

**Address by Professor Bartha Knoppers, Professor of Law, Faculty of Law, University of Montreal**

I was asked to speak to you today about genetic discrimination in insurance and employment, particularly as concerns American and Canadian practices. I will begin my presentation by describing some current practices and the results of a recent survey that puts into question alleged genetic discrimination of the last decade. Then I will describe to you the difference between Canadian and USA practices, followed by current concerns for genetic discrimination in insurance and employment, and spend most of my time on current North American approaches in Canada and the US and finally, propose conclusions.

Insurers in Canada and the United States do not currently require applicants to undergo genetic testing. It is not a requirement to take a genetic test. But they do rely, and have always relied, on actuarial information and health questionnaires which could include questions, and have always included questions, related to family health and previous genetic tests. A recent study demonstrates that genetic discrimination in the United States and Canada exists, but it is rare. And where it exists, it is largely in the eye of the beholder.

In a survey done by Dorothy **Wertz** among health professionals, primary care physicians and the public in Canada and the United States, some reported "that because of a genetic or inherited disability or disease they, or a family member, had been denied or let go from a job, or had been refused life insurance. When asked to give details of their refusals, however, almost all described situations that are characteristic of broad, general employment practices, or general insurance practices. They were apparently objecting to what they perceived as unfair insurance practices in general, rather than practices specific to genetics."

I'll come back to this issue of perception at the end talk, but I think it's very important because people often point to the dangers of genetic testing or participating in genetic research, because of the North American market system and the alleged discrimination that exists, which this study shows not to be true.

Now, in the United States you have an option to be self-insured, also in Canada, but in terms of health insurance, Canada has a universal healthcare system. For the rest, in terms of other options available to employees or insurance applicants, the choices are pretty well the same.

So here we have, one continent, two situations. In Canada, universal healthcare system is based on solidarity – the idea that by contributing to the whole, there will be greater equity and justice for all citizens. In contrast, there are 43 million Americans who are uninsured or uninsurable in terms of health insurance. Most Americans subscribe to what are called HMOs. HMO stands for health management organisations. And this is interesting, because a recent study showed the following. Eighty per cent of Americans belong to health management organisations, mainly through contributing through their employers. You have a double effect here – your

employer, in the United States, also provides you with health insurance. You can see how intimately linked questions of access are in this area.

Car manufacturers in the United States spend more on healthcare than on buying steel. In 1995, General Motors, the largest purchaser spent 3.6 billion on healthcare for 1.6 million people. Big employers shop around to find cheap HMOs and form partnerships with them to make healthcare delivery more efficient. For their part, HMOs look for employers with healthy workforce, and restrict the kind and extent of services that they are ready to offer. This is fine if you are not pregnant, not old or not chronically ill. In the end it is an insurance contract, not a physician, who may decide what tests are ordered and when a referral is made, and what treatments are offered.

I'd like also to mention that we have been very slow in Canada in integrating genetic tests into our universal healthcare system. One, because we're not sure of their efficiency in terms of scientific validity, but also because in a universal healthcare system, as you know, important choices have to be made in the allocation of resources. And when you're dealing in our society with a phenomenon **gentrification** that is, where the population group aged 80 – 90 is increasing at a faster rate than a population under 25, you can see why the widespread integration of genetic tests would have a tremendous implication on costs if you are also mandated to provide genetic counselling.

So genetic discrimination is still relatively irrelevant for Canadian health insurance, compared to American health insurance, where it could play an important role.

Now, in the absence of any specific prohibitions or laws or moratoria, genetic information is currently subject to the same confidentiality rules as other health information. And we know that with the "consent" of the person concerned, employers and insurers already have access to healthcare data. It is a condition for the contract.

So what is this tool – how accurately, (leaving the monogenic mendellian diseases aside with their 1 in 2, 1 in 4 pattern), will genetic tests predict future health conditions? There are also economic, environmental and socio-cultural factors that come into play. What will be the impact on treatment?