

## FOCUS ON PRIVACY LAW

# COMMENTARY: insurance companies should abandon their defensive approach

By Yann Joly

“Genetic discrimination” is quickly becoming a buzzword in Canada. According to a recent privacy survey (Government of Canada, *Public Opinion Research Into Genetic Privacy Issues*, 2003 Ottawa, Pollara Research and Earncliffe Research and Communications) commissioned by the Canadian government, 91 per cent of Canadians felt that insurance companies should not be allowed access to their customers’ genetic information for insurance underwriting. Although Canadians don’t necessarily consider that genetic information warrants fundamentally different treatment than other health information, they do feel that it constitutes sensitive health information and deserves a high degree of protection.

Canadian insurers have taken a “defensive approach” to the situation, believing the controversy to be mostly fuelled by misconceptions about both basic insurance principles and the emerging fields of genetics. Consequently, they seek to convince the public and politicians of the continued validity of their classic argument that risk classification in insurance is intended to be fair to all policyholders and that making an exception for genetic test results would not serve the interests of the majority of them. Accordingly, the Canadian Life and Health Insurance Association’s position is that if genetic testing has been done and the information is available to the applicant or his physician,

insurers will request to be given that information (Canadian Life and Health Insurance Association



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Inc., *Reference Document: CLHIA Position Statement on Genetic Testing*, 2000, updated in 2003, Toronto).

Canadian insurance law does not offer much protection to consumers. According to both the *Uniform Insurance Act* and the *Quebec Civil Code*, insurance applicants have to disclose “all information that is material to the risk” on penalty of having their contract annulled by the insurer. This sanction applies even if the concealment or misrepresentation is unconnected to the circumstances of the insured person’s death. Contractual freedom could even allow insurance companies to impose genetic testing as a precondition for insurance coverage, although this is not current

industry practice. The only court case of direct relevance to the debate, *Audet c. L’Industrielle-Alliance* [1990], involved a man who was aware that he carried a genetic mutation and who failed to disclose this information to his insurer. Following his death, the insurance company sought to have the life insurance policy annulled. The Quebec Superior Court found in favour of the insurer. The policy owner did in fact have the genetic condition at the time of his initial declaration, but was asymptomatic, the disease being highly variable in its expression.

Beyond insurance law, privacy and human rights legislation offers only a very limited degree of protection to insurance applicants. Privacy laws, both federal and provincial, generally allow for third party access to personal

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information with the individual’s consent. Thus, it has become standard practice for insurers to request on insurance application forms that individuals consent to have their health information verified. Interestingly, consumers signing an insurance proposal also consent to have some of their personal health information (including genetic information) shared with other insurers through the Medical Information Bureau

(MIB). Human rights legislation could offer some degree of protection to the insurance applicant through its anti-discrimination provisions. Although explicit insurance exceptions exist to the extent that distinctions in underwriting practices related to health are “reasonable and *bona fide*”, the recent Supreme Court of Canada decisions in *British Columbia Public Service Employee Relations Commission v. BCGSEU* [1999] S.C.J. No. 46 and *Colombie-Britannique Superintendent of Motor Vehicles v. Colombie-Britannique Council of Human Rights* [1999] S.C.J. No. 73 have started a shift in Canadian equality law by introducing a new uniform test to determine if a standard can be considered as a *bona fide* justification. It remains to be seen whether this will have a positive impact on the genetic discrimination debate (Trudo Lemmens “Genetics and Insurance Discrimination: Comparative Legislative, Regulatory and Policy Developments and Canadian Options” (2003) special edition *Health Law Journal* 41).

A popular approach in countries with a common law tradition such as England and Ireland, has been the adoption of voluntary moratoria by insurers. A moratorium can be defined as a voluntary agreement by a group of insurers (often through an official representative organization), neither to request genetic testing of insurance applicants nor to use genetic test results. The main appeal of a moratorium is its flexibility and ease of implementation. This approach was favoured by a multidisciplinary pan-Canadian task force (the Canadian Genetics and Life Insurance Task Force) that recently convened in order to find a Canadian solution to the genetics and life insurance controversy (Canadian Genetics and Life Insurance Task Force, *Genetics and Life Insurance in Canada: Points to Consider*, 2004 170:9 *CMAJ* 1-3).

In this climate of growing anxiety about possible genetic discrimination in Canada, the insurance industry would be well advised to abandon its current defensive position and adopt a more proactive approach. A moratorium on the part of Canadian insurers would not only appease popular anxiety, it might also prevent the enactment of specific legislation that would be premature at this early stage of the genetic revolution.

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## PIPEDA applies to some charity activities

If charitable and non-profit organizations are not subject to PIPEDA, it is not because they are exempted as a class, but because they do not engage in commercial activities *per se*.

By U. Shen Goh

As of Jan. 1, 2004, the federal *Personal Information Protection and Electronic Documents Act* (“PIPEDA”) applied to every organization in Canada that collects, uses and discloses personal information in the course of commercial activities. Since then, charitable and non-profit organizations have asked whether PIPEDA applies to them, *i.e.*, whether the activities they engage in constitute commercial activities. Commercial activity is defined by PIPEDA as “any particular transaction, act or conduct of any regular course of conduct that is of a commercial

character, including the selling, bartering or leasing of donor, membership or fundraising lists.”

In response, the federal privacy commissioner released a fact sheet making it clear that “the bottom line is that non-profit status does not automatically exempt an organization from [PIPEDA].”

This confirmed that if charitable and non-profit organizations are not subject to PIPEDA, it is not because they are exempted as a class, but because they do not engage in commercial activities *per se*, as is the case with most charities, minor hockey associations, clubs, community groups

and advocacy organizations. Furthermore, the fact sheet cites collecting membership fees, organizing club activities, compiling membership lists, mailing out newsletters, and fundraising as examples of what the federal privacy commissioner does *not* consider commercial activities. However, the fact sheet also made it clear that to the extent that charitable and non-profit organizations did engage in commercial activities, they would be subject to PIPEDA, “*for example, many golf clubs and athletic clubs, may be engaged in commercial activities.*”

Many of the statements in the

fact sheet were later affirmed by the Ontario Superior Court in *Rodgers v. Calvert*, [2004] O.J. No. 3653, the first case in which a court in Canada discussed “commercial activity” under PIPEDA. In this case, Rodgers brought a motion to compel The Peel County Game and Fish Protective Association (the “Association”) to disclose the membership list to him so he may communicate his concerns regarding the Association to its other members. The Association refused to disclose the membership list on the grounds that such disclosure was barred by PIPEDA. In deciding that the Association must produce the membership list, as its activities did not constitute commercial activities to which PIPEDA would apply, the court made the following points:

- The test for commercial activity is not one of “preponderant purpose”. The preponderant purpose test states that “if the pre-



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ponderant purpose of the activity is the making of a profit, then the activity may be classified as a business. However, if there is another preponderant purpose to which any profit earned is merely incidental, then it will not be clas-

see PURPOSE p. 17

## Court set out what was not commercial activity

### PURPOSE

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sified as a business.”

• The test for commercial activity requires more than a mere “exchange of consideration”. The court found that although the Association collected membership fees in exchange for the services and benefits of membership in the Association, this exchange of consideration did not in itself constitute commercial activity for the purposes of PIPEDA.

• The federal privacy commissioner’s statement that “[c]ollecting membership fees, organizing club activities, compiling a list of members’ names and addresses and mailing out newsletters are not considered commercial activities” is correct.

Although the court did not set out a clear test for interpreting the term “commercial activities”, nor did it set out criteria as to what constitutes a commercial activity for charitable and non-profit organizations, the court did shed light on what was *not* “commercial activity”.

For charitable and non-profit organizations in Quebec, B.C. and Alberta, the above discussion may be merely academic as they are exempted from PIPEDA under s. 26(2)(b), because those provinces have enacted privacy legislation that is “substantially similar” to PIPEDA. The privacy legislation in these provinces applies to every organization that collects, uses and

discloses personal information, regardless of whether or not it was for commercial purposes. However, charitable and non-profit organizations in these provinces will still be subject to PIPEDA under certain circumstances, as it will continue to apply to commercial activities relating to the exchange of personal information between provinces and outside of Canada.

Although some charitable and non-profit organizations may be exempt from privacy legislation, because they do not engage in commercial activities and because they are located in provinces that have not enacted privacy legislation that is “substantially similar” to PIPEDA, it is still important for those organizations to adhere to the underlying privacy principles. Not only is this the recommendation of the federal privacy commissioner, it is also an expectation of donors and members that the charitable and non-profit organizations they support recognize their right to privacy as an essential issue.

For more information on the application of privacy legislation to charitable and non-profit organizations, see *Charity Law Bulletins* No. 28, 42 and 70 available at [www.charitylaw.ca](http://www.charitylaw.ca).

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## Ontario court ruled differently

### THERAPY

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is important for present and future health, is emergent and has only recently been recognized as medically required. Applying this comparator group, the court said that differential treatment had not been established.

The court concluded there was no evidence suggesting that the government’s approach to ABA/IBI therapy was different than its approach to other comparable, novel therapies for non-disabled persons or persons with a different type of disability. In the absence of such evidence, a finding of discrimination could not be sustained. Funding may be legitimately denied or delayed because of uncertainty about a particular program, competing claims on limited resources and administrative difficulties related to its recognition and implementation.

While not unsympathetic to the

difficult circumstances of parents with autistic children, provincial governments (most of which intervened in the appeal) are undoubtedly relieved the court upheld their authority to make funding decisions as to the kind of treatments and therapies that are funded under the medicare system. However, their sense of relief may be short-lived.

A few months later, on April 1, 2005, the Ontario Superior Court issued its decision in *Wynberg et al. v. Ontario* and *Deskin et al. v. Ontario*. In a combined judgment, which determined claims brought on behalf of 35 children with autism, Justice Frances Kiteley upheld their claim of discrimination and concluded that the failure of the Ontario government to fund ABA/IBI treatment for school-aged children with autism violated their equality rights under s. 15 of the *Charter*.

Contrary to the finding of the Supreme Court of Canada in *Auton*, Justice Kiteley held that

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### Researchers hold subscriptions

#### DATABASES

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researcher will have ready access to resources and experience in knowing what sources to query. They will hold subscriptions with multiple sources, allowing them to search for references to individuals or companies in a highly thorough and comprehensive manner. A good example of this is with regard to media archives. There are a number of different subscription based databases providing access to national and international media publications, news wires and broadcast transcripts. However, each of the databases contains archives of different daily newspapers, journals, publications and so on. Thus, having access to more than one of these databases helps to ensure that you are searching as many sources as possible.

Other facets of information gathering include telephone and in-person inquiries. These methods are required in a variety of situations, such as pre-employment screening, confirming address and location information, conducting trade-mark infringement investigations, verification of professional licences or designations, and/or obtaining building permits.

Another important aspect of investigative research is understanding how to build a profile and how to satisfy the requirements of what you need to know based on whatever information is initially provided. As the information avail-

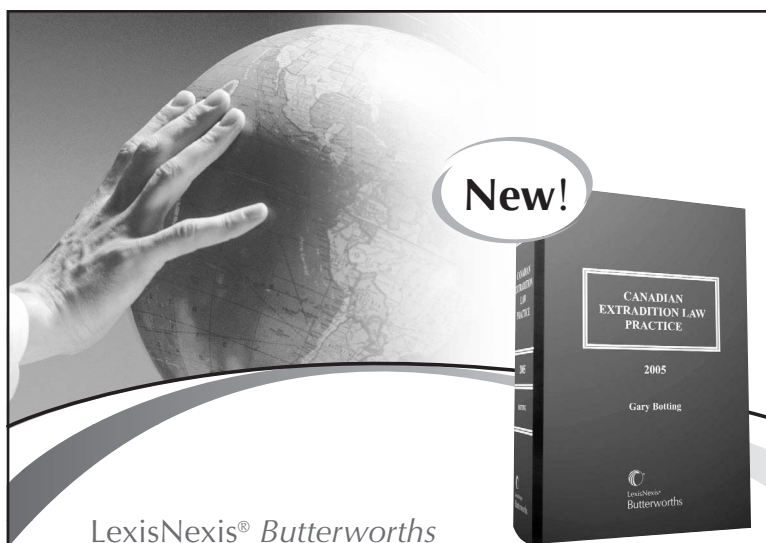
able at the beginning of an investigation is often limited, it is important to have a grasp of the flow of information by understanding how details from one source can then lead you to another source. It is much like putting together pieces of a puzzle. One of the values that an investigative researcher has to offer is his or her ability to work through the network of information providers efficiently and effectively. As a function of carrying out such work on a daily basis, an investigative researcher will have developed a keen eye for weeding through what can be a high volume of results.

Finally, when an investigative body engages in the collection, use and/or disclosure of personal information, Industry Canada

requires that they conduct such inquiries and activities in a way that impairs privacy as minimally as possible, while meeting the needs of the investigation. As such, it is required that you document the purpose for collecting any personal information at the beginning of your investigation.

As outlined above, there is a great deal of useful information available through public records. With the proper grounds and resources, valuable investigative research can easily be conducted within the framework of PIPEDA.

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