

#### Think before you spit: DNA testing and the new *Genetic Non-Discrimination Act* Overview, Insurance, Privacy, Human Rights and Labour Matters

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Disclaimer: This presentation was prepared for general information and discussion only and should not be used in substitution for legal advice.

Presented by Vivian E Rachlis, Thompson Dorfman Sweatman LLP





#### Acknowledgments

#### THINK BEFORE YOU SPIT: DNA TESTING AND THE NEW GENETIC NON-DISCRIMINATION ACT

With thanks to:

- Canadian Bar Association and the Manitoba Bar Association, Health Law Section.
- Elisabeth Olson, Legal Department, Winnipeg Regional Health Authority.
- Co-panelists, Dr. Rockman-Greenberg and Charles Murray.
- Bailey J. Harris, Thompson Dorfman Sweatman LLP.







### Objectives and overview

- Legislative history
- Human rights/Discrimination law.
- Labour law.
- Privacy law.
- Insurance law.
- Criminal law sanctions.
- Constitutional/ Division of Powers issues.





#### The Genetic Non-Discrimination Act: History

- Unlikely legislative history.
- First introduced 2013 in the Senate, 3<sup>rd</sup> time was the Senate Bill that passed.
- Passed in the Senate as Bill S-201.



https://sencanada.ca/en/senators/





### Genetic Non-Discrimination Act: History

- Bill S-201, 1<sup>st</sup> Sess, 42<sup>nd</sup> Parliament.
- Brought forward by a Liberal backbench MP as a private member's bill.
- Vote 222/60. Yeas: Conservative, NDP, Green, 100 backbench Liberals. Nays: Cabinet and remaining backbench government MPs.
- Royal Assent May 4, 2017.





#### Bill S-201: Further background

- OPC first identified genetic non-discrimination as a strategic priority in 2007.
- Coincided with explosion in genetic tests.
- You will hear more on the numbers, costing and availability of tests from Dr. Rockman-Greenberg.





#### Bill S-201: Further background

- Senator James S. Cowan's advocacy.
- Canada last member of G7 to pass legislation.



http://www.g7italy.it/en/multimedia/g7-summit





#### Bill S201: Overview

- 1. Definitions
- 2. Prohibitions against:
  - a) requiring a person to take a test or disclose results;
  - b) taking certain steps on the grounds a person has refused to take a test or refused to disclose results;
  - c) collect, use or disclose test results without written consent.
- 3. Offences.
- 4. Canada Labour Code.
- 5. Canadian Human Rights Act.





# Definitions

#### Definitions

2 The following definitions apply in this Act...

*genetic test* means a test that analyzes DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring, diagnosis or prognosis.





### Prohibitions against requiring a test

Genetic test

3 (1) It is prohibited for any person to require an individual to undergo a genetic test as a condition of

(a) providing goods or services to that individual;

(b) <u>entering into or continuing a contract</u> or agreement with that individual; or

(c) offering or continuing <u>specific terms or conditions in a</u> <u>contract</u> or agreement with that individual.





#### Prohibitions when person refuses a test

Refusal to undergo genetic test

3 (2) It is prohibited for any person to refuse to engage in an <u>activity</u> described in any of paragraphs (1)(a) to (c) in respect of an individual on the grounds that the individual <u>has refused</u> to undergo a genetic test.







# Prohibitions against requiring disclosure

#### Disclosure of results

4 (1) It is prohibited for any person to require an individual to disclose the results of a genetic test as a condition of engaging in an activity described in any of paragraphs 3(1)(a) to (c).

#### Refusal to disclose results

(2) It is prohibited for any person to refuse to engage in an activity described in any of paragraphs 3(1)(a) to (c) in respect of an individual on the grounds that the individual has refused to disclose the results of a genetic test.





### Prohibitions against use of info without consent

Written consent

5 It is prohibited for any person who is engaged in an activity described in any of paragraphs 3(1)(a) to (c) in respect of an individual to collect, use or disclose the results of a genetic test of the individual without the individual's written consent.





# Prohibitions: Exceptions

Exceptions: health care practitioners and researchers

6 Sections 3 to 5 do not apply to

(a) a physician, a pharmacist or any other health care practitioner in respect of an individual to whom they are providing <u>health</u> <u>services</u>; or

(b) a person who is conducting medical, pharmaceutical or scientific research in respect of an individual who is a participant in the research.





### Offences and sanctions

- Imprisonment
- Fines







### Offences

Offences and Punishment

Contravention of sections 3 to 5

7 Every person who contravenes any of sections 3 to 5 is guilty of an offence and is liable

(a) on conviction on <u>indictment</u>, to a fine not exceeding \$1,000,000 or to imprisonment for a term not exceeding <u>five years</u>, or to both; or

(b) on <u>summary conviction</u>, to a fine not exceeding <u>\$300,000</u> or to imprisonment for a term not exceeding <u>twelve months</u>, or to both.





#### Canada Labour Code

• Prohibitions in employment







### Canada Labour Code: Division XV.3

#### 247.98 (1), (2), (3):

Definition: "genetic test, in relation to an employee, means a test that analyzes the employee's DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring, diagnosis or prognosis."

Employee rights:

- Right of employee not to undergo a genetic test
- Right of employee to not disclose or be required to disclose the results of a genetic test.







### Canada Labour Code: Division XV.3

247.98(4), (5), (6):

Employer prohibitions:

1. No discipline, lay off, demotion etc. on the basis of a test; or because an employee has refused a request to undergo a test or to disclose the results of a test.

2. No collection or use of the results the results of a genetic test without written consent of the employee who has undergone the test.

Prohibition on third parties:

1. No disclosure to employer without consent of employee that employee has undergone a genetic test or the results of a genetic test.







# Canada Labour Code: Division XV.3

#### S. 247.99 (1) – (9):

Complaint and remedies:

- Employee can make written complaint to inspector.
- 90 day time limit (discoverability).
- Reference to adjudication if cannot be resolved.
- Powers of adjudicator *inter alia:* reinstate, order to pay compensation, rescind discipline, order employer to do "any other thing that is equitable."





# Canadian Human Rights Act

• Anti-discrimination provisions



http://nationalmagazine.ca/Blog/September-2016/Canada-s-human-rights-system-Reform-on-the-way.aspx

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### Canadian Human Rights Act

- s. 2 general purpose statement clarifies jurisdictional reach: "... within the purview of matters coming within the legislative authority of Parliament ..."
- Adds "genetic characteristics" to s. 2 list of grounds applicable to the general purpose clause.
- Adds "genetic characteristics" to s. 3(1) list of prohibited grounds.





### Canadian Human Rights Act

Note new s. 3 (3) of the CHRA:

Idem

(3) Where the ground of discrimination is refusal of a request to undergo a genetic test or to disclose, or authorize the disclosure of, the results of a genetic test, <u>the discrimination shall be</u> <u>deemed to be on the ground of genetic characteristics</u>.





Relv on

# What is not included in Bill S-201?

• Medical examinations in litigation? Would *Adacsi v. Amin* be decided the same way in today's climate?

https://www.canlii.org/en/ab/abca/doc/2013/2013abca315/2013ab ca315.pdf

- ABCA upheld the decision of a chambers judge ordering a blood test to determine presence of HD mutant gene:
  "...relevant in assessing damages ..." in lifetime income loss claim (@para. 14).
- Other scenarios?



#### Insurance Impacts

- Duty of Good Faith
- Duty to Disclose Section 160 of *The Insurance Act*, C.C.S.M. c. 140
- Obligation to disclose material issues, facts or events.
- Materiality is to be considered only from the point of view of the reasonable insurer, not the insured.
- Innocent failure to disclose?
- Badenhorst v. Great-West Life Assurance Co., 2013 MBCA 5







#### Insurance Industry Concerns

- Canadian Life and Health Insurance Association ("CLHIA") committed (2016):
  - never ask an applicant to take a genetic test; and
  - will not ask for or use genetic testing information for new applications up to \$250,000.
  - This covers more than 85% of all applications for new life insurance policies.
- Concern by Canadian Institute of Actuaries (CIA) higher premiums:
  - 30% for men
  - 50% for women
  - group insurance
- Concern that will act as a deterrent to purchasing health/life insurance.
- Critical illness insurance.





#### Insurance Industry Response

- Insurers are still entitled to ask for medical information and require prospective insureds to take medical tests but not genetic tests.
- Physician forms need to make clear that not to disclose results of genetic testing.
- Quaere: Have applicants been previously denied due to genetic test results? Will it be available to such applicants to now reapply?





#### What Is The Genetic Non-Discrimination Act?

The Senate's Bill S-201, the Genetic Non-Discrimination Act, regulates the use of Genetic Information by insurers, employers, and other organizations.

This Act, which received Royal Assent and became law in May 2017, prevents employers and insurance companies from requiring individuals to take a genetic test or to disclose results from such testing. S-201 does not cover tests required by healthcare practitioners and researchers. Learn more about S-201.

23andMe strongly opposes genetic discrimination and was an active supporter of S-201 in Canada. We will continue to advocate for legislation and other actions that will protect individuals from discrimination on the basis of genetic information.

https://ca.customercare.23andme.com/hc/en-us/articles/115007685807-What-is-the-Genetic-Non-Discrimination-Act-







#### Canadian Coalition for Genetic Fairness:

"The Genetic Non-Discrimination Act was passed into law on May 4, 2017. It was a significant step forward for Canadians, in all provinces and territories, to now have their genetic test information protected."

http://ccgf-cceg.ca/en/about-ccgf/

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Financial/insurance planners:

"Probably the biggest issue for the insurance industry is the anti-selection risk. Some applicants for insurance knowing their higher risk factors due to genetic testing <u>are certain to act</u> <u>upon this incentive to buy more insurance</u> than they otherwise would at what would be lower than free market rates."

http://financialconfidence.com/the-genetic-non-discrimination-act-and-its-impact-on-life-insurance/

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Canadian Life and Health Insurance Association:

"Our Industry's Commitment to Canadians

Canada's life and health insurers are sensitive to the concerns of Canadians about the use of genetic testing information and commits to:

•Never ask a person applying for life insurance to take a genetic test.

•Not ask for, or use, genetic testing information for applications for life insurance of \$250,000 or less, effective January 1, 2018.

If a person is applying for more than \$250,000 in life insurance coverage, the insurer:

•May ask for and use genetic testing information for tests that have already been done;

•Will not ask for the results of a genetic test if a test was done for medical research purposes and the person applying and his/her doctor are not aware of the results; and

•Will not require genetic testing information of anyone (e.g., family members) other than the applicant."

 $\underline{https://www.clhia.ca/domino/html/clhia/clhia\_lp4w\_lnd\_webstation.nsf/page/A3631B474D9EAC088525805600474A4C}$ 





Product marketing

1. <u>https://www.concertgenetics.com/wp-</u> <u>content/uploads/2017/05/10\_ConcertGenetics\_CurrentLandscapeofGeneticTesting\_201</u> <u>7Update.pdf</u>

Legislation

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- 3. *Canada Labour Code*, RSC 1985, c. L-2, <u>https://www.canlii.org/en/ca/laws/stat/rsc-1985-c-l-2/latest/rsc-1985-c-l-2.html?autocompleteStr=canada%20labour%20code&autocompletePos=1</u>
- 4. *Canadian Human Rights Act*, RSC 1985, c. H-6, <u>https://www.canlii.org/en/ca/laws/stat/rsc-1985-c-h-6/lates</u>







Case law

- 5. Badenhorst v. Great West Life https://www.canlii.org/en/mb/mbca/doc/2013/2013mbca5/2013mbca5.htm 1
- 6. *Adacsi v. Amin* https://www.canlii.org/en/ab/abca/doc/2013/2013abca315/2013abca315.p df





Insurance/Actuarial

- 7. Canadian Life and Health Insurance Association, opening remarks to the Standing Committee on Justice and Human Rights on Bill S-201, November 22, 2016 <u>https://www.clhia.ca/domino/html/clhia/CLHIA\_LP4W\_LND\_Webstation.nsf/4b9ffde4250</u> 7452b8525791b0069e13b/490c8c6ea4aa48b685258073005b4715!OpenDocument
- 8. CLHIA News Release, January 11, 2017, <u>https://www.clhia.ca/web/CLHIA\_LP4W\_LND\_Webstation.nsf/page/07AC1F9D1616B528</u> 852580A4006D544E!OpenDocument
- 9. CLHIA, Our Industry's Commitment to Canadians <u>https://www.clhia.ca/web/clhia\_lp4w\_lnd\_webstation.nsf/page/A3631B474D9EAC0885258</u> <u>05600474A4C</u>
- 10. <u>https://www.thelawyersdaily.ca/articles/3150/genetic-non-discrimination-act-creates-fundamental-change-for-insurance-industry</u>







Insurance/Actuarial continued

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- 13. Hoy and Durnin, *The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance*, March 2012, published by the Office of the Privacy Commissioner: https://www.priv.gc.ca/media/1747/gi\_hoy\_201203\_e.pdf







Constitutional Law

- 14. <u>http://www.thecourt.ca/genetic-non-discrimination-act-valid-exercise-federal-criminal-law-power-part-1/</u>
- 15. <u>http://www.thecourt.ca/genetic-non-discrimination-act-valid-exercise-federal-criminal-law-power-part-2/</u>







Privacy

- 16. OPC *Strategic privacy priorities* <u>https://www.priv.gc.ca/en/about-the-opc/opc-strategic-privacy-priorities/</u>
- 17. OPC, Policy statement on the collection, use and disclosure of genetic test results, <u>https://www.priv.gc.ca/en/privacy-topics/health-genetic-and-other-body-information/s-d\_140710/</u>
- 18. OPC, *Direct-to-consumer genetic testing and privacy*, <u>https://www.priv.gc.ca/en/privacy-topics/health-genetic-and-other-body-information/02\_05\_d\_69\_gen/</u>







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- 21. Huntington Society of Canada, https://www.huntingtonsociety.ca/







Media

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- 24. <u>http://nationalpost.com/pmn/news-pmn/why-insurers-are-wrong-about-canadas-genetic-non-discrimination-law</u>
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#### Contact

Vivian E. Rachlis

Thompson Dorfman Sweatman LLP

- T: (204) 934-2536
- E: <u>ver@tdslaw.com</u>
- W: <u>https://www.tdslaw.com/person/vivian-e-rachlis/</u>
- <u>https://www.linkedin.com/in/vivian-rachlis-8841505b/</u>

