



Canadian Coalition for Genetic Fairness/
Coalition Canadienne Pour L'équité Génétique

Presentation to:

CIAJ – Medical genetics, law and ethics

Impact of Genetic Discrimination

and

Recommendations for

Genetic Non-Discrimination

Protection

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Genetic Discrimination Stories

- Brothers at risk for Long QT – one tested and will be treated, one refused due to fear of discrimination and will not be treated. (Who wins?)
- Healthy male in 20s, non-smoker, healthy weight, active life style. Grandmother died of ALS, parents show no signs. Denied life insurance unless he proves through a genetic test, a negative result.
- Male 50yrs from HD family. Proved through genetic test he did not have mutation. Still denied life insurance because he “could get” HD.
- Young healthy professional starting Chiropractic Practice. Father has HD mutation but A-symptomatic and is now retired. Individual denied life insurance until she proved she did not have the HD mutation.



The Research

Beyond the Patient: The Broader Impact of Genetic Discrimination Among Individuals at Risk of HD-Yvonne Bombard et al – December 2011

- 86% fear discrimination – influences behavioural patterns and can result in high levels of distress.
- Most - 63% had concerns for themselves and their families
- 49.7% experienced genetic discrimination
- Concern about discrimination associated with taking action to avoid discrimination, and keeping quiet about ones genetic risk



Genetic Discrimination

- *Genetic discrimination occurs when people are treated unfairly due to actual or perceived differences in their genetic information that may cause or increase the risk to develop a disorder or disease.*
- Many face discrimination based on a predisposition or familial potential for a genetic disease until they prove through a genetic test a negative result.



Who has perfect genes? Do you?





No one has perfect genes!

Countries who support genetic fairness and have taken steps to eliminate genetic discrimination include:

- United States
 - » Enacted GINA 2008—support by US Insurance Industry—most States followed and included life and disability ins
- United Kingdom
- European Union
- Australia
- Israel



The Current Landscape

- Canada is the only G7 country that does not protect citizens against genetic discrimination.
- Canadian Law permits insurers to require health information (including genetic test info) and to use it.
- Science and technology have outperformed legislation.
- Privacy legislation is not enough nor is it clear.
- 10 years ago 100 genetic tests, now several thousand.
- In Canada we cannot discriminate against, race , gender, disability etc., but we can against DNA.



All Canadians are Affected

Being denied insurance and employment on the basis of one's genetic traits has serious consequences for individuals, families and society as a whole.

Genetic test information is much more accessible through DTC (23andme), Blackberry app.; Doctors can access patients' genetic data. Employers to offer genetic testing as part of Employee benefit packages.

Individualized medicine will enable medical professionals to predict and to some degree prevent and better treat disease based on an individual's genetic information. Canadians are choosing not to get genetic tests out of fear for themselves and their children. Genetic discrimination is a barrier to the health and well being of Canadians.



Genetic Discrimination is Real in Canada

The issue continues to grow in Canada as science and technology increase access to genetic information.

Private information can easily be obtained and shared.

It is unreasonable to use genetic test information to determine who should be hired or insured.

Practices are inconsistent with public opinion. 91% of Canadians feel insurance companies should not be allowed to access their genetic information. (*Government of Canada Public opinion research*

on genetic information and privacy. Pollara Research, Earnscliffe Research and Communications 2003. Ottawa)
Canadian Coalition for Genetic Fairness/ Coalition Canadienne pour L'Équité Génétique



Legislation Inadequate

- Current legislation does not address the concept of “future disability” or prevent discrimination.
- Rather, it offers remedies **after** discrimination has occurred and the fear of escalated discrimination prevents victims from stepping forward.
- It is up to the individual that has been discriminated against to pay the legal costs of proving discrimination. The cost is prohibitive.



What is Required and Why?

An ***explicit*** Canadian genetic non-discrimination strategy tailored to our own unique circumstances.

Canada has a leadership opportunity to do it right.

Educate Canadians re: risk of genetic discrimination.

Canadians need to trust that genetic test information is used to benefit, without fear of repercussion.



URGENT: Action Needed Now

The Canadian Federal and Provincial Governments need to develop and implement an effective strategy to **eliminate genetic discrimination in Canada.**



Achievements To Date

- Canadian Coalition for Genetic Fairness (2008) – 18 organizations and growing
- The 2013 Speech from the Throne: *Prevent employers and insurance companies from discriminating against Canadians on the basis of genetic testing*. Continue to work with PMO and Justice to meet the commitment. PMO committed to show leadership and present legislation to end genetic discrimination before the Federal election 2015
- Office of the Privacy Commissioner statement 2014-“urge life and health insurance industry to refrain from requesting access to existing genetic test results...”
- Federal Senate Bill S-201 – Genetic Non-Discrimination Bill- Sen James Cowan-October, 2013- Hearings completed Dec 2014. Clause by clause discussion basically gutted Bill S-201
- Ontario –Private Members Bills presented in past – will revisit
- Alberta – exploring next steps to genetic fairness



The Next Steps

- Continue to educate Federal Members of Parliament and Members of Provincial Parliaments
- Continue to support the essence of Bill S-201
- Continue to work with PMO and push for commitment in SFT to be realized – genetic discrimination legislation
- Engage all Canadians - everyone is at risk
- Encourage positive engagement by insurance industry (2003-Canadian Genetics and Life Insurance Task Force convened to find solution– no action). Other G7 countries, insurance industry outside



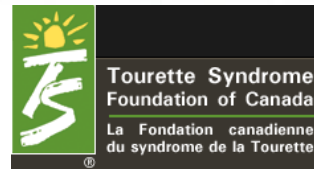
Thank You!

Discussion/Questions?

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Members of CCGF



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