who is the director of policy.

Welcome.

[*Translation*]

We also have with us Mr. Richard Marceau, General Counsel and Senior Government Advisor at the Centre.

Welcome, Mr. Marceau.

**Mr. Richard Marceau (General Counsel and Senior Government Advisor, Centre for Israel and Jewish Affairs):** Thank you.

[*English*]

**The Chair:** We also have, from the Canadian Association of Genetic Counsellors, Clare Gibbons, who is the genetic counsellor and past president. Welcome.

All of the witnesses know that they have eight minutes to speak, and we're going to start with Ms. Heim-Myers.

**Ms. Bev Heim-Myers:** Thank you very much, Mr. Chair, and honourable members.

Thank you for inviting the Canadian Coalition for Genetic Fairness, and, indeed, all Canadians, to have their voice heard here today. I truly appreciate it.

I'm going to focus on three areas: the fear of and examples of genetic discrimination, the evidence-based research, and the impact of not protecting genetic test information.

Let's start with the stories.

A young mother expecting her second child was approved for life insurance. Before she received her policy, she found out that her own mother was diagnosed with breast cancer and was subsequently found to have the BRCA gene. This young mom notified her insurance company to let them know that she too wanted to be tested for the BRCA gene so that she could inform her health decisions going forward, and her insurance was rescinded.

A graduating chiropractor applied for life insurance so that she could practise after she graduated. She was initially denied because she was from a Huntington disease family until she proved through a genetic test that she in fact did not have the gene. She reluctantly had a genetic test and does not have the mutation, but the story continues. Five years later, when she was given the opportunity to buy into the practice, the insurance industry said she had to get another genetic test to prove she still did not have the genetic mutation for Huntington disease. Finally her physician stepped in and said, “This is a waste of health care dollars. She doesn't need another test”. However, then her family stepped in and said, “Please stop talking to the media, because we're now getting questions from our employers. Please stop telling them about your experience.”

In Toronto, Ontario, the landlord of a supportive housing site has been asking tenants to provide medical information, including genetic test information. The landlord has approached current tenants directly to ask for this information and is holding back other privileges, like using the common room, until they provide that information. It is unclear why the landlord is asking, but it clearly sets a very frightening precedent.

A gentleman from Ottawa in his fifties was recently diagnosed with frontotemporal dementia. He would like to participate in clinical trials to try to find answers for this disease. His children are in their twenties and are furious at him for even considering getting tested and participating in clinical trials, for the impact it may have on them down the line. This has created a division in the family at a time when he really needs support from his children.

A young man, who was upset at work one day after receiving genetic test results that he had the Huntington disease mutation—although he won't manifest for 20 years—was asked by his employer, “Why are you so upset today?” He told his employer that he had the gene mutation, that he'd be okay for 20 years, but he had to figure out his life. That was on a Friday. On Monday morning this young man went into work and was fired. The employer said he was fired because he was worried for his equipment. The young man was a web designer. To this day he's afraid to apply for another job, and he's 22 years old.

Yesterday, I received a note from an individual wanting to help and support the coalition. When I asked her if she herself had experienced genetic discrimination, she answered, “Thankfully, no, but I would like to move back to Canada and work in the field of genetics, which at this point in time is at a standstill until Canada protects genetic test information.”

Allowing genetic discrimination to occur creates a barrier to personalized medicine. Dr. Yvonne Bombard has published many papers on genetic discrimination, and the impact it has on behaviours. In a recent paper she found that 86% of people in the HD community fear genetic discrimination for themselves and their family members. Fifty per cent of them have experienced genetic discrimination.

In another paper focusing on personalized medicine, Dr. Bombard concludes, “Individuals' concern about genetic discrimination can create barriers to access to genetic services that may offer them important therapeutic or management opportunities, and can result in suboptimal care for those who undergo genetic testing under conditions of anonymity or aliases.”

In other words, genetic discrimination is a barrier to the health and well-being of people living in Canada because people do not seek out the information in order to make informed health decisions.

Pharmacogenetics is a science that can provide life-saving information, eliminate potential adverse drug reactions, and expedite healthy outcomes through the use of the most effective drugs for an individual. The challenge is clearly the barrier of genetic discrimination.

● (1210)

Recently a woman who survived breast cancer had an adverse reaction to tamoxifen, a maintenance drug taken after surviving breast cancer. After taking this drug, she developed a life-threatening pulmonary embolism due to the drug. She has three daughters. Her daughters want to know if they also have a sensitivity to tamoxifen, in case they need to take it one day. Their doctor advised against testing because they would open themselves up to genetic discrimination.

In a paper published in the U.K., R.G. Thomas concluded that there was great push-back from the insurance industry against protecting genetic test information because of a concern that people would top up insurance policies if they knew they may get a future disease.

That has not transpired. In fact, the U.K. Insurance Key Facts 2014 paper, published by the Association of British Insurers, describes the insurance industry as a U.K. success story, and total premium income is lower than in other countries.

The Office of the Privacy Commissioner commissioned two papers looking at the economic and actuarial impact of the insurance industry if they did not have access to genetic test information, and the conclusion was, “it is not clear that the collection and use of genetic test results by insurance companies is demonstrably necessary, effective, proportionate or the least intrusive means of achieving the industry's objective at this time.”

To date, Ontario has tabled Bill 30, and it unanimously passed at second reading. This is a non-discrimination bill in Ontario, and they've been working on it for about four years. This bill addresses adding genetic characteristics to the Ontario Human Rights Code, and it is acknowledged by the sponsor of the bill, MPP Mike Colle, that in order for Ontarians to be protected, Bill S-201 has to go through at the federal level in its entirety, and for this added impact at the Ontario level, by adding genetic characteristics to the Ontario Human Rights Code. This would avoid a patchwork approach. In every province we would have an overriding pan-Canada protection. People could move from Ontario to Manitoba, and they would still be protected. It's seems clear that as Ontario is acting, other provinces will follow to strengthen their human rights act.

These are exciting times in medical science, and yet Canadians cannot take advantage of advances because legislation has not caught up with science and technology. Young people already have access to genetic testing and reproductive options enabling them to make informed decisions before they have children and potentially pass on a genetic mutation. Many young people don't get the genetic tests that could inform reproductive decisions because they fear of genetic discrimination.

Canadians are not participating in clinical trials that necessitate a genetic test for fear of genetic discrimination against themselves and their children. This is a barrier to medical progress in Canada. Parents are making the excruciating decision not to have their children genetically tested in order to inform disease treatment, because they are afraid of genetic discrimination against other siblings in the family. The paper “Genetic discrimination: international perspectives” identifies 37 countries. Of those 37 countries, 16 have specific genetic non-discrimination legislation, and 28 of the 37 have also signed on to a state-led moratorium and have agreed not to use genetic test information. Canada is on neither of those lists.

The time is past due to pass robust legislation protecting genetic test information and allowing all people living in Canada fearless access to personal information about disease prevention, targeted treatment, and management. This can only lead to the increased health and well-being of all people living in Canada. If the government chooses to amend Bill S-201 and decrease its robust approach at this time, Canadians will continue to be disadvantaged.

Thank you very much for your time.

● (1215)

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

We'll move to the Centre for Israel and Jewish Affairs, and Mr. Shack.

**Mr. Noah Shack (Director of Policy, Centre for Israel and Jewish Affairs):** Thank you, Chair, and honourable committee members. I appreciate the opportunity to speak here today in support of Bill S-201.

The Centre for Israel and Jewish Affairs is the advocacy agent of the Jewish Federations of Canada, a national, non-profit, non-partisan organization representing the perspectives of 150,000 Jewish Canadians affiliated through local federations from coast to coast. Our mission is to improve the quality of Jewish life in Canada by advancing public policy interests of our vital community.

Enacting Bill S-201 could have a tremendous impact on the health of many Jewish Canadians. Jews of European descent are 10 times more likely than the general population to carry the BRCA genetic markers indicating a significantly elevated risk of breast and ovarian cancers. For women with these markers, this means up to an 85% chance of developing breast cancer and up to a 65% chance of developing ovarian cancer, compared to 12% and 1.8% respectively for the general population. Once tested, a patient can ensure proper screening and take preventative steps to radically reduce, if not eliminate, their cancer risk.

Unfortunately, too many, too often, refuse genetic testing due to fear of genetic discrimination. Those who do get tested are at risk of being penalized for being responsible.

This is the justice committee, so let me give you an example from a legal context. A friend and colleague of mine, an Ashkenazi Jewish woman, was advised to forgo genetic testing when she was beginning her legal career at a major Toronto law firm. She was warned that a BRCA marker would likely inhibit progress in her career, precluding her from being able to make partner in that firm. Also, it could possibly limit access to the insurance she would need to establish her own independent practice, if she chose to do so.

No Canadian should be forced to choose between their life and their livelihood.

While this experience is particularly concerning for the Jewish community, we're by no means the only group impacted. Others are increasingly susceptible to genetic discrimination as research progresses, whether they are of Scandinavian, South Asian, African, French Canadian, or first nations descent. It's not just minority groups that face this challenge. Genetic testing can be a lifeline for all Canadians. From rare disorders to cancer, diagnostic and treatment options are developing at an exponential rate. We've reached a point where the major barriers to these advances are no longer just scientific, they're legislative. Parliament can harness the full potential of these breakthroughs by ensuring that those who are tested do not fear or suffer from genetic discrimination.

With taxpayer dollars being wisely allocated to cutting-edge genetic research, the protections provided by Bill S-201 are essential to ensure a meaningful return on investment and to maximize the potential health benefits for all Canadians. Moving forward, genetic screening and subsequent treatment and lifestyle changes could conceivably help to prevent a variety of illnesses from requiring costly treatment at an acute stage.

Fortunately, there's broad cross-party support for Senator Cowan's initiative. During the 2015 federal election, CIJA organized a debate in Toronto, in which candidates from all three major parties participated. All the candidates pledged to make it illegal to discriminate based on the results of genetic testing, if their party were to form the government. Bill Morneau, now the Minister of Finance, who represented the Liberal Party at this debate, stated that the Liberals would make sure they introduced into Parliament, which they thought they could do with all-party support, a bill that would prevent insurance companies from using genetic testing or pre-existing conditions either to preclude someone from getting access to insurance or to price insurance so high that it wasn't accessible to them.

Of course, we're all here today because the House of Commons unanimously supported this bill and bringing it to committee.

Fundamentally, preventing genetic discrimination can help save lives. We encourage the enactment of Bill S-201 without delay.

● (1220)

[*Translation*]

**Mr. Richard Marceau:** Thank you.

It is always a great pleasure for me to take part in the work of the Standing Committee on Justice and Human Rights. As you know, I spent several years sitting where you sit, as a member of this committee, as justice critic for the party I belonged to at the time.

That party as you know, is very protective of provincial prerogatives. Although I am no longer a member of any political party and have not been for several years, I remain sensitive to and respectful of provincial jurisdictions.

That is in fact what I would like to highlight today. It has been said that Bill S-201 is unconstitutional because it attacks civil law on contractual matters, principally as concerns insurance and the right to employment.

When we became aware of this, at the Centre for Israel and Jewish Affairs, we contacted representatives of 10 of the 13 Canadian provinces and territories. In fact, who is in a better position than the provinces and territories themselves to speak to the constitutionality issue? In the replies we received, none of the provinces or territories said that Bill S-201 posed some type of jurisdictional issue. Moreover, none of them said that the issue of genetic discrimination was not a matter of federal jurisdiction.

This consensus was strengthened by legal opinions, which you have surely read, from professor Bruce Ryder, of Osgoode Hall, who unless I am mistaken will be testifying here next week, as well as from professor Pierre Thibault of the University of Ottawa. The research I have done led me to adopt a position that is very similar to that of Bruce Ryder.

In my opinion, when one studies Bill S-201, the main question is this: what is the dominant characteristic of the bill? Is it that it puts in place interdictions, accompanied by sanctions, to grapple with a social ill, genetic discrimination, or is it rather that it regulates an industry, such as the insurance industry? In the first case, this is a matter of federal jurisdiction. If it is the second, then it is a matter of provincial jurisdiction.

[*English*]

Let's consider what Bill S-201 does and what it does not do.

Bill S-201 does not contain a licensing scheme or industry regulations. It contains prohibitions and penalties in line with criminal law. It does not target any particular industry or type of actor. The clear purpose of this bill is to address a significant social problem across Canada. By prohibiting and penalizing genetic discrimination, the Parliament of Canada is within its power.

Bill S-201 will encourage Canadians to get tested, unlocking tremendous, potentially life-saving health benefits. This is the objective of the legislation before you, and I submit to you that it is within the federal domain.

● (1225)

[*Translation*]

Of course, it may be true that employers and insurers are affected by Bill S-201. However, the fact that a bill may have repercussions on provincial matters of jurisdiction does not make it unconstitutional as such. We may legislate on genetic discrimination at both the federal and provincial levels.

[*English*]

As Professor Ryder noted, it's not uncommon to have overlapping laws in areas of shared jurisdiction, and it's often the role of the federal Parliament to show leadership and to set out some basic national standards. In fact, Bill S-201 has already started to do this. As was mentioned previously, there is now a bill in front of the Ontario legislature to ban genetic discrimination, which passed second reading with unanimous support.

[*Translation*]

In closing, Mr. Chair, I invite the members of the committee to support Bill S-201 and to vote in favour of it without amendment, and to report it to the House of Commons. In doing so, members of the committee and other members, you would be sending a strong message that there is no room for genetic discrimination in Canada in 2016.

Thank you.

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

Would it be possible to send copies of the letters you received from the provinces and territories, which you referred to, to the members of the committee ?

[*English*]

**Mr. Richard Marceau:** Yes, we'll do that.

[*Translation*]

**The Chair:** Thank you.

[*English*]

Ms. Gibbons, it's over to you.

**Ms. Clare Gibbons (Genetic Counsellor and Past President, Canadian Association of Genetic Counsellors):** Thank you, Mr. Chair and honourable members, for the opportunity for the Canadian Association of Genetic Counsellors to express its opinion on genetic discrimination and Bill S-201. This is a pressing issue, and CAGC would like to protect Canadians from genetic discrimination so that it no longer impacts their genetic test decisions.

When genetic counsellors offer genetic testing, we feel compelled to mention the possibility of genetic discrimination since many of us are aware of patients we or our colleagues have seen who have experienced genetic discrimination. The actual cases are few, but we cannot guarantee that the patient we are seeing will not be one of those few and, as a result, we must mention it to all of our patients.

Recently, a clinic was asked to include the possibility of genetic discrimination in its consent form for genetic testing because of this concern. Even though the number of cases may be small, the fear of potential genetic discrimination is frequent, and it is affecting Canadians' genetic test decisions and therefore their medical care.

Genetic testing has evolved from being able to look for specific genes to doing broad scanning of our genome, and with this there is an increased probability of finding something that could be used in a negative capacity.

There is also a trend toward preventive genetic testing. This means screening for genetic markers that people could use to help manage their health.

The future of genetic testing promises amazing advances, but with these advances there is also the increased potential for misuse of this information and for discrimination. Here are some examples. We recently had in our clinic a patient with colon cancer who was offered testing for something called Lynch syndrome. This was offered because Lynch syndrome has a higher risk not only for colon cancer but also for cancer of other organs, like stomach and liver. If we knew that this individual had Lynch syndrome, enhanced screening would be offered to them, and their close relatives could also be identified and screened. This person declined testing for Lynch syndrome, because they were concerned about genetic discrimination against their relatives.

We are also able to do genetic panels and sequencing of genes. When doing this, we may find DNA variants that are of unknown significance. These variants could mean that there is a problem with that gene and that person has the syndrome, but they could also be actually a benign variation in our DNA. We just don't have enough information right now to really be able to classify whether or not that person has the syndrome. Could this potentially be used against them because of that uncertainty? It is certainly a possibility.

Also, microarray testing and exome sequencing are a broad way of looking for genetic differences. One potential case would be of a woman who is offered prenatal testing because of unusual ultrasound findings. She would be offered this testing so we could determine the implications of those ultrasound findings and figure out the prognosis for her unborn child. That testing, though, could discover things like a neuropathy, early-onset Alzheimer's, or a predisposition to cancer. If one of those things is found, that would make that unborn fetus—and potentially one of the parents, who probably carries that genetic change as well—uninsurable.

It's a lot to put on a woman, who has to make difficult decisions about a pregnancy, to also consider this possibility, though small, while she is trying to make that decision. We do take measures to try to minimize the likelihood of finding these unexpected findings, but they could be found inadvertently, and we would have to explain this to her. It adds complexity to an already challenging case and the challenging decisions that she has to make.

For preventative genetics, they are looking at factors in genes that would maybe modify a person's health risk. One example is Factor V Leiden. This is a genetic change that's found in 3% to 8% of the Caucasian population, and carriers of this genetic variation have an increased risk of blood clots. Though there is increased risk of blood clots, there are things a person may be able to do to reduce that risk, for example being cautious about what medications are prescribed.

● (1230)

For instance, oral contraceptives would be inadvisable for someone who carries Factor V Leiden nor would sitting for long periods of time. You would want to move around to reduce that risk.

Could that person who finds out about Factor V Leiden, so that they can try to minimize the risk or choose what type of birth control they would use, have that used against them when they're applying for, let's say, travel insurance or disability insurance?

There are many more possibilities, and there are even ones that we cannot conceive of at this time because of the advances that are happening in genetics and where those may take us.

CAGC, or the Canadian Association of Genetic Counsellors, believes that legislation is needed to protect Canadians. Bill S-201 offers the most protection, and this bill would allow Canadians to be reassured that they will not experience genetic discrimination. It will allow patients to make decisions about genetic testing to optimize their health management without being influenced by the fear of genetic discrimination.

Thank you.

**The Chair:** Thank you very much, Ms. Gibbons.

We'll now move to questions, and we're going to be starting with Mr. Cooper.

**Mr. Michael Cooper (St. Albert—Edmonton, CPC):** Thank you, Mr. Chair, and thank you to the witnesses for appearing this afternoon.

Members of the committee received a statement from the Minister of Justice.

I don't know if you have had an opportunity to review that statement issued today. In the letter from the Minister of Justice, the minister states that the government supports the amendments to the Canadian Human Rights Act but objects to, in particular, the penalty provisions contained in Bill S-201 on the basis that they are inconsistent with the general approach that has been taken to other forms of discrimination in a human rights law context rather than a criminal law context.

I wonder if you might be able to comment on that observation by the minister.

**Ms. Bev Heim-Myers:** Do you want me to start?

I'm not a lawyer, so I'll put that on the table.

I think it's critically important to change the Canadian Human Rights Act. We've worked with Justice since 2010, and they've been very onside with making the Canadian Human Rights Act more explicit, so that there is no question and no grey area. That's very important, because that will filter down to the provinces, and provinces will take a lead and do that.

That's not the only important part of this bill. It's very important to have pan-Canada protection. It's very important that we don't have a patchwork. The issue with a patchwork approach, where at a pan-Canada level we don't have the same protection right across Canada, is that every province will do it differently; there will be holes in the legislation; and people will be disadvantaged and actually misled because of that. They won't know what their protections are.

It's critically important, in our opinion and in the opinion of the Canadian Coalition for Genetic Fairness, to have the pan-Canada bill, the genetic non-discrimination act, in conjunction with the clarity in the Canadian Human Rights Act, in the Labour Code, and in the provincial human rights acts. It's all necessary for all Canadians to be protected.

● (1235)

**Mr. Richard Marceau:** Mr. Cooper, I was given by the clerk only a few minutes ago, so I haven't had the chance to review that. I was looking forward to knowing where the government stood, because we were also hearing some noises that they were uncomfortable with the.... We'll have to review that and get back to you.

Let me just say that it's not only a question of discrimination. There are also health implications to this. As a society, if people knew about the genetic problems they had, and they could use preventative measures, that could save the government and our health care system, which is strapped, a lot of money. It goes beyond simply discrimination as to how we could use the Canadian Human Rights Act. There is also the social evil, so to speak, that we're fighting, which necessitates penalties that are in line with that.

**Mr. Noah Shack:** I would only add that it's not just about the discrimination, which in and of itself is a bad thing and needs to be addressed. The outcome of that discrimination can have life-and-death implications for people's health, so it does have multiple dimensions that other forms of discrimination may not have.

**Mr. Michael Cooper:** Thank you for that. I certainly agree with the observation, from all of the witnesses, that people are effectively penalized right now. They are put at risk for taking proactive steps that benefit individuals' health and Canadian society as a whole.

As you said, Mr. Marceau, it may have the impact of reducing the overall health cost over the long term.

In terms of the patchwork, is Ontario the only province that has legislation pending on this?

**Ms. Bev Heim-Myers:** As far as I know, at this point in time, yes, it is.

**Mr. Michael Cooper:** Okay.

One observation you made, Ms. Heim-Myers, was that certain persons don't want to undertake genetic testing out of fear not only for themselves but also for their relatives.

Clause 5 of this act provides that an individual can consent to disclosure of information related to their genetic testing, but we know that when one undertakes genetic testing, and that testing indicates a predisposition to a disease, it may also indicate a predisposition for relatives or family members.

There are also privacy issues in that context, and I was wondering if you might be able to comment on that a little further.

**Ms. Bev Heim-Myers:** If I understand correctly, you are asking if people are not getting genetic testing because they are worried for their family members. Is that right?

**Mr. Michael Cooper:** Well, you observed that people are not getting genetic testing out of fear for themselves but also for family members, and I was just making the observation that, with genetic testing, results can indicate a predisposition to a disease not only in an individual but also perhaps in certain family members as well.

**Ms. Bev Heim-Myers:** Yes. People are choosing not to get genetic testing because they are afraid that they will out their entire family. When you talk about a privacy issue with insurance—and it isn't just about insurance, but this an example to make it clear—if an individual has genetic testing and their physician knows about it, then, when the person signs off for life insurance and they sign off for their physician to give health information, that's part of the file. The whole family is now part of this file, and that is a concern.

**The Chair:** The current draft of Bill S-201 says that a person can themselves consent to disclose, and by consenting to disclose, they are potentially impairing their family members.

I think what Mr. Cooper was asking was whether you recommend any amendment to that section.

**Mr. Michael Cooper:** That was the question.

**Ms. Bev Heim-Myers:** If we have the genetic non-discrimination act, whereby you cannot use genetic test information against an individual, and it criminalizes the behaviour, that is the deterrent. That is the protection. If it's just in the Human Rights Act, it's not a deterrent, and people would be open to discrimination in the family.

● (1240)

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

Mr. Fraser, go ahead.

[*Translation*]

**Mr. Colin Fraser:** Thank you, Mr. Chair.

I thank all of the witnesses for being here with us today and for providing this information.

[*English*]

I'd like to start with you, Ms. Heim-Myers, if I could. You talked about other jurisdictions that have taken measures to combat discrimination against genetic testing. In those jurisdictions that you referenced, since people are no longer worried that they are potentially going to face discrimination, has the amount of genetic testing gone up? Do we have any information on how that works in other countries?

**Ms. Bev Heim-Myers:** I'm sorry, I don't have a statistic showing that genetic testing has gone up. I do know that the premiums in other countries have gone down, so the health and well-being of the community have gone up in different jurisdictions. It's the tie of being able to manage your health and being able to understand your predisposition to what could be a disease—early detection, early prevention, and appropriate treatment.

I'm sorry, I don't have a statistic on the actual genetic tests.

**Mr. Colin Fraser:** Generally speaking, if the premiums have gone down, is that tied directly to the fact that people are now able to get genetic testing, or is it just overall? Could it be for other reasons?

**Ms. Bev Heim-Myers:** I'll choose that it's tied because people are taking more control of their health without fear.

**Mr. Colin Fraser:** Okay.

I'd like to ask Mr. Shack or Mr. Marceau if they have any information about other jurisdictions where you can't discriminate for genetic testing. Have numbers gone up? Have we seen this in Jewish communities and other jurisdictions where there is no longer this discrimination?

**Mr. Noah Shack:** I can't tell you specific numbers in other communities. I can tell you that in our community it's a priority to inform people about the values of genetic testing. We try to get the word out about what's possible and the potential benefits. One of the major stumbling blocks to doing that, and getting more people to take control of their health is, of course, genetic discrimination. Addressing that problem would enable more people to know about the benefits and to take action, so conceivably it would result in more people doing so as well.

**Mr. Richard Marceau:** I can tell you in the, let's say, more orthodox segments of our community, before people actually get married, they pass genetic tests as a matter of course. If there are issues, they will call off the marriage, and that's not unheard of. Having to pass those tests early on at 18 or 19—we're talking about people who get married very young—and having to disclose those tests could have an impact for the rest of their lives.

**Mr. Colin Fraser:** When we had Senator Cowan in on Tuesday, one of the things he raised was that if this is placed only in the Canadian Human Rights Act and not in the other measures provided for in this legislation, would there be a worry of a false sense of confidence by Canadians that they are protected because it's in the Canadian Human Rights Act, but there would actually not be the protection Canadians thought there was?

I'd like all of you to comment on that, please.

**Mr. Noah Shack:** I agree with that assessment. The average person on the street doesn't understand the distinction between the different areas of law that we're talking about in the bill. Somebody hears that the Canadian Human Rights Act has been amended to prevent genetic discrimination and they think it's comprehensive. It's limited. It doesn't do everything. Certainly we want to avoid that perception and ensure that people don't put themselves in harm's way.

**Ms. Bev Heim-Myers:** It's very important for it to go into the Canadian Human Rights Act and the provincial human rights acts, but it's not a deterrent. It's not a deterrent to the behaviour of using genetic information against people. It's their personal private information, and if a person takes it through the courts or takes it to the tribunals, if a breach has happened in the human rights act, the onus is on the individual. It often happens that when people are young they don't have the financial wherewithal, and they don't want to out their entire family. In a case like that, you're taking your whole family to the provincial human rights tribunals. If there is a deterrent in an overriding pan-Canadian law, that will be the deterrent, and people will be protected.

● (1245)

**Ms. Clare Gibbons:** It's an interesting question. I think the burden will still fall on the physician and the genetic counsellor who are offering the genetic tests to the patient to explain to the patient whether they're protected or not. If we continue to hear of cases that we consider to be genetic discrimination after the amendment to the human rights occurs, then we will continue to have to bring this up to our patients. The big questions that come up are about insurance and employment. Again, if we don't feel there's enough protection there, we will have to tell them, and it will continue to affect their decisions about whether to go on with genetic testing.

**Mr. Colin Fraser:** Thank you.

Do I have time for another quick one?

**The Chair:** You have 20 seconds.

**Mr. Colin Fraser:** Okay. That's fine. I'll leave it there.

Thank you.

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

Maybe Mr. MacGregor will ask your question.

Mr. MacGregor.

**Mr. Alistair MacGregor:** I hope I can do it.

Thank you, Mr. Chair.

Mr. Marceau, I'll start with you. I'm going to read you a quote from the minister's brief here. She states, "...the scope of the criminal law power should not be extended in ways that potentially undermine the constitutional division of powers." Then she goes on to say, of course, "The regulation of contracts and the provision of goods and services are subject matters that ordinarily fall within provincial legislative jurisdiction."

Is it your opinion that the criminal law power expressed within Bill S-201 fits within the constitutional jurisdiction of the federal government? Just looking at the minister's statement, are you in disagreement with her? Do you feel that what we're doing here with this bill should go ahead unamended and as is?

**Mr. Richard Marceau:** It is my professional opinion that Bill S-201 would stand a constitutional test based on the division of power, and I agree with your colleague, former minister Nicholson, who said earlier that the creation of such a criminal offence falls squarely within federal jurisdiction.

**Mr. Alistair MacGregor:** Perfect.

I'll turn to you, Ms. Heim-Myers. You were talking about a patchwork quilt, and that was one of your greatest fears because, of course, Canada is a federation of 10 provinces and three territories. When I think about patchwork quilts, I look at existing federal statutes, such as the Canada Health Act. That is the federal government using its power of the purse to make sure that all of our provincial systems, if they want to have the federal health transfer, conform to public administration, universality, and portability to try to eliminate that patchwork quilt context.

I was wondering if you could go into a bit more detail about your fears with this bill. If we were to rip out some of the guts of it, how might that lead to a patchwork quilt situation across the country?

**Ms. Bev Heim-Myers:** If we don't have the overriding legislation and deterrent to genetic discrimination, then we will move forward with the provinces, and it will be similar to what has happened in the States. In the U.S., they have GINA, but that doesn't cover life insurance or disability insurance, and 24 states have subsequently implemented legislation but different legislation. If you go from California to a different state, then the legislation would be very different. You don't know what your protection is.

One of the dangers of that is that we want to do clinical trials in Canada, specifically for Huntington disease. We are very close to a treatment for Huntington disease. It's a devastating disease, but we need people to participate in clinical trials so they can move forward and potentially get drugs to save their lives and the lives of generations to come.

If they participate in a clinical trial in Ontario, and Ontario is protecting genetic test information, and if Ontario chooses to put legislation through beyond that by adding to the Human Rights Act, but then they go to B.C. to continue in clinical trials, they won't have protection. That is detrimental to the individual, detrimental to science, and detrimental to clinical trials happening in Canada.

**Mr. Alistair MacGregor:** So you would agree that pursuing this law is very much in the public good and the public interest, and that it overwhelmingly goes above and beyond any perceived private interests that may conflict. By eliminating that fear of discrimination, we're encouraging people to really take hold of their own health choices and to find out what markers they may have, so that they can maybe take some steps not only to save their own lives down the line and lead healthier lives but also to save the health care system potentially millions of dollars down the road.

● (1250)

**Ms. Bev Heim-Myers:** Absolutely.

**Mr. Alistair MacGregor:** I'm going to just read a quick quote, and I'd like to have all of you respond. On Tuesday, we had the sponsors of the bill here. Mr. Oliphant stated, and I quote here:

> 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—

and that's Bill S-201

> —ensure that the crown is 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....

Ms. Gibbons, starting with you, I'd like to hear comments from all of you on that specific quote, whether you agree with it, and so on.

**Ms. Clare Gibbons:** Absolutely, I would agree with that quote. It is hard for an individual to be the one to come forward and to say they have experienced genetic discrimination, and it's important that there be some protection for these people in that case. Right now, when we hear about these cases of genetic discrimination, there's not much we can do. We feel powerless at this point when we have given patients test results and they come back to us a year later or call us a year later to tell us about something that has happened. In some cases, we've tried writing letters and doing things to advocate on their behalf, but we feel that we just don't have a lot of power to help these people.

**Mr. Alistair MacGregor:** I have 30 seconds left, so I want to quickly hear from all of you, just to get it on the record.

**Ms. Bev Heim-Myers:** I absolutely agree, and time is of the essence, because genetic information is quadrupling as we speak. Thirteen years ago, 100 genetic diseases had been identified. Now there are over 6,000, and there are over 33,000 genetic tests. This is going very quickly.

**Mr. Alistair MacGregor:** Thank you.

Mr. Shack.

**Mr. Noah Shack:** I would echo what my colleagues have said here already, and just add that the criminal provision is even more important, given the wide variance in priority that different provinces put on this. We discovered in our consultations that there's a wide degree of variance in how quickly people really want to move forward with this and prioritize it. Ontario is moving, but....

**Mr. Richard Marceau:** I want the sword hanging over the head to be as heavy as possible, so that if you do discriminate, then you know a heavy sword will fall on your head.

**Mr. Alistair MacGregor:** Thank you.

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

Mr. Bittle.

**Mr. Chris Bittle:** Thank you.

Mr. MacGregor touched on this very briefly and I wonder if the witnesses could expand on it. We heard testimony that healthier people lead to lower insurance rates.

Can each of you comment a bit on what effect that will have on the public health care dollars that we spend?

**Ms. Clare Gibbons:** In particular, in the area of the genetic testing, where you can screen to try to optimize healthy people, we do feel that knowledge will improve that. Even for people who have a medical condition and who choose not to be tested, such as the person with the colon cancer, having them develop stomach cancer or liver cancer or their relatives developing stomach or liver cancer puts a much bigger burden on the health care system than going ahead with genetic testing would have, let alone the social impact of a person perhaps passing away because of this fear.

**Ms. Bev Heim-Myers:** I'll give you an example. Two brothers in a family in their early twenties have long QT syndrome, a genetic heart disease, which means they could die very young from a heart attack. One brother is job hunting and the other brother isn't. One is tested for long QT and knows it is in his family. He has the gene, and he'll be on beta blockers for the rest of his life, and he'll be fine. The other brother decides not to get tested, because he's job hunting, and he doesn't want anybody to find out that this is in his family. Who wins when he's 35 years old and dies, leaving a family behind, when it could have been managed his whole life? Prevention is huge in saving health care dollars, but it's really about saving lives.

**Mr. Noah Shack:** I believe that genetic predisposition is the number two determinant of health, after lifestyle. Just touching on the long QT example, recent studies have indicated that the incidence of long QT syndrome is 20 times higher in certain first nations communities in northern British Columbia, and the specific genetic markers for long QT are linked to type 2 diabetes, which is, of course, a major health concern in first nation communities.

When we're talking about this, it could have significant public health benefits across Canada.

● (1255)

**Mr. Chris Bittle:** I'd like to flip back to the employment side of the argument. I've heard some examples, and perhaps you can help me understand things. If an individual receives a result from a genetic test, then it's personal and private information, so why is there a concern that a potential employer might find out? Under what circumstances are employers finding out about this?

**Ms. Bev Heim-Myers:** I would say there are fewer examples with employers at this time, but employers now in Canada are looking to add genetic testing to their benefits packages. I had a call from a human resources individual asking me how they can teach their employers to understand genetic information for the benefit of the company. How can they take this information and use it? They're putting it in their benefits packages as something that might benefit the individual, but where is this going? I don't think we even know where this is going.

There are doctors who will be testifying here, and their life's work is better understanding the human genome. An employer is not going to learn about that in a very short period of time. The information does not belong in the hands of people who are going to misread the information or not understand multifactorial diseases that may or may not manifest, let alone make life-changing decisions based on it. They're wanting to do that now.

**Mr. Richard Marceau:** I have nothing to add.

**Mr. Chris Bittle:** Monsieur Marceau, you mentioned that you're a member of a particular political party and you have insight into that particular political party. I asked this question of the Department of Justice earlier, and perhaps you'll appreciate it. Have you known provinces to be particularly shy when they have concerns about the constitutionality of a particular piece of legislation going through the federal Parliament?

**Mr. Richard Marceau:** No, it is to the contrary, and what we found in consultation with the provinces, when we met with provincial law officials across the country was that they were looking to Ottawa for some kind of leadership. When we were meeting with them, we were saying that this was happening, and they would ask what Ottawa was doing and what the plans were, and say that they would like, if there was a need, to do some complementary legislation. That was a very strong desire that came through, despite being jealous of their prerogatives of looking to have federal leadership on this file. That really struck me throughout the work we have been doing.

**Mr. Chris Bittle:** I know it's difficult, and there was mention that there aren't any statistics available, but are there any numbers of people walking away from either clinical trials or genetic tests? Do we have any information on that in hard numbers?

**Ms. Bev Heim-Myers:** With respect to the Huntington disease community, there is a genetic test for Huntington disease. There has been one since 1993, and fewer than 18% of people at risk will be tested for Huntington disease.

**Mr. Chris Bittle:** Thank you.

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

We're closing in on one o'clock. Does anyone have a really short question?

**Hon. Rob Nicholson:** We've run out of time, have we?

**The Chair:** It's almost one o'clock. Do you have a short question, Mr. Nicholson?

**Hon. Rob Nicholson:** Well, not really, but anyway—

**The Chair:** You sound as though you're wishing you did have a short question.

**Hon. Rob Nicholson:** No, but I'll conclude by saying thank you for making a very compelling case on behalf of this legislation.

Monsieur Marceau, thank you for your comments, as well, about outlining in the federal jurisdiction completely unacceptable behaviour. I liked the comments about the human rights boards. Very often the people are victims to begin with, and they're the least able, many times, to come forward to make these cases.

The comment I was going to make was that I'd be interested in the names of some of these people or these employers who are involved in this disgusting behaviour.

Mr. Shack, I'd be interested in knowing what law firm in Toronto would fire some guy on a Monday morning because of his genetic testing, and I'd love to know the name of that employer who fired somebody because they had testing for Huntington disease that may come in 20 years.

I'd like to invite them to the committee here, but I'd love to have their names, if you can give us their names.

● (1300)

**Mr. Noah Shack:** I'd have to get permission from the person who shared their story with me before—

**Hon. Rob Nicholson:** Please do. I know we're very polite, and we don't like to point fingers at people, but if there is some employer that's requiring people to have genetic testing, I think everybody should know about that, and if there is a law firm that doesn't have.... I won't start describing what that law firm may be like, but I think everybody should know that.

Would you advise any of your clients to go to a law firm that involves the kind of behaviour, that would fire somebody with respect to genetic testing?

I'd ask you all, if you can come up with those names, I'd love to have them. I'd love to make them public.

Thank you.

**The Chair:** Thank you again for coming. Your testimony was very helpful to the committee, so thank you all so much.

[*Translation*]

**Mr. Richard Marceau:** Thank you.

[*English*]

**Mr. Noah Shack:** Thank you.

**Ms. Bev Heim-Myers:** Thank you.

**The Chair:** The meeting is adjourned.

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