

# INTRA-FAMILIAL OBLIGATIONS TO COMMUNICATE GENETIC RISK INFORMATION: WHAT FOUNDATIONS? WHAT FORMS?

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*Genetic information is not only personal information, it is also familial as well as universal. Although most individuals who undergo genetic testing report feeling some obligation to communicate their results with family members, such communication is highly context specific and will be shaped by many factors, including the type of genetic condition at issue (i.e., a single-gene or multifactorial genetic condition), familial relationships, individual personalities and perceptions of what is in the family's best interest. Moreover, the foundation and forms for such an obligation are not clear. How would such an obligation be grounded? Is it a moral obligation? Is it a legal obligation?*

*This article explores the possible foundations and forms for an intra-familial obligation to communicate genetic information. Possible foundations could lie in approaches to defining the genetic family and genetic information, the special obligations that arise as members of families, notions of autonomy, theories of ownership and control of genetic information, the limits of health care providers' obligations, and the role of privacy within the family.*

*These foundations function as justifications in some of the international, regional, and national normative documents that articulate an intra-familial obligation to communicate genetic information. These articulations do not create a binding legal obligation and can therefore be said only to acknowledge a moral obligation. Such an obligation is not created in any legislative regime worldwide and, moreover, it would be difficult to make out a claim for civil liability under Canadian common law and Quebec civil law rules. It is therefore important for policy makers to address this issue and clarify whether there is or is not a legal obligation to communicate genetic information within families. Legislation that creates a legal obligation is ill-advised as it may cause difficulties for families, given the context specificity of decision-making around intra-familial communication. Rather, such a regime should acknowledge perceived obligations and provide mechanisms for individuals and families to meet these obligations in a manner and setting that is appropriate for each family context.*

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## INTRODUCTION

Developments in genetics have been accompanied by, or have perhaps even instigated, a shift in medical ethics. Stalwart ethical principles of the second half of the twentieth century, such as privacy, justice, equality, equity, and above all, autonomy, are still prominent today. However, the complexity of genetic factors around common, multifactorial diseases, as well as the familial and social implications of genetic information, have given rise to new trends in ethics, namely, the emergence of the principles of reciprocity, mutuality, solidarity, citizenry, and universality.<sup>1</sup> One mark of this shift toward more “relational” principles is found in the growing consensus that health professionals may, in certain circumstances, justify a breach of patient confidentiality in order to inform a patient’s genetic relatives of their own genetic risk. Another possible mark is emerging in the debate that is confronted in this article: whether there are intra-familial obligations to communicate genetic risk information.

Both of these “marks” of the shift in ethics around genetics highlight the philosophically divisive task of settling on the contours of duties that arise with respect to genetic information. It has been argued that defining the very nature of genetic information is less a matter of circumscribing the information itself than contemplating an embodiment of the philosophical debate between liberalism and communitarianism.<sup>2</sup> This is because genetic information is not only personal, insofar as it reveals an individual’s unique genetic code, but also familial, because it has the potential to unveil information relevant for genetic relatives, and universal, because it imparts knowledge that is relevant for all of humanity.<sup>3</sup>

While the issue may be divisive at the level of principles, matters become even more complicated in clinics and within families. Basic tasks such as defining genetic testing, genetic information, and the genetic family are challenging enough. Accounting for familial relationships and context compounds these challenges. Although most individuals who undergo genetic testing report feeling some obligation to communicate their results with family members, such communication is highly context specific and will be shaped by many factors, including the type of genetic condition at issue (*i.e.*, a single-gene or multifactorial genetic condition), familial relationships, individual personalities, and perceptions of what is in the family’s best interest.<sup>4</sup> Moreover, the foundation and forms for such an obligation are not clear. How would such an obligation be grounded? Is it a moral obligation? Is it a legal obligation?

These questions are important for several reasons. An increasing prevalence of genetic testing will result in greater awareness of genetic risk information among individuals and families. It is important to consider whether such knowledge ever gives rise to obligations so that individuals and families can prepare for the implications of genetic testing. Also in need of clarification is whether and how health professionals’ obligations to disclose to patients’ at-risk relatives intersect with individual obligations, so all are better able to understand their roles with respect to genetic information. Additionally, an increasing prevalence of direct-to-consumer (DTC) genetic testing will give rise to situations where health professionals may be absent in the genetic testing process. DTC genetic testing is a separate and complex issue that is outside the scope of this paper; nonetheless, it is important to acknowledge this development in the context of intra-familial obligations.<sup>5</sup> Finally, although there is a growing body of research, and perhaps an emerging consensus, on the obligations of health

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<sup>1</sup> Bartha Maria Knoppers & Ruth Chadwick, “Human Genetic Research: Emerging Trends in Ethics” (2005) 6 *Nature Reviews Genetics* 75.

<sup>2</sup> Dean Bell & Belinda Bennett, “Genetic Secrets and the Family” (2001) 9 *Medical Law Review* 130 at 157.

<sup>3</sup> Bartha Maria Knoppers, “Genetic Information and the Family: Are We Our Brother’s Keeper?” (2002) 20 *Trends in Biotechnology* 85.

<sup>4</sup> Gillian Nycum, Bartha Maria Knoppers & Denise Avaré, “Factors Influencing Intra-Familial Communication of Hereditary Breast and Ovarian Cancer Genetic Information” (25 March 2009) *European Journal of Human Genetics* 1.

<sup>5</sup> See Kathy Hudson *et al.*, “ASHG Statement on Direct-to-Consumer Genetic Testing in the United States” (2007) 110 *Obstetrics & Gynecology* 1392 for more information on direct-to-consumer testing.

professionals with respect to genetic information<sup>6</sup> and with regards to research addressing intra-familial *experiences* with communication of genetic information,<sup>7</sup> very little work has addressed intra-familial *obligations* in this context.<sup>8</sup>

This article tackles these questions in three parts. Part I is a background discussion that defines the genetic family and genetic information. Part II is a discussion of possible *foundations* for intra-familial obligations to communicate genetic risk information according to the following components: special obligations as members of families; notions of autonomy and relational autonomy; ownership and control of genetic information; the limits of health professional obligations to communicate genetic information with patients' relatives; and the role, or possible lack thereof, of individual privacy within the family sphere. Part I and II both draw on ethics literature and international, regional, and national laws and policies. Their transdisciplinary outlook seeks to open up a range of potential definitions for the genetic family and for genetic information as it explores possible foundations for intra-familial communication obligations. Part III is a discussion of the potential *form* for such obligations as either moral or legal. It draws on national and international policy that articulates an obligation to communicate genetic information within families and it assesses whether a failure to communicate genetic information to potentially at-risk genetic relatives could give rise to a claim in civil liability in Canadian common law and Quebec civil law.

While this paper references the positions developed both through laws and regulations enacted by legislative bodies, and via policy statements issued by international non-governmental and governmental organizations, the reader is reminded of the distinction between the two. Generally, adherence to laws and regulations is enforced through the judicial system, whereas policy statements do not carry the same obligatory force. Nevertheless, as policy documents often provide rich analysis and important insight, their conclusions can shape public opinion, and may carry significant weight in the political domain.

A brief word about the terminology used in this paper is in order. *Disclosure* refers to the revealing of information that is secret by one person or group to another; it is a marked and singular event characterized by the use of language in a sender-receiver model of communication.<sup>9</sup> It can also be understood as a long process of linguistic and non-linguistic signs, signifiers, and silences.<sup>10</sup> This latter understanding is closer to *communication* as used here. Within families, communication can be complex, as members are often able to read non-verbal cues and behaviours and to gather meaning from informal or unstructured interactions. In the context of genetic risk information, "clues" such as family history information may pair up with other indicators, with the result that communication about genetic risk is nuanced. *At-risk relative*, *genetic relative*, *biological relative*, or simply *relative* are the terms used here to refer to those members of a family who are biologically related and who therefore might share some of the same genes. In contrast, *family* or *family members* refers to the family as a social unit and includes non-biologically related members.

This analysis focuses on genetic information that living adults obtain in a clinical context in Canada. The analysis does not explicitly consider obligations with respect to information about deceased adults, or information generated in the context of research. The analysis also concerns only genetic information generated as health information to the exclusion of that generated for other purposes, such as paternity testing.

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<sup>6</sup> Béatrice Godard *et al.*, "Guidelines for Disclosing Genetic Information to Family Members: From Development to Use" (2006) 5 *Familial Cancer* 103.

<sup>7</sup> Nycum, Knoppers & Avar, *supra* note 4.

<sup>8</sup> But see Ellen Wright Clayton, "What Should the Law Say About Disclosure of Genetic Information to Relatives" (1998) 1 *J. Health Care L. & Pol'y* 373; Rosamond Rhodes, "Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge" (1998) 23 *Journal of Medicine and Philosophy* 10 at 11; Lori d'Agincourt-Canning, "Experiences of Genetic Risk: Disclosure and the Gendering of Responsibility" (2001) 15 *Bioethics* 231.

<sup>9</sup> Brenda J. Wilson *et al.*, "Family Communication About Genetic Risk: The Little That Is Known" (2004) 7 *Community Genetics* 15 at 16.

<sup>10</sup> *Ibid.*

## I

## BACKGROUND: DEFINING THE GENETIC FAMILY AND GENETIC INFORMATION

## A. Who is the “Family”?

Starting by defining the “family” in the genetics context is important because it not only aids in identifying who is at genetic risk, but it also helps define the scope of individuals to whom familial obligations, if any, may be owed. The following discussion outlines approaches to defining “family” used in Canadian family law, discusses policy documents that suggest approaches to linking “family” and “genetics”, and outlines approaches to defining the “genetic family” proposed by scholars.

There are two prevailing approaches to defining “family” used in Canadian family law. One is the biological or “formal” approach, which relies on “objective criteria” for determining family status such as relation “by blood or marriage”.<sup>11</sup> The other is the social or “functional” approach whereby family membership is based on relationships and on whether a group of individuals “as a whole act” like a family and meet the “day-to-day functions” of a family.<sup>12</sup> For example, while parental links may be determined solely based on biological relation, such as where DNA testing is ordered to establish filiation,<sup>13</sup> they may also be based solely on social relationship, such as when step-parents are found to stand in the place of biological parents.<sup>14</sup> The biological approach is more common historically, but the functional approach has become increasingly common in Canadian law as reconstituted families have come under the legal microscope.<sup>15</sup> In the context of genetics, a purely social or functional approach to defining family may mean that some biological relatives will fall outside familial boundaries. A purely biological approach may omit some non-biological relatives even where genetic information may have relevance for their life plans.

Given these important distinctions between the biological and sociological definitions of the family, one can ask how the “genetic family” is defined. One approach to defining the “genetic family” links “family” to those who have an interest in the information.<sup>16</sup> One justification for this approach is that shared biological risks create special interests with respect to the information.<sup>17</sup> This approach is the closest that normative documents come to defining the “genetic family”. The European Commission states that “genetic testing has consequences not only for the individual, but also for relatives, including offspring.”<sup>18</sup> The French National Consultative Ethics Committee for Health and Life Sciences agrees, opining that “[t]he results of a genetic test are not the sole concern of the [individual tested]. They also affect the whole family, ascendants, descendants, collaterals, and possibly spouses.”<sup>19</sup> More broadly, the German Society of Human Genetics declares that information that becomes available from medical genetic studies is also “relevant to the personal health, family planning and future plans of family members and relatives.”<sup>20</sup> Finally, the Australian *Genetic Privacy and Non-Discrimination Bill* leaves the door open to great flexibility, envisioning that family “means the biological and legal relatives of an individual who may have a material interest in the genetic infor-

<sup>11</sup> Roy Gilbar, *The Status of the Family in Law and Bioethics* (Hampshire: Ashgate Publishing Group, 2005) at 60–61.

<sup>12</sup> See e.g. *ibid.* at 61; Philippe Jestaz, “La parenté” (1996) 41 McGill L.J. 387; Benoît Moore, “Quelle famille pour le XXI<sup>e</sup> siècle: Perspectives québécoises” (2003–2004) 20 Can. J. Fam. L. 57 at 91–93.

<sup>13</sup> See e.g. art. 535.1 C.C.Q.; *Child and Adult Support Services Regulation*, Alta. Reg. 61/2004, s. 5(1)(c).

<sup>14</sup> *Divorce Act*, R.S.C. 1985, c. 3, ss. 2, 15, 16; *Family Law Act*, R.S.O. 1990, c. F.3, s. 1 (“child”).

<sup>15</sup> See e.g. *Chartier v. Chartier*, [1999] 1 S.C.R. 242, 168 D.L.R. (4th) 540; *V.A. v. S.F.*, [2001] R.J.Q. 36 (C.A.).

<sup>16</sup> Graeme Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambridge University Press, 2002) at 113–129.

<sup>17</sup> Joan Stephenson, “Ethics Group Drafts Guidelines for Control of Genetic Material and Information” (1998) 279 *Journal of the American Medical Association* 184.

<sup>18</sup> The Independent Expert Group of the European Commission, “Ethical, Legal and Social Aspects of Genetic Testing: Research, Development, and Clinical Applications” (2004), s. 7.1.1, online: <[http://ec.europa.eu/research/conferences/2004/genetic/pdf/report\\_en.pdf](http://ec.europa.eu/research/conferences/2004/genetic/pdf/report_en.pdf)>.

<sup>19</sup> France, National Consultative Ethics Committee for Health and Life Sciences, *Opinion No. 76 Regarding the Obligation to Disclose Genetic Information of Concern to the Family in the Event of Medical Necessity* (2003) at 2 [*Opinion No. 76*]. All Opinions are available in French online: Comité Consultatif National d’Éthique <<http://www.ccne-ethique.fr/avis.php>>.

<sup>20</sup> German Society of Human Genetics, “Position Paper of the German Society of Human Genetics” (1998) at 6.

mation of the individual.”<sup>21</sup> Whereas the European Commission arguably limits interest in genetic information to biologically related relatives, the French, German, and Australian documents appear to take a broader approach to linking family and interest in genetic information. The French document includes the *whole* family and possibly spouses. The German document suggests that family members and relatives are separate categories. The Australian document refers to legal as well as biological relatives. While there are differences among these groups regarding the scope of the family, there appears to be a consensus within the normative literature that accepts a broad definition of the genetic family.

Conceptions of the genetic family emanating from the academic community appear to impart a dynamic dimension to the idea. Graeme Laurie categorizes interests in genetic information as follows: personal, economic, societal, and paternalistic. However, he defines “family” as a unit of biological relatives and spouses.<sup>22</sup> With interests defined broadly, but family conceptualized narrowly, the implication is that health and medical interests prevail over other interests. An approach that gives priority to health and medical interests will not have a static family membership; such membership will instead change depending on the nature of the information, including patterns of inheritance and disease penetrance, meaning the probability that an individual carrying a given genetic mutation will go on to develop the disease. There may be less medical interest in awareness of risk for conditions like Huntington’s Disease (HD), a serious, non-preventable disease with 100% penetrance, than there is for a condition like genetic breast cancer, which has less than 100% chance of disease onset and for which surveillance and prevention measures are available. However, non-medical interests, such as financial planning, may be associated with a serious degenerative disease such as HD. Additionally, family membership premised on medical interest may change based on the life stage of the informee. For example, if the informee is too young or too old to be considered at risk of developing the genetic condition associated with a mutation, he or she may be perceived as lacking a medical interest in the information. Finally, defining interest in a purely medical way leads to difficulties since it requires a deep understanding of the complexities of genetic information. Such an understanding typically exceeds the capabilities of the general population.

Roy Gilbar critiques Laurie’s approach and argues that defining the genetic family based on medical interest limits one’s understanding to biology or formalism.<sup>23</sup> Gilbar advocates in favour of a biosocial definition of the genetic family, where both biology and social relationships play a role, but argues that if there is no social relationship whatsoever, recognition of genetic family status cannot come out of biology alone.<sup>24</sup> This approach causes difficulties. For example, Gilbar flags the issues that arise in cases where a child who discovers he has a genetic mutation was raised by his mother and has no relationship with his biological father.<sup>25</sup> However, Gilbar may be too restrictive in his definition of a social relationship. If the child in his example was conceived naturally, the mother is likely to know the identity of the father. This awareness may suffice to ground a biosocial relationship and establish the father as a member of the child’s genetic family. This scenario stands in contrast to situations of artificial insemination where the sperm donor’s identity is unknown; in such cases, paternity is not recognized.<sup>26</sup>

Defining the “genetic family” based on who has an interest in genetic information may represent less of a challenge for policy makers, legislators, and health care providers if *interest* is defined broadly. Loose categories for defining interest could include: reproductive risk management, personal risk management, and management of family history. Reproductive risk management would include awareness of the potential for reproductive risk and planning to manage the risk accordingly. Personal risk management is a broader interest category and can include everything from health and

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<sup>21</sup> *Genetic Privacy and Non-Discrimination Bill 1998* (Cth.), s. 7 [*Genetic Privacy Bill*].

<sup>22</sup> Laurie, *supra* note 16 at 114–117.

<sup>23</sup> Gilbar, *supra* note 11 at 65.

<sup>24</sup> *Ibid.* at 67–68.

<sup>25</sup> *Ibid.* at 68.

<sup>26</sup> See art. 538.2 C.C.Q where it states that the contribution of genetic material to a “third party parental project” does not create a bond of filiation unless the material was provided by sexual intercourse.

lifestyle management, to financial management and life planning, to family care management. Finally, management of family history involves awareness of genetic risk in the family and ensuring that the information is managed appropriately and in accordance with the needs and values of the family as a whole as well as with those of individual members.

## B. What is “Genetic Information”?

Like defining “genetic family”, characterizing “genetic information” in one way or another can form the basis of arguments for or against communication obligations. Obligations to communicate within families follow more readily from characterizations of genetic information as distinct from other kinds of personal information in that it is shared between genetic relatives and belongs to the kinship. If unique, and uniquely shared, this may justify a special legal and ethical regime for genetic information.<sup>27</sup> A contrary view characterizes genetic information as no different from other forms of medical information, and thus properly regulated using existing regimes for medical or health information.<sup>28</sup>

This section begins by highlighting the difficulties in defining precisely what is included within the ambit of the term “genetic information”, including whether family history information is or should be included therein. Then, various characterizations of genetic information found in Canadian law and policy, as well as selected national, regional, and international laws and policies are discussed.

### 1. Defining Genetic Information

What kinds of information are included in the phrase “genetic information”? Is genetic information strictly the result of DNA or other tissue testing as implied in normative documents from UNESCO,<sup>29</sup> Australia,<sup>30</sup> Switzerland,<sup>31</sup> and Israel?<sup>32</sup> Or, might it be broader and also include any information that points to hereditary characteristics in an individual or related individuals as implied in documents from the Council of Europe,<sup>33</sup> the European Commission,<sup>34</sup> the United Kingdom,<sup>35</sup> the United States,<sup>36</sup> Luxembourg,<sup>37</sup> and Estonia.<sup>38</sup> Of particular concern is whether family history information falls into the category.

A step back to consider how “genetic testing” is defined may be of assistance. In a recent document, the European Commission’s Eurogentest, discussed a narrow and a broad definition of genetic testing.<sup>39</sup> The narrow definition is based on the *methods used* to obtain genetic information, for example DNA assay testing, protein analysis, or constructing a family pedigree from family history information.<sup>40</sup> The broad definition is based on the *information generated* by the test. If the informa-

<sup>27</sup> Loane Skene, “Patients’ Rights or Family Responsibilities? Two Approaches to Genetic Testing” (1998) 6 Med. L. Rev. 1 at 35.

<sup>28</sup> Bell & Bennett, *supra* note 2 at 158.

<sup>29</sup> UNESCO International Bioethics Committee OR, 32d Sess., 20th Plen. Mtg., UN Doc. 32 C/Res. 22 (2003) 39, art. 2(i).

<sup>30</sup> *Genetic Privacy Bill*, *supra* note 21 art. 8(1).

<sup>31</sup> *Loi fédérale sur l’analyse génétique humaine*, R.S. 810.12, 8 October 2004, art. 3(l).

<sup>32</sup> *Genetic Information Law*, 5761–2000, 13 December 2000, art. 2.

<sup>33</sup> Council of Europe, Committee of Ministers, *Recommendation R(97)5 on the Protection of Medical Data* (1997) 39 Inf. Bull., art. 1.

<sup>34</sup> EC, Data Protection Working Party, *Working Document on Genetic Data*, [2004] 12178/03/EN WP91, art. 2.

<sup>35</sup> U.K., Human Genetics Commission, *Balancing Interests in the Use of Personal Genetic Data* (May 2002) at 26, online: <<http://www.hgc.gov.uk/UploadDocs/DocPub/Document/insideinformation.pdf>>.

<sup>36</sup> U.S., Bill H.R. 493, *Genetic Information Non-Discrimination Act of 2008*, 110th Cong., 2008, s. 101 (d)(6)(A) [*Genetic Information Act*].

<sup>37</sup> *Loi no. 91 du 2 août 2002 relative à la protection des personnes à l’égard du traitement des données à caractère personnel*, J.O., 13 August 2002, 1835, art. 2(g).

<sup>38</sup> *Human Genes Research Act 2001*, RT I, 13 December 2000, at art. 2(9).

<sup>39</sup> Jorge Sequeiros & Bárbara Guimarães, “Definitions of Genetic Testing”, 3<sup>rd</sup> draft (2007) Eurogentest, online: Eurogentest <<http://www.eurogentest.org/web/files/public/unit3/DefinitionsGeneticTesting-3rdDraf18Jan07.pdf>>.

<sup>40</sup> This approach was adopted by the Council of Europe in the *Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Genetic Testing for Health Purposes*, Council of Europe, 27 November 2008, Eur. T.S. 164, at

tion generated reveals genetic risk, the test is properly defined as a genetic test. Using the broad definition, genetic risk revealed through the collection of family history would constitute genetic information.

Whether family history is classified as genetic information can impart significant consequences on how it is shared. Like genetic test results, family history information may reveal a previously unknown genetic risk for specific individuals in a family. This means that family history information, like genetic information, may make individuals and families vulnerable to discrimination on the basis of future health status,<sup>41</sup> and has led to efforts in the United Kingdom to protect against insurance discrimination based on family history.<sup>42</sup> Moreover, the informed consent requirements that apply to genetic testing may not apply to the collection of family history information.<sup>43</sup> For those who are unaware of the predictive implications of family history, a more stringent informed consent process for the collection of family history information may be required.<sup>44</sup>

There are also implications inhering in the *source* and the *certainty* of the information at issue. Family history information is revealed in many ways: through day-to-day family life, through intra-familial communication of health information, and through active seeking of family history. The information obtained is often incomplete or inaccurate, as patterns of communication within families are influenced by complex factors.<sup>45</sup> In comparison, information that results from DNA testing has a clearer source: the individual tested. The results may be inconclusive or may reveal a multifactorial condition, which perforce entails some degree of uncertainty. This uncertainty, however, is medical; it does not stem from complex family relationships and communication. This is not to suggest that one form of uncertainty is somehow preferable to the other; but it is important to consider whether the same obligations arise with respect to these two sources of information.

The complex relationship between genetic information and family history information is a topic that requires additional consideration. For simplicity, this article will not distinguish starkly between family history information and genetic information: we will adopt the broad definition of genetic testing, which is based on the *information generated* by the test.

## 2. Characterizing Genetic Information

Similar difficulties arise when it comes to characterizing genetic information, as it does not fall naturally into any established legal category. Although it is *personal*, it also possesses characteristics of shared, familial, and universal information. As a result, the views of legislative and policy documents regarding the confidential nature of genetic information fall along a continuum. At one end of the spectrum, some bodies consider that genetic information is like any other type of personal information and should be treated likewise. At the other end, some groups deem genetic information to be unique, and thus recommend the reexamination of the extent of the confidential status granted to it. In between, we find bodies that hold no specific position regarding the nature of genetic information. Here we review the current Canadian federal and provincial legislated positions regarding genetic information before turning our attention to the perspectives adopted in policy documents worldwide.

Canadian provincial and national laws only rarely offer explicit characterizations of genetic information. Where they do mention it, they often lack clarity. In Alberta, the *Freedom of Information And Protection of Privacy Act (2000) (FIPPA)* defines “personal information” as “recorded information about an identifiable individual, including... the individual’s fingerprints, other biometric information, blood type, genetic information, or inheritable characteristics.”<sup>46</sup> This definition would seem

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art. 2.

<sup>41</sup> Dagmar Schmitz & Urban Weising, “Just a Family Medical History?” (2006) 332 *British Medical Journal* 297; Anneke Lucassen, Michael Parker & Robert Wheeler, “Implications of Data Protection Legislation for Family History” (2006) 332 *British Medical Journal* 299.

<sup>42</sup> U.K., Human Genetics Commission, *supra* note 35 at 121ff.

<sup>43</sup> Schmitz & Weising, *supra* note 41 at 298.

<sup>44</sup> *Ibid.*

<sup>45</sup> Nycum, Knoppers & Avard, *supra* note 4.

<sup>46</sup> *Freedom of Information and Protection of Privacy Act*, R.S.A. 2000, c. F-25, art. 1(n)(vi) [FIPPA].

to include both the results of DNA testing as well as family history information under the umbrella of *personal* information. Interestingly, however, the *FIPPA* includes health information in its definition of personal information, but on a separate subsection.<sup>47</sup> This suggests that genetic information falls into a category of personal information different from the category into which health information falls. Also in Alberta, the *Health Information Act (HIA)* defines “health information” as “diagnostic, treatment and care information,”<sup>48</sup> which is further defined, *inter alia*, as “any [...] information about an individual that is collected when a health service is provided to the individual.”<sup>49</sup> This is a very broad definition and would quite reasonably include information derived from genetic testing. Given these inconsistencies between *FIPPA* and *HIA*, the Alberta information protection regime does not provide a clear indication as to whether genetic information should be considered similar to other health information or treated as unique and thus meriting special consideration with regards to confidentiality.

Elsewhere in Canada, however, more coherent views have emerged. For example, in Manitoba the *Personal Health Information Act* and the *Freedom of Information and Protection of Privacy Act* adopt consistent positions with regards to health information where personal health information is defined as “recorded information about an identifiable individual that relates to the individual’s health, or health care history, including genetic information about the individual.”<sup>50</sup> Further, the federal *Assisted Human Reproduction Act* also includes genetic information in its definition of “health reporting information”,<sup>51</sup> an approach taken up by the Council of Europe in its definition of “medical data”, and by the Australian legislature in its definition of “health information”.<sup>52</sup> The implication is that genetic information is to be treated similarly to health information generally.

While they are aware of the distinction between the two, some policymaking bodies have adopted a classification for genetic information that is similar to the one they use for medical information. For example, the Manitoba position is reflected in the guidelines of the Canadian Medical Association (CMA) that state that

[h]ealth information’ means any information about a patient that is confided or collected in the therapeutic context, including information created or generated from this information and information that is not directly or indirectly linked to the provision of health care.<sup>53</sup>

This broad definition of health information would seem to include genetic information as equivalent to other medical information. For the purpose of confidentiality protections, the CMA makes no exception for genetic information: “information about oneself is considered worthy of protection against use or disclosure despite its potential benefit to others for example, genetic information or HIV, Hepatitis C status.”<sup>54</sup> Likewise, the Canadian College of Medical Geneticists (CCMG) and the American Society of Human Genetics (ASHG) do not differentiate between medical and genetic information when it comes to confidentiality protections. The ASHG states that for the purposes of confidentiality, “genetic information should be considered as medical information.”<sup>55</sup> However, it goes on to recognize that genetic information is “both individual and familial in nature,”<sup>56</sup> thus differentiating genetic information from health information.

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<sup>47</sup> *Ibid.*

<sup>48</sup> *Health Information Act*, R.S.A. 2000, c. H-5, art. (1)(k)(i) [*HIA*].

<sup>49</sup> *Ibid.* art. (1)(i).

<sup>50</sup> *Personal Health Information Act*, S.M. 1997, c. S1, C.C.S.M. c. P33.5, s.1; *Freedom of Information and Protection of Privacy Act*, S.M. 1997, c. S1, C.C.S.M. c. F175, s. 1.

<sup>51</sup> *Assisted Human Reproduction Act*, S.C. 2004, c. 2, art. 3(a).

<sup>52</sup> *Privacy Act 1988*, (Cth.), s. 6.

<sup>53</sup> Canadian Medical Association, *Health Information Privacy Code* (1998), s. B (“health information”), online: Canadian Medical Association <[http://www.cma.ca/index.cfm/ci\\_id/3216/la\\_id/1.htm](http://www.cma.ca/index.cfm/ci_id/3216/la_id/1.htm)>.

<sup>54</sup> Canadian Medical Association, “Listening to our Patient’s Concerns: Comments on Bill C-54”, Submission to the House of Commons Standing Committee on Industry (18 March 1999).

<sup>55</sup> American Society of Human Genetics, Social Issues Subcommittee on Familial Disclosure, “Professional Disclosure of Familial Genetic Information” (1998) 62 *American Journal of Human Genetics* 474 at 474.

<sup>56</sup> *Ibid.* at 476.

Other policy approaches also acknowledge that genetic information has special characteristics while endorsing strict confidentiality protections. UNESCO's International Declaration on Human Genetic Data states that genetic information has special status because of its impact on the family, offspring, and future generations,<sup>57</sup> yet the regime uses a standard medical confidentiality approach for genetic information.<sup>58</sup> Similarly, the European Commission acknowledges public perceptions that genetic information is somehow special, but also states that genetic information should have equivalent confidentiality protection as other comparably sensitive medical data.<sup>59</sup>

By contrast, other international policy documents acknowledge that the special nature of genetic information with respect to family members requires an exceptional stance when considering the regulation of its confidentiality. The Human Genome Organisation (HUGO) maintains that "special considerations should be made for access [to genetic information] by immediate relatives"<sup>60</sup> and the HUGO Ethical, Legal and Social Issues (ELSI) Committee finds that although confidentiality must be protected, special considerations may be needed to protect the "actual or potential" interests of family members.<sup>61</sup> The UK's Nuffield Council has stated that if genetic information is to be treated with special status, this should be limited to information about monogenic conditions and not extended to genetic information generally.<sup>62</sup>

Finally, some documents are explicit as to the unique or shared nature of genetic information. The World Health Organization (WHO) put forth the view that genetic information gives rise to unusual situations by virtue of being "both uniquely personal and the shared property of families."<sup>63</sup> The WHO also supports the view that in some genetics cases, the "true patient" may be the family.<sup>64</sup> Similarly, the European Commission believes that genetic information has characteristics that make it singular, namely, its family dimension, which transforms it into a form of shared information.<sup>65</sup> In Australia, the National Health and Medical Research Council (NHMRC) acknowledges that genetic information is "distinguished from other medical information in that it can potentially provide information about people other than the individual concerned."<sup>66</sup> The 2008 U.S. *Genetic Information Non-Discrimination Act* includes genetic information about "the genetic tests of family members" in its definition of information about the individual.<sup>67</sup>

As indicated above, while current legislative positions in Canada appear to favour the notion that genetic information is subject to the same regime of confidentiality as other types of personal health information, efforts aimed at acknowledging the limitations associated with this view are underway. Ontario's Provincial Advisory Committee on New Predictive Genetic Technologies asserts that genetic information "brings the ethical, legal and social issues involved in the use of health information to a different level." It adds that the information's familial implications complicate the rules regarding third-party notification and give rise to ethical dilemmas.<sup>68</sup> At the federal level, on the other

<sup>57</sup> UNESCO International Bioethics Committee OR, *supra* note 29, s. 4; see also *Report on Confidentiality and Genetic Data*, UNESCO OR, 2000, BIO-503/99/CIB-6/GT-2/3 at 4.

<sup>58</sup> UNESCO International Bioethics Committee OR, *ibid.*, s. 14.

<sup>59</sup> EC, *25 Recommendations on the Ethical, Legal and Social Implications of Genetic Testing* (Brussels: EC, 2004), art. 10.

<sup>60</sup> Human Genome Organization, "HUGO Ethics Committee Statement on DNA Sampling: Control and Access" (1998) 8 *Eubios Journal of Asian and International Bioethics* 56, online: Human Genome Organization <<http://www.eubios.info/HUGO2.htm>>.

<sup>61</sup> Human Genome Organization, "Statement on The Principled Conduct of Genetic Research" (1996) 6 *Eubios Journal of Asian and International Bioethics* 59, online: Human Genome Organization <<http://eubios.info/HUGO.htm>>.

<sup>62</sup> Nuffield Council on Bioethics, *Pharmacogenetics Ethical Issues* (London: Nuffield Council on Bioethics, 2003) at paras. 3.43, 5.34–5.35, online: Nuffield Council on Bioethics <[http://www.nuffieldbioethics.org/fileLibrary/pdf/pharmacogenetics\\_report.pdf](http://www.nuffieldbioethics.org/fileLibrary/pdf/pharmacogenetics_report.pdf)>.

<sup>63</sup> D.C. Wertz, J.C. Fletcher & F.K. Berg, *Review of Ethical Issues in Medical Genetics*, WHO/HGN/ETH/00.4 (2003) at 50, online: WHO <[http://www.who.int/genomics/publications/en/ethical\\_issuesin\\_medgenetics%20report.pdf](http://www.who.int/genomics/publications/en/ethical_issuesin_medgenetics%20report.pdf)>.

<sup>64</sup> *Ibid.*

<sup>65</sup> EC, Data Protection Working Party, *supra* note 34 at 4.

<sup>66</sup> Austl., National Health and Medical Research Council, *Ethical Aspects of Human Genetic Testing: An Information Paper* (Canberra: Commonwealth of Austl., 2000) at 48.

<sup>67</sup> *Genetic Information Act*, *supra* note 36, s. 101(d)(6)(A).

<sup>68</sup> Ontario Provincial Advisory Committee on New Predictive Genetic Technologies, *Genetic Services in Ontario: Map-*

hand, the Canadian Biotechnology Advisory Committee has stated that while familial issues in genetics are important, “family relevance of genetic information *per se* does not make genetic information unique.”<sup>69</sup>

While efforts to acknowledge the unique nature of genetic information are laudable, we should understand the consequences of conceiving of genetic information as shared. There are at least two alternative implications. Either relatives of patients are themselves data *subjects* and as such have personal rights with respect to the information, or relatives have not *rights* but *interests*, which are limited to instances when the genetic information is relevant to their own health and future life.<sup>70</sup> The former would correspond with the view that the true patient in genetics may be the family.<sup>71</sup> This approach subverts the individual as the *source* of the information,<sup>72</sup> either by having his or her own tissue tested or by providing a family history, and arguably fails to account for the *personal* or *individual* aspect, alongside the *familial* aspect, of the information. This approach may also imply that the consent of relatives is required before generating genetic information, a requirement whose complexity threatens to bar access to genetic services in most cases.<sup>73</sup> For these reasons, the second interpretation of the “shared information” perspective, which de-emphasizes relatives’ rights and embraces their interests, may be preferable.

## II

### THE BASES OF INTRA-FAMILIAL OBLIGATIONS TO COMMUNICATE GENETIC INFORMATION

As noted above, who is the “genetic family” and what is “genetic information” can point to bases for intra-familial obligations to communicate genetic information. Who is considered a genetic family member will determine the range of family members to whom such an obligation is owed. Some characterizations of genetic information are more amenable to communication obligations than others. This section explores other possible bases for intra-familial communication obligations, including the following: special obligations as members of families; notions of autonomy and relational autonomy; ownership and control of genetic information; the limits of health professionals’ obligations to communicate genetic information to relatives; and the role, or possible lack thereof, of individual privacy within the family sphere.

#### A. Special Obligations to Communicate Genetic Information as Members of Families

Being a member of a family incurs certain rights as well as duties with respect to other members of that family.<sup>74</sup> Some of these rights and duties are moral, and some are legally mandated. Is there a right to be informed of familial genetic information and a corresponding duty to communicate such information to family members? What might be the justification for such an obligation and its possible contours? The following discussion takes up these questions.

Several international normative documents that address genetic information ground the moral obligation to communicate genetic information on the kinship bond and on an assumed desire to protect family members.<sup>75</sup> This is primarily a moral obligation between family members. As dis-

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*ping the Future* (2001) at 27, online: Ontario Legislative Assembly <<http://www.ontla.on.ca/library/repository/mon/3000/10301455.pdf>>.

<sup>69</sup> Trudo Lemmens & Lisa Austin, Canadian Biotechnology Advisory Committee, *Of Volume, Depth and Speed: The Challenges of Genetic Information* (Ottawa: Industry Canada, 2001) at 23, online: Industry Canada <[http://strategis.ic.gc.ca/eic/site/cbac-cccb.nsf/vwapj/GenInfo\\_Challenges\\_Lemmens\\_e.pdf/\\$FILE/GenInfo\\_Challenges\\_Lemmens\\_e.pdf](http://strategis.ic.gc.ca/eic/site/cbac-cccb.nsf/vwapj/GenInfo_Challenges_Lemmens_e.pdf/$FILE/GenInfo_Challenges_Lemmens_e.pdf)>.

<sup>70</sup> EC, Data Protection Working Party, *supra* note 34.

<sup>71</sup> Wertz, Fletcher & Berg, *supra* note 63 at 50.

<sup>72</sup> Bell & Bennett, *supra* note 2 at 132.

<sup>73</sup> Michael Parker & Anneke Lucassen, “Concern for Families and Individuals in Clinical Genetics” (2003) 29 *Journal of Medical Ethics* 70 at 72.

<sup>74</sup> Gilbar, *supra* note 11 at 70.

<sup>75</sup> Laura E. Forrest *et al.*, “Communicating Genetic Information in Families—A Review of Guidelines and Position Papers” (2007) 15 *European Journal of Human Genetics* 612 at 615 [emphasis added, Laura E. Forrest *et al.*, “Communicating”].

cussed in more detail below,<sup>76</sup> legal obligations between parents and children, as well as spouses, and obligations to care for dependent adults are typically limited to alimentary support; however, they are sometimes broader than this and can include non-financial obligations. There is no legal grounding for obligations between other family members, although one scholar has argued that siblings owe each other respect and care that would be breached by a failure to communicate genetic information.<sup>77</sup>

In the context of genetic information, one justification for special family obligations is that although only one family member obtains it in the course of testing or treatment, it has implications for the entire family. If genetic testing is predictive rather than diagnostic, the patient's account of her family history may have given away clues about the possibility of a genetic risk in the first place. Information about genetic relatives will typically be collected as part of a pre-test consultation,<sup>78</sup> and a family history may be needed to supplement test results, to make them meaningful, or to confirm a diagnosis.<sup>79</sup> Once a treating physician generates genetic information on behalf of an individual by any means, the new knowledge may have health implications for other genetic relatives and future generations.<sup>80</sup> Thus, family ramifications exist and matter both at the outset and in the aftermath of genetic testing. In this way, the familial implications of genetic information are full circle, appearing at every stage of the genetic investigation. Indeed, direct family involvement is often needed for genetic testing to be effective.<sup>81</sup>

Real life perceptions of who is "family", and the corresponding perceived obligations to share information with identified family members, are often determined by social relationship rather than by biological relationship.<sup>82</sup> Moreover, lay knowledge about genetic inheritance is often inconsistent with Mendelian patterns of inheritance,<sup>83</sup> giving rise to difficulties in identifying at-risk genetic relatives. Often, but not always, there is no sense of obligation to communicate with (biological) family members with whom there is no, or a distant, relationship.<sup>84</sup> The lack of moral impulse in the absence of a social relationship mirrors the biosocial approach to defining the genetic family suggested by Gilbar and discussed above.<sup>85</sup>

Rosamond Rhodes refutes the moral obligation to communicate genetic information on the basis of genetic ties, noting that although human beings are genetically similar to mice, we do not feel the same moral obligations to mice as we do to fellow human beings.<sup>86</sup> Rhodes argues that moral responsibility comes out of intimacy, dependency, a history of interactions, and the current context.<sup>87</sup> It follows from this view that distance in a relationship might weaken the moral obligations shared between the parties, even among genetic relatives. Rhodes nonetheless makes room for certain instances where obligations may be based on biology alone, such as legally enforceable support obligations. She also allows for moral obligations arising in situations where an individual with genetic information may be the sole source of an indication of genetic risk. Ultimately for Rhodes, as well as

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<sup>76</sup> See part III, section 2, below.

<sup>77</sup> Charles Weijer, "Family Duty is More Important than Rights" (2000) 321 *British Medical Journal* 1466 at 1466.

<sup>78</sup> Skene, *supra* note 27 at 6–7.

<sup>79</sup> This may play out for example in the context of hereditary breast and ovarian cancer, where it may be necessary for family members to undergo genetic testing in order to verify a patient's risk or to clarify the meaning of the results. See Beth N. Peshkin *et al.*, "BRCA 1/2 Testing: Complex Themes in Result Interpretation" (2001) 19 *Journal of Clinical Oncology* 2555 at 2556.

<sup>80</sup> Bell & Bennett, *supra* note 2 at 156; Skene, *supra* note 27 at 40.

<sup>81</sup> Robert J. Moss, Shelly A. Cummings & Mary B. Mahowald, "Genetic Testing as a Family Affair" in Mary B. Mahowald *et al.*, eds., *Genetics in the Clinic: Clinical, Ethical, and Social Implications for Primary Care* (St. Louis: Mosby, 2001) 189 at 192–3.

<sup>82</sup> Nycum, Knoppers & Avar, *supra* note 4.

<sup>83</sup> Martin Richards, "Families, kinship and genetics" in Theresa Marteau & Martin Richards, eds., *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge: Cambridge University Press, 1996) at 268.

<sup>84</sup> Nycum, Knoppers & Avar, *supra* note 4.

<sup>85</sup> See part I, section A, above.

<sup>86</sup> Rhodes, *supra* note 8 at 21.

<sup>87</sup> *Ibid.*

for other scholars, obligations around genetic information will depend primarily on the multiple contextual factors of any given situation.<sup>88</sup>

Proximity, be it social or biological, might help delineate intra-familial obligations to communicate genetic information. Communication around genetic risk information is often considered a parental responsibility.<sup>89</sup> For example, aunts and uncles may not inform nieces and nephews of their risk directly. Rather, the communication of genetic risk will be left to their siblings—the parents.<sup>90</sup> This could be done out of respect for intimate family relationships and to avoid the appearance of usurping parental authority.<sup>91</sup> This scenario offers plausible contours for intra-familial obligations to communicate genetic information: sharing information with members of one's own nuclear family could exhaust obligations by transferring them to the sphere of another nuclear family. Within these boundaries, once communication with a sibling occurs, communication within the sibling's nuclear family becomes the sibling's own responsibility. This would apply similarly in the context of disclosure to aunts and uncles by proceeding through a parent.<sup>92</sup> These parameters both respect the perceived intimacy of the nuclear family and place a limit on the obligations to disclose genetic information within families. At the same time, they are problematic given that “nuclear” families are uncommon and that family constitutions extend well beyond the limits of the so-called nucleus.

Another basis for obligations to communicate genetic information within families is the notion of assumed obligations. These are the obligations that parents undertake toward their children because failure to do so might cause harm to the child. The parents' obligations are “assumed” because they flow from the fact that the parents chose to bring the child into the world.<sup>93</sup> As such, assumed obligations on this basis do not extend to other family relationships. It is worth noting, however, that, particularly in the case of minor children, the communication of genetic risk information may not lead to any immediate benefit for the child, especially where the information relates to adult-onset conditions. Moreover, such communication may cause harm to the child by leading to negative social, financial, and psychological consequences.<sup>94</sup>

In sum, rationales to impose special obligations to communicate genetic information on family members may be based on perceptions of who has an interest in the information and is therefore owed a duty. These perceptions often stem from social rather than biological relationships. While the drawbacks of a strictly social approach to defining the genetic family are that this may leave interested biological relatives uninformed, a strictly biological approach could give rise to obligations to distant relatives with whom there is no contact or relationship whatsoever. In some cases, the nuclear family and the assumed obligations of parents toward their children may create useful contours for the intra-familial obligation to communicate genetic information. In all cases where context points to communication obligations however, the issue of the autonomy of those possessing genetic information arises.

## B. Autonomy as a Ground for Communication or Non-Communication

The notions of individual autonomy that are valued within the legal and democratic societies can represent a challenge for policy makers and health care providers in the context of genetics. In Western society, autonomy has developed as an individual right and the “group” nature of claims con-

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<sup>88</sup> *Ibid.* at 25; d'Agincourt-Canning, *supra* note 8.

<sup>89</sup> Karen Forrest Keenan *et al.*, “It's Their Blood not Mine': Who's Responsible for (Not) Telling Relatives About Genetic Risk?” (2005) 7 *Health, Risk & Society* 209; Karen Forrest *et al.*, “To Tell or Not to Tell: Barriers and Facilitators in Family Communication About Genetic Risk” (2003) 64 *Clinical Genetics* 317 [Karen Forrest *et al.*, “Barriers”].

<sup>90</sup> Keenan *et al.*, *ibid.*

<sup>91</sup> Keenan *et al.*, *ibid.* at 216.

<sup>92</sup> Josephine Green *et al.*, “Family Communication and Genetic Counseling: The Case of Hereditary Breast and Ovarian Cancer” (1997) 6 *Journal of Genetic Counseling* 45 at 51.

<sup>93</sup> Lori Andrews, “Gen-Etiquette: Are There Moral and Legal Responsibilities to Share Genetic Information Within Families?” in Mark Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven: Yale University Press, 1997) at 258.

<sup>94</sup> Andrea Farkas Patenaude, Karine Sénécal & Denise Avard, “Whither Pediatric Research and Predisposition Genetic Testing?” (2006) 4:2 *GenEdit* 1 at 2.

cerning family information poses a serious conceptual threat to this paradigm.<sup>95</sup> On the one hand, it has been argued that an emphasis on individual autonomy, particularly in medical law and ethics, is paradoxical in the context of the genetic family, which has nothing to do with choice.<sup>96</sup> It has also been argued that an emphasis on individual autonomy as a root of moral decision-making renders the genetic family amoral because biological relationships are not freely chosen. One scholar has observed that the effect is that the moral solidarity of families has been de-emphasized as individual autonomy has flourished as an ethical value.<sup>97</sup> On the other hand, within theories such as Gilbar's notion of the biosocial family, there may indeed be a significant amount of choice. After all, you cannot choose with whom you are biologically related, but culture and society allow room to be selective with respect to whom one considers "family".<sup>98</sup> As a result, neither view of individual autonomy adequately addresses the issue of how to approach the obligation to share genetic information.

Authors have cited problems with the concept of autonomy regarding genetic information as it applies to women and their role within families. In a study by Hallowell and colleagues, women who had been diagnosed with breast cancer were motivated to undergo BRCA1/2 genetic testing to provide genetic risk information for their family members. This was done so as to facilitate relatives' autonomous decision-making around their own genetic risk, rather than so as to benefit the women themselves.<sup>99</sup> This sense of obligation to generate genetic information for the benefit of family members may mean that the decision to undergo genetic testing is not fully autonomous.<sup>100</sup>

However, this concern may come out of an overly simplistic view of autonomy within family relationships. Theories of relational autonomy, which take relationships and context into consideration, may be better suited to the matter of genetic information-sharing within families. Susan Sherwin has argued that rather than conceiving of autonomy in abstract, absolute terms, the concept of relational autonomy takes stock of the political, social, interpersonal, and other types of factors that influence one's ability to make an autonomous decision.<sup>101</sup> Emphasizing the autonomy of individuals as isolated entities, as opposed to individuals as part of relationships, fails to account for the complexities of decision-making. In the context of health care, "many decision makers, especially women, place the interests of others at the center of their deliberations."<sup>102</sup> In so doing, these decision makers do not demonstrate a fully realized (and possibly unattainable) individual autonomy, but are still making deliberate choices that embody their agency.<sup>103</sup> Martha Minow argues that conceiving the patient by highlighting the importance of the patient's relationship with others does not infringe individual autonomy. Individual autonomy, she says, is rightly reconceived in light of patients' relationships with others because it *includes* interpersonal relationships, rather than existing around them or in spite of them.<sup>104</sup> Similarly, Gilbar argues that in deliberating over whether to communicate genetic information with family members, it should be recognized that decisions will affect the maintenance of relationships and the family environment and will therefore have an impact not only for relatives, but also for those who initiate communication.<sup>105</sup> To put it another way, relational autonomy locates the "costs and benefits associated with disclosure of genetic information within the context of people's everyday lives."<sup>106</sup>

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<sup>95</sup> Laurie, *supra* note 16 at 4.

<sup>96</sup> Kaja Finkler, Cecile Skrzynia & James P. Evans, "The New Genetics and its Consequences for Family, Kinship, Medicine and Medical Genetics" (2003) 57 *Social Science & Medicine* 403.

<sup>97</sup> Janet Dolgin, "Choice, Tradition, and the New Genetics: The Fragmentation of the Ideology of Family" (2000) 32 *Conn. L. Rev.* 523.

<sup>98</sup> Andrews, *supra* note 93 at 257.

<sup>99</sup> N. Hallowell *et al.*, "Balancing Autonomy and Responsibility: The Ethics of Generating and Disclosing Genetic Information" (2003) 29 *Journal of Medical Ethics* 74.

<sup>100</sup> *Ibid.* at 78.

<sup>101</sup> Susan Sherwin, "A Relational Approach to Autonomy in Health Care", in Susan Sherwin, ed., *The Politics of Women's Health: Exploring Agency and Autonomy* (Philadelphia: Temple University Press, 1998) at 19.

<sup>102</sup> *Ibid.* at 34.

<sup>103</sup> *Ibid.*

<sup>104</sup> Martha Minow, "Who's the Patient?" (1994) 53 *Md. L. Rev.* 1173 at 1173-74.

<sup>105</sup> Gilbar, *supra* note 11 at 72.

<sup>106</sup> d'Agincourt-Canning, *supra* note 8 at 237.

Relational autonomy may provide an adequate explanation for feelings of moral obligations toward family, but it also risks placing exclusive focus on social relationships. An ideal approach to autonomy in this context may be one where notions of individual autonomy are balanced against relational or communitarian notions.<sup>107</sup> Angela Davey has proposed “family comity”—or, considerate behavior toward family members—as an alternative guiding principle that would recognize relational autonomy and social responsibility as inhering in genetic information because of its hereditary nature.<sup>108</sup> In this way, comity is a counterbalance to autonomy and requires that individual interests be checked in order to respect the interests of others. “Family comity” may therefore be one way to balance individual and relational notions of autonomy.

### C. Ownership or Control of Genetic Information

Another way of grounding intra-familial obligations to communicate genetic information focuses on who owns or controls such information and who may have access to it. There are few laws and policies that create or discuss ownership or property rights with respect to genetic information. In Canada, medical information is treated as belonging to the individual while the medical record itself belongs to the physician or hospital where it is kept. Patients have rights of access to their information except in unusual circumstances where allowing access would be inappropriate or dangerous.<sup>109</sup> Because the genetic information contained in a medical record is also “related” to the patient’s relatives, it is arguable that the relatives could also be considered to “own” the information, and as such gain access to it. Granting exclusive access rights to the patient solely because she is the *source* of knowledge unduly sidelines the relatives’ own legitimate interest in the information.<sup>110</sup>

Worldwide, there appears to be a wide spectrum of legislative views regarding ownership of genetic information. For example, the Icelandic government has taken the position that genetic information is a national resource and as such, there are no individual property rights with respect to it.<sup>111</sup> On the other hand, a few U.S. states have enacted legislation that clearly restricts ownership of genetic information to the individual tested.<sup>112</sup> Colorado legislation states that genetic information is the property of the person to whom it pertains.<sup>113</sup> This is more ambiguous because the information could *pertain* to genetic relatives.

Policy making bodies, however, appear to favour a broad view of ownership of genetic information, one that does not place access to the information solely in the hands of the individual tested. The Human Genetics Society of Australasia puts forth that “information about the gene mutation *belongs* to all blood relatives,”<sup>114</sup> and the Australian National Health and Medical Research Council creates an individual property regime with a right of access to records of the individual tested by her relatives.<sup>115</sup> In this regime, records, including tissue sent for genetic testing, are the “property of the bodies that make the records or hold the tissues.” However, “[t]he presumption should be that relatives and descendants should have access to those materials for purposes of assessment of their own risk.”<sup>116</sup>

The approach where multiple individuals hold rights of ownership, control, or access to genetic information is embodied in the “joint account theory” of genetic information. This theory puts forth that genetic information is owned by multiple parties. As such, the conventional model of confidenti-

<sup>107</sup> Angela Davey, Ainsley Newson & Peter O’Leary, “Communication of Genetic Information Within Families: The Case for Family Comity” (2006) 3 *Bioethical Inquiry* 161 at 164.

<sup>108</sup> *Ibid.*

<sup>109</sup> *McInerney v. MacDonald*, [1992] S.C.R. 138, 93 D.L.R. (4th) 415.

<sup>110</sup> Laurie, *supra* note 16 at 93.

<sup>111</sup> Richard A. Spinello, “Property Rights in Genetic Information” (2004) 6 *Ethics and Information Technology* 29 at 32.

<sup>112</sup> Alaska Stat. tit. 18 § 13.010(a)(2) (2004); Fla. Stat. Ann. tit. 44 § 760.40(2)(a) (1992); Ga. Code Ann. tit. 33 § 54-1(1) (1995).

<sup>113</sup> C.R.S.A. tit. 10 § 3-1104.7(1)(a) (2002).

<sup>114</sup> Laura E. Forrest *et al.*, “Communicating”, *supra* note 75 at 614, Table 1 (“Summary of Guidelines”).

<sup>115</sup> Austl., National Health and Medical Research Council, *Familial Aspects of Cancer: A Guide to Clinical Practice* (Canberra: Commonwealth of Austl., 1999).

<sup>116</sup> *Ibid.* at 17.

ality should be reversed and genetic information should be available to all “account holders”, or relatives to whom the information relates, unless there is sufficient reason to do otherwise.<sup>117</sup> Questions remain as to what this regime would look like and what its effects would be. There is no precedent for regulating information that is both personal and shared or simply shared, other than the all-encompassing notion of the public domain. It is worth noting that the WHO has called for a revision of ownership laws to reflect the special nature of genetic information and to clear up legal obligations with respect to it.<sup>118</sup> The Organization has also asserted that individuals are entitled to rights to control their genetic samples and information in a manner akin to property rights.<sup>119</sup>

An alternative approach that is often called upon as a counter-argument to property regulation discussions revolving around blood, tissue, organs, pituitary glands, corneal tissue, corpses, and biological tissue is to treat genetic information as *sui generis*, or in a category of its own. This would warrant the adoption of a specific regulatory regime.<sup>120</sup> The advantage of this approach—flexibility—is also its disadvantage. Flexibility allows the many and varied interests in genetic information to be addressed on a case-by-case basis, but it also provides very little guidance for policy makers on how to regulate in the area.<sup>121</sup> This approach also faces the criticism of genetic exceptionalism for treating genetic information as special and severable from other forms of personal information.<sup>122</sup> The criticism is apt in some regards. The purported “special characteristics” of genetic information, including its predictive quality, its relevance to family members, its potential use in discriminating against individuals and groups, and its ability to cause serious psychological harm, are in fact also true of other forms of information.<sup>123</sup> On the other hand, it is also the case that genetic information is the only form of medical information to possess *all* of these characteristics.

#### D. Limits of Health Care Providers’ Obligations

There is a growing body of literature, policy, and law addressing health care providers’ communication of genetic information with patients’ relatives without the patients’ consent. Several approaches to the role of health care providers in this context are discussed here, followed by an analysis of how intra-familial obligations line up, or intersect, with health care providers’ obligations.

One approach to the role of health care providers, as articulated by the American Society of Human Genetics (ASHG) is that such communication may occur at the physician’s discretion in a limited set of circumstances, as follows: where “attempts to encourage disclosure on the part of the patient have failed; where the harm is likely to occur and is serious and foreseeable; where the at-risk relative(s) is identifiable; and where either the disease is preventable/treatable or medically accepted standards indicate that early monitoring will reduce the genetic risk.”<sup>124</sup> The justification for the ASHG position is that under such circumstances, the harm from failing to disclose will outweigh the harm from disclosure and thereby justify non-consensual disclosure.

The Canadian Medical Association takes a different approach, stating that health information should not be collected, used, disclosed, or accessed without patient consent except “under strict conditions” and in the “very limited circumstances” where it is “permitted or required by legislation

<sup>117</sup> Anneke Lucassen, “Should Families Own Genetic Information? Yes” (2007) 335 *British Medical Journal* 22 at 22; Michael Parker & Anneke Lucassen, “Genetic Information: A Joint Account?” (2004) 329 *British Medical Journal* 165.

<sup>118</sup> Wertz, Fletcher & Berg, *supra* note 63 at 51.

<sup>119</sup> Graeme Laurie, “Genetic Databases: Assessing the Benefits and the Impact on Human and Patient Rights—A WHO Report” (2004) 11 *Eur. J. Health L.* 87 at 88.

<sup>120</sup> Trudo Lemmens, Mireille Lacroix & Roxanne Mykitiuk, *Reading the Future?: Legal and Ethical Challenges of Predictive Genetic Testing* (Montreal: Éditions Thémis, 2007) at 242.

<sup>121</sup> *Ibid.*

<sup>122</sup> Thomas Murray, “Genetic Exceptionalism and ‘Future Diaries’: Is Genetic Information Different from Other Medical Information?” in Mark Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven: Yale University Press, 1997).

<sup>123</sup> M.J. Green & J. Botkin, “Genetic Exceptionalism in Medicine: Clarifying the Differences Between Genetic and Non-Genetic Tests” (2003) 138 *Annals of Internal Medicine* 571.

<sup>124</sup> American Society of Human Genetics, *supra* note 55 at 474.

or regulation” or “when ordered or decided by a court of law.”<sup>125</sup> The Canadian Medical Association Code of Ethics states that health professionals should only disclose patients’ personal health information to third parties “with their consent, or as provided by law, such as when the maintenance of confidentiality would result in a significant risk of substantial harm to others” and requires that the patient be informed that his or her confidentiality will be breached.<sup>126</sup> An interesting question with respect to the CMA documents is: Who is a “third party” in the context of genetic information? Given the relevance of the information in the eyes of genetic relatives, there may be room to argue that they are not third parties with respect to this information.

Some organizations hold that the extent of health professionals’ obligations is to ensure patients are aware of the importance of communicating test results to family members.<sup>127</sup> Many others appear to make an exception to their policies of non-directive genetic counseling and advise genetic counselors to actively encourage patients to inform their family members.<sup>128</sup> Indeed, research has shown that genetic counselors often believe that family members have a moral obligation to share genetic information.<sup>129</sup>

Whether health professionals have a legal duty to warn relatives of genetic risk is the subject of some debate. The professional duty to warn third parties of a threat of harm first arose in a California case in the context of threats made by a psychiatric patient against a third party during sessions with his psychiatrist.<sup>130</sup> In that case, the key considerations triggering liability for a failure to warn included the fact that the potential harm to an identifiable party was serious and foreseeable, that there was a close connection between the conduct and the injury suffered, and that moral blame attached to the defendant’s conduct. Also, the psychiatrist should have been privy to existing policies on the prevention of future harm. Other factors that weighed against the doctor were the (minimal) extent of the burden of warning, the positive community consequences of imposing such a duty, and the availability and cost of insurance to protect against such a risk. A similar professional duty has also been recognized by a Canadian court in the context of a physician’s duty to warn third parties at risk of acquiring a sexually transmitted disease from a patient.<sup>131</sup> Health professionals’ duty to warn has also been discussed by American courts in the genetics context<sup>132</sup> and in some cases a duty to warn has been found.<sup>133</sup>

The standards laid out by the ASHG and other organizations regarding health professionals’ duty to warn third parties and regarding their discretion to disclose information, are difficult to meet in the genetics context. To begin, in the psychiatric and infectious disease duty to warn cases, the threatening or infected party is herself an agent of the potential harm—a harm that may be preventable if the individual at risk is warned. In the genetics context, however, the potential harm has in a sense already been done. Either an individual has a genetic mutation as part of his or her genetic code or she does not; the patient is not a causal agent of the genetic harm. Another requirement for health professionals’ duty to warn is that the warning will be beneficial to the person warned. Although genetic risk information may, in some circumstances, be helpful to prevent or monitor the

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<sup>125</sup> Canadian Medical Association, “CMA Health Information Privacy Code” (1998), Principle 3.4, online: Canadian Medical Association <[http://www.cma.ca/index.cfm/ci\\_id/3216/la\\_id/1.htm](http://www.cma.ca/index.cfm/ci_id/3216/la_id/1.htm)>.

<sup>126</sup> Canadian Medical Association, “Code of Ethics of the Canadian Medical Association” (2004), art. 35, online: Canadian Medical Association <<http://policybase.cma.ca/PolicyPDF/PDO4-06.pdf>>.

<sup>127</sup> American Society of Clinical Oncology, “Policy Statement Update: Genetic Testing for Cancer Susceptibility” (2003) 21 *Journal of Clinical Oncology* 2397; Human Genetics Society of Australasia, *The Protection of Human Genetic Information* (2007) at 2–3, online: Human Genetics Society of Australasia <<http://www.hgsa.com.au/images/UserFiles/Attachments/PROTECTIONOFHUMANGENETICINFORMATION1.pdf>>.

<sup>128</sup> Laura E. Forrest *et al.*, “Communicating”, *supra* note 75; Knoppers, *supra* note 3; Kenneth Offit *et al.*, “The ‘Duty to Warn’ a Patient’s Family Members About Hereditary Disease Risks” (2004) 292 *Journal of the American Medical Association* 1469 at 1471.

<sup>129</sup> Jon Torgny R. Wilcke, “Late Onset Genetic Disease: Where Ignorance is Bliss, Is It Folly to Inform Relatives?” (1998) 317 *British Medical Journal* 744.

<sup>130</sup> *Tarasoff v. Regents of the University of California*, (1976) 551 P.2d 334 (Cal. Sup. Ct.).

<sup>131</sup> *Pittman Estate v. Bain*, (1994) 112 D.L.R. (4th) 257 (Ont. Ct. Div.).

<sup>132</sup> *Pate v. Threlkel*, (1995) 661 So.2d 278 (Fla. Sup. Ct.); *Safer v. Pack*, (1996) 677 A.2d 1188 (N.J. Super. Ct.) [*Safer*].

<sup>133</sup> *Safer, ibid.*

onset of a genetic condition, knowledge of genetic risk is valued differently by individuals and may not, in all cases, be experienced as a benefit.<sup>134</sup>

Other difficulties include defining what constitutes serious harm in the genetics context,<sup>135</sup> and determining in which cases prevention and surveillance measures are sufficiently available and effective to give rise to the duty to warn. Finally, non-consensual disclosure to relatives involves the relative's right to know outweighing the patient's right to confidentiality. However, there is reason to be skeptical that the relative's right to know can ever outweigh the patient's right to confidentiality in the genetics context, typically because of the problem of establishing the imminence of the genetic risk. The imminence of genetic risk is typically uncertain, particularly in the context of multifactorial genetic diseases such as breast cancer, where genetic risk information is never more than probabilistic information with regards to the realization of the risk.<sup>136</sup>

The relevance of this discussion in the context of articulating intra-familial obligations to communicate genetic information is that the limits of health care providers' obligations may implicate limits for intra-familial obligations. Would the limits of health professionals' obligations also apply to family members, or might intra-familial obligations be more robust?

Australian policy has put forth the view that patients have obligations more often than health professionals.<sup>137</sup> It may simply be that it takes less to trigger a patient's obligation to disclose. In that case, even where the criteria discussed above are not met, an intra-familial obligation may yet arise. This could be justified simply by reference to the fact that there is lower threshold for obligations within families as compared to that for professional-patient obligations. Another argument in favour of more robust intra-familial obligations is that relatives would gain access to important health information without health professionals breaching patient confidentiality. This respect of the duty of confidentiality is valued as a fundamental element of the medical system and is necessary to reassure those who seek testing about the protection of their privacy rights. However, there is a flipside to the strong presumption in favour of maintaining duties of confidentiality save in very special circumstances: patients have corresponding ethical responsibilities. The duty of confidentiality presupposes that patients undertake responsibility for managing their illness.<sup>138</sup> It is arguable that the fact that most laws and policies do not allow non-consensual disclosure by health professionals (except in limited circumstances) implies an obligation for patients to communicate where such circumstances are not met.

#### E. Familial Privacy Versus Individual Privacy

Confidentiality involves the prevention of the use or disclosure of information known about a person by another for unauthorized purposes, and "privacy is about an individual not being required to provide certain types of information about themselves to others."<sup>139</sup> Confidentiality is the duty of health professionals toward their patients. It may only be subject to exceptions in very limited circumstances. But when a third party professional is not part of the scenario, how do privacy rights play out? Can an individual have a privacy right to maintain his or her own personal information private even where the

<sup>134</sup> Jennifer Gold, "To Warn or Not to Warn? Genetic Information, Families, and Physician Liability" (2004) 8 McGill Journal of Medicine 72 at 76.

<sup>135</sup> Bartha Maria Knoppers *et al.*, "Defining 'Serious' Disorders in Relation to Genetic Services: Who Should Decide?" (1995) 57 (suppl.) American Journal of Human Genetics 296A.

<sup>136</sup> Gold, *supra* note 134 at 76.

<sup>137</sup> Anti-Cancer Society of Victoria, Cancer Genetics Ethics Committee, *Ethics and Familial Cancers: Including Guidelines on Ethical Aspects of Risk Assessment, Genetic Testing and Genetic Registers* (1996) being ch. 2 of Australia, National Health and Medical Research Council, *Clinical Practice Guidelines: Familial Aspects of Cancer: A Guide to Clinical Practice* (1999) 13 at 18, online: National Health and Medical Research Council <[http://www.nhmrc.gov.au/publications/synopses/\\_files/cp67.pdf](http://www.nhmrc.gov.au/publications/synopses/_files/cp67.pdf)> [Victoria Guidelines, 1996].

<sup>138</sup> *Ibid.* at 17–18.

<sup>139</sup> Government of Canada, "Chapter 5: Human Rights Issues Related to Genetic Information and Privacy" in *A Brave New World: Where Biotechnology and Human Rights Intersect* (July 2005) at 5–9, online: Government of Canada <[http://dsp-psd.pwgsc.gc.ca/Collection/Iu199-6-2005E\\_Biotech\\_CH5.pdf](http://dsp-psd.pwgsc.gc.ca/Collection/Iu199-6-2005E_Biotech_CH5.pdf)>.

information could help a genetic relative and/or withholding the information could result in otherwise preventable harm?

Two questions are important in this analysis. The first is whether privacy rights are an appropriate fit in the context of genetic information given its possible qualification as shared, or personal and shared. Privacy protections have emerged to prevent unfair discrimination on the basis of genetic information, particularly in the employment and insurance contexts.<sup>140</sup> However, these protections can be as effectively provided through legislation that addresses the wrongful use of genetic information, rather than through the creation of privacy rights.<sup>141</sup>

The second question is whether individual rights to privacy have a place within the family context. It may be that within families, individual members do not have privacy rights against other members and that families enjoy privacy protection as a unit. Individual privacy protection in Canada does not apply within the family sphere and between family members. The right to privacy has been read into the *Canadian Charter of Rights and Freedoms*<sup>142</sup> but these protections apply to government actors and not between private citizens. They also only arise where there is a reasonable expectation of privacy, which is questionable in the context of genetic information. Individual privacy rights with respect to personal information are created in the federal *Privacy Act*<sup>143</sup> and *Personal Information and Electronic Documents Act*<sup>144</sup>, and in provincial privacy legislation. These regimes protect the individual against privacy infringement by state actors and in some cases, in the context of commercial activities, and do not apply between private citizens or outside of the realm of commerce.

One scholar has argued that relationships within families are not well described using the language of rights. He asserts that rights are part of justice between strangers, that they are wholly procedural, and that they consequently have no place within families.<sup>145</sup> Duties, not rights, govern families.<sup>146</sup> This view of families, rights, and duties marks a move toward recognizing a duty of care between family members by simple virtue of their shared membership in a family. In this view, genetic relatives may not have a right to be informed of their genetic risk (although they may have a right to be informed by a health professional who is a stranger), but a patient nonetheless has a duty to communicate genetic information with them.

It is interesting to note that articulations of privacy in international, national, and regional normative documents include the family sphere as a protected realm of individual privacy.<sup>147</sup> If—in addition to the individual's personal privacy—the individual's private realm of the family is protected from interference by external parties, this arguably weighs against non-consensual disclosure by health professionals since this would be an infringement of the individual's private family sphere. This in turn may implicate more robust intra-familial communication obligations.

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<sup>140</sup> See e.g. *Genetic Information Act*, *supra* note 36.

<sup>141</sup> Skene, *supra* note 27 at 2.

<sup>142</sup> See e.g. *Hunter v. Southam Inc.*, [1984] 2 S.C.R. 145, 11 D.L.R. (4th) 641; *R v. Dyment*, [1988] 2 S.C.R. 417, 55 D.L.R. (4th) 503.

<sup>143</sup> *Privacy Act*, R.S.C. 1985, c. P-21.

<sup>144</sup> *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5.

<sup>145</sup> Weijer, *supra* note 77 at 1466.

<sup>146</sup> *Ibid.*

<sup>147</sup> *Universal Declaration of Human Rights*, GA Res. 217(III), UN GAOR, 3d Sess., Supp. No. 13, UN Doc. A/810 (1948) 71, s. 12; *International Covenant on Civil and Political Rights*, GA Res. 2200A (XXI), UN GAOR, Supp. No. 16, UN Doc. A/6316 (1966) 52, art. 17; OAS, General Assembly, *American Declaration of the Rights and Duties of Man*, OR OEA/Ser.L/V/E.23 Doc.21 (1948) ch. 1, art. 5; *American Convention on Human Rights*, 18 July 1978, O.A.S. T.S. 36, 1144 U.N.T.S. 123 at ch. 2, art 11; *European Convention for the Protection of Human Rights and Fundamental Freedoms*, 3 September 1953, 213 U.N.T.S. 222 at s. 1, art. 8.

## III

## THE FORMS FOR INTRA-FAMILIAL OBLIGATIONS TO COMMUNICATE GENETIC INFORMATION

Up to now, this article has focused on possible foundations for intra-familial obligations to communicate genetic risk. The following section switches gears to address the possible forms that such obligations could take. The first section is an analysis of various national and international policies that articulate a moral obligation in this context. The second section is an analysis of Canadian common law and Quebec civil law rules as they apply to intra-familial communication obligations. It also draws on the legislative approach to intra-familial communication of genetic risk enacted in France.

## A. Intra-familial Communication as a Moral Obligation: An International Comparison

Some international and national policies articulate an obligation on the part of family members to disclose genetic information;<sup>148</sup> however, there are no such articulations made by Canadian policy organizations. These articulations are typically of moral obligations and they draw on the various foundations that are discussed above.

The WHO bases an obligation to communicate genetic information within families on duties to protect family members from harm<sup>149</sup> that lies at the root of the function of families. According to the WHO, kinship bonds and the principle of non-maleficence give rise to an obligation to share genetic information that may extend to distant relatives.<sup>150</sup> An alternative root for the obligation, according to a separate WHO document, is the notion that families “own” genetic information together because it is shared.<sup>151</sup> The WHO also makes some effort to clarify moral obligations regarding genetic information between spouses. There is a moral obligation to disclose genetic information to one’s spouse, even where no children are planned, if the information will affect the spouse’s life.<sup>152</sup> Where DNA has been banked, spouses should not have access to samples, but they may be informed that their spouse’s DNA has been banked.<sup>153</sup> When a couple is planning on having children, it is the moral obligation of the partner who has had DNA banked to disclose relevant information associated with the banking to his or her spouse.<sup>154</sup>

Another international organization that has made a statement in this area, the Human Genome Organisation (HUGO), creates a moral obligation in the context of genetic information, on the basis that “shared biological risks create special interests and moral obligations.”<sup>155</sup>

Several national organizations have policy statements that mention moral obligations within families in the genetic context. France has a fairly well-developed position. The French National Consultative Committee for Health and Life Sciences states that it is “morally condemnable” to withhold information that could avoid or treat illness in relatives.<sup>156</sup> This marks a retreat from an earlier statement where the patient’s interests were recognized as fundamental.<sup>157</sup> The Committee justifies this on grounds that strict observance of the principle of individual autonomy threatens to put the lives of blood relatives in danger.<sup>158</sup> Accordingly, the Committee allows one nuance. It recognizes that the complexities that mar health professionals’ disclosure of *unpreventable* and *untreatable* diseases militate against the creation of a duty to warn relatives in such cases. These complexities

<sup>148</sup> Karen Forrest, “Barriers”, *supra* note 89.

<sup>149</sup> WHO, *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services* (1998) at 5, Table 3, online: <[http://whqlibdoc.who.int/hq/1998/WHO\\_HGN\\_GL\\_ETH\\_98.1.pdf](http://whqlibdoc.who.int/hq/1998/WHO_HGN_GL_ETH_98.1.pdf)>.

<sup>150</sup> *Ibid.*

<sup>151</sup> Wertz, Fletcher & Berg, *supra* note 63 at 51.

<sup>152</sup> *Ibid.* at 54.

<sup>153</sup> WHO, *supra* note 149.

<sup>154</sup> *Ibid.*

<sup>155</sup> Human Genome Organization, *supra* note 60.

<sup>156</sup> *Opinion No. 76*, *supra* note 19 at 6–7.

<sup>157</sup> France, National Consultative Committee for Health and Life Sciences, *Opinion No. 70 Regarding Consent for the benefit of another person* (2001). All Opinions are available in French online: Comité Consultatif National d’Éthique <<http://www.ccne-ethique.fr/avis.php>>.

<sup>158</sup> *Opinion No. 76*, *supra* note 19 at 6–7.

include the many sources of genetic information, the psychological difficulties associated with communication and knowledge of genetic information, the existence of a right not to know, and the fact that health professionals and third parties are mediated by patients. In cases where there is no offer of therapeutic hope, the Committee states that it is unimaginable to impose a communication obligation.<sup>159</sup> Where there is no therapeutic hope, health professionals cannot disclose genetic information because doing so would rupture confidence in the patient-physician relationship and so it is preferable that the information be communicated by the patient.<sup>160</sup>

The United Kingdom (U.K.) has several organizations representing professionals, patient groups, and bioethics committees with statements in this area. The Nuffield Council on Bioethics states that persons “acting responsibly” would normally want to communicate information and receive information about genetic risk,<sup>161</sup> and that “the primary responsibility for communicating genetic information to a family member or other third party lies with the individual and not the doctor.”<sup>162</sup> However, the Council contends that even where relatives have a legitimate interest in knowing genetic information, this should not always supersede patients’ privacy rights.<sup>163</sup> Moreover, the Council stands explicitly against legally enforceable obligations in this context: “We have difficulty in contemplating how any such legal obligation would work and how any legal right of family members (assuming that they could always be identified) could be enforced. In any event, in certain circumstances there may be perfectly good reasons why an individual would not wish to inform family members about the result of a genetic test.”<sup>164</sup>

This approach is supported by the U.K. Genetic Interest Group, a patient organization that encourages patients to “act ethically”. It exhorts patients to communicate genetic information as an ethical imperative, but does not advocate in favour of punishment should a patient fail to do so.<sup>165</sup> Similarly, the British Medical Association commented that “all patients have duties of some sort, which may include voluntarily disclosing information to other people who may be affected.”<sup>166</sup> But the Association adds that consent to sharing information must not be forced.<sup>167</sup>

In Australia, there are two statements about intra-familial obligations to communicate genetic information, made by two organizations. The first is the National Health and Medical Research Council (NHMRC), which recognizes both individual and familial interests: “It is generally accepted that an individual has responsibilities to his/her family as well as a right to the privacy and confidentiality of his/her genetic information.”<sup>168</sup> Although there is no legal duty to warn in family relationships recognized in Australia, the NHMRC states that in deciding whether to disclose genetic information to relatives, patients “will need to balance carefully their own right to privacy with the fact that disclosure could lead to the avoidance of substantial harm for their relatives.”<sup>169</sup> The NHMRC also states that “[u]nlike ... blood relatives ..., [spouses and partners] are not at increased risk of developing the genetic disorder, but they should be informed if their present/future children could develop/inherit the disorder.”<sup>170</sup> In a separate document that deals specifically with hereditary cancer, the NHMRC states that disclosure to spouses may not be as compelling as disclosure to genetic rela-

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<sup>159</sup> *Ibid.* at 5.

<sup>160</sup> *Ibid.* at 5–6.

<sup>161</sup> Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues*, (London: Nuffield Council on Bioethics, 1993) at 49, online: Nuffield Council on Bioethics <[http://www.nuffieldbioethics.org/fileLibrary/pdf/genetic\\_screening.pdf](http://www.nuffieldbioethics.org/fileLibrary/pdf/genetic_screening.pdf)>.

<sup>162</sup> *Ibid.*

<sup>163</sup> *Ibid.*

<sup>164</sup> *Ibid.*

<sup>165</sup> Genetic Interest Group, *Confidentiality Guidelines* (London: Genetic Interest Group, 1998), ss. 2.6–2.7, online: Genetic Interest Group <[http://www.gig.org.uk/docs/gig\\_confidentiality.pdf](http://www.gig.org.uk/docs/gig_confidentiality.pdf)>.

<sup>166</sup> British Medical Association, *Human Genetics: Choice and Responsibility* (Oxford: Oxford University Press, 1998) at 12.

<sup>167</sup> *Ibid.* at 19.

<sup>168</sup> National Health and Medical Research Council, *supra* note 66.

<sup>169</sup> *Ibid.*

<sup>170</sup> *Ibid.* at 49.

tives because it is impossible to disclose to spouses without disclosing the identity of the patient and because there is no immediate risk to the health of spouses.<sup>171</sup>

The second policy document that deals with this issue is the Cancer Council of Victoria, which ties the moral obligation to communicate information about some familial cancers in some families to family history:

It is as members of families that [patients] are at risk, and because of a family history which they share with many others that they may end up having a genetic test. [...] Ethically speaking, [patients] should be prepared to shoulder their share of the burden, and to contribute to the benefits, [...] and this includes [patients] being ready to allow for the possibility of relations being informed of their own potential for genetic risk.<sup>172</sup>

The Council also states that spouses may have an interest in the information, especially when children are planned who may be at risk of inheriting the mutation.<sup>173</sup> More broadly, the Council advocates a shift away from the language of individual rights and toward an emphasis on wider responsibility and communal concerns.<sup>174</sup>

Statements of moral obligation to communicate genetic information within families are made in several other national documents. The German Society of Human Genetics articulates a moral obligation to share knowledge of genetic make-up and to inform partners insofar as it can implicate offspring.<sup>175</sup> According to the Greek National Bioethics Commission, all patients who know about their genetic risk “must [...] assume responsibility for informing any third persons involved”.<sup>176</sup> In the United States, the American Society of Clinical Oncology states that health professionals best fulfill obligations to family members by communicating relevant information to the tested patients themselves, and not to their at-risk family directly.<sup>177</sup> In Denmark, the Danish Council of Ethics states that even in serious cases, the disclosure of genetic information to family is a decision to be made by the patient tested. Genetic information is solely a family affair and the communication initiative must come from the patient.<sup>178</sup> These approaches imply that any obligation that health professionals may have to patients’ family members is passed over to the patient when the health professional communicates risk information to her.

Even where a moral intra-familial obligation is articulated, it is not entirely clear what the effect of such an articulation might be. Such obligations are not enforceable in the same way that professional ethical obligations are, such as by suspension of professional license or through other punishment. Perhaps such articulations aim merely to cause a change in public perceptions of genetic information and of the obligations that flow from it.

## B. Intra-familial Communication as a Legal Obligation

Legal obligations, on the other hand, are enforceable. Although some family members owe each other legal duties of care, particularly parents and children, spouses, and guardians toward dependents, it is unlikely that a legal obligation to communicate genetic information within families can be founded on either Canadian common law or Quebec civil law rules. This section begins with a discussion of a legal regime enacted in France where legislative efforts have specifically targeted intra-familial communication of genetic information. It then moves on to investigate barriers to a finding of liability under Canadian common law and Quebec civil law rules for a failure to communicate ge-

<sup>171</sup> National Health and Medical Research Council, *supra* note 115 at 18.

<sup>172</sup> Anti-Cancer Society of Victoria, Cancer Genetics Ethics Committee, *Ethics and Familial Cancers: Including Guidelines on Ethical Aspects of Risk Assessment, Genetic Testing and Genetic Registers* (March 1997) [Victoria Guidelines, 1997].

<sup>173</sup> Victoria Guidelines, 1996, *supra* note 137 at 18.

<sup>174</sup> Bell & Bennett, *supra* note 2 at 135, citing Victoria Guidelines, 1997, *supra* note 172 at 38.

<sup>175</sup> German Society of Human Genetics, *Position Paper of the German Society of Human Genetics* (1998) at 6, online: [http://www.medgenetik.de/sonderdruck/en/Position\\_paper.pdf](http://www.medgenetik.de/sonderdruck/en/Position_paper.pdf).

<sup>176</sup> Greece, National Bioethics Commission, *Recommendation on the Collection and Use of Genetic Data* (2002), s. B.1(a), online: National Bioethics Commission <[http://www.bioethics.gr/media/pdf/recommendations/recom\\_genetic\\_data\\_eng.pdf](http://www.bioethics.gr/media/pdf/recommendations/recom_genetic_data_eng.pdf)>.

<sup>177</sup> American Society of Clinical Oncology, *supra* note 127 at 2397.

<sup>178</sup> Danish Council of Ethics, *Ethics and Mapping the Human Genome* (Copenhagen: Danish Council of Ethics, 1993).

netic information within the family. There is no statute in Canada that outlines a legal obligation to communicate genetic information within families. Indeed, the Ontario *Report of the Provincial Advisory Committee on New Predictive Genetic Technologies* calls for the creation of legislation dealing specifically with genetic information, but states that such legislation “should not impose a duty to disclose genetic information to high-risk relatives.”<sup>179</sup>

### 1. France’s Legislative Regime

In France, the *Loi relative à la bioéthique 2004* creates a specialized regime for intra-familial communication of genetic information. Relevant text of the regime is extracted here:

En cas de diagnostic d’une anomalie génétique grave posé lors de l’examen des caractéristiques génétiques d’une personne, le médecin informe la personne ou son représentant légal des risques que son silence ferait courir aux membres de sa famille potentiellement concernés dès lors que des mesures de prévention ou de soins peuvent être proposées à ceux-ci. L’information communiquée est résumée dans un document signé et remis par le médecin à la personne concernée, qui atteste de cette remise. Dans ce cas, l’obligation d’information à la charge du médecin réside dans la délivrance de ce document à la personne ou à son représentant légal.

La personne concernée, ou son représentant légal, peut choisir d’informer sa famille par la procédure de l’information médicale à caractère familial. Elle indique alors au médecin le nom et l’adresse des membres de sa famille dont elle dispose en précisant le lien de parenté qui les unit. Ces informations sont transmises par le médecin à l’Agence de la biomédecine qui informe, par l’intermédiaire d’un médecin, lesdits membres de l’existence d’une information médicale à caractère familial susceptible de les concerner et des modalités leur permettant d’y accéder. Les modalités de recueil, de transmission, de conservation et d’accès à ces informations sont précisées par un décret en Conseil d’Etat, pris après avis de la Commission nationale de l’informatique et des libertés.

Le fait pour le patient de ne pas transmettre l’information relative à son anomalie génétique dans les conditions prévues au troisième alinéa ne peut servir de fondement à une action en responsabilité à son encontre.<sup>180</sup>

This regime outlines the responsibilities of both health professionals and patients with regard to genetic information. Health professionals must explain the implications of the information for relatives and provide a letter for patients to pass along to relatives. This absolves the health professional of his or her obligations and transfers these obligations to the patient. The patient may then decide to inform relatives directly, or use an external mechanism set up for the exchange of such information, “l’information médicale à des fins familiales.” The information passes through the patient’s physician, the Agence de la biomédecine, and the relative’s physician before it reaches the relative. These communication requirements only arise when a serious genetic anomaly is found. Finally, the law makes clear that no basis for civil liability can be made out either against a patient or against a health professional for failure to inform potentially affected relatives.

### 2. Negligence in Canadian common law

A finding of civil liability in Canadian common law requires proof of a breach of a duty of care, a compensable injury, and a causal link between the fault and the injury. The following discussion applies the common law rules for each stage of the civil liability analysis to the circumstances where an individual has failed to communicate genetic risk information to a potentially affected relative and that relative has developed a genetic disease, had a child affected with genetic disease, or has died.

*Breach of the duty of care* - With the exception of obligations between spouses and parents and their minor children, there is no special duty of care between family members for reason only of their familial relation. Family duties set out in family law demonstrate the level of care that is expected by the state between family members. They also provide a statutorily mandated duty of care for the purposes of civil liability. In the Ontario *Family Law Act*, for example, the obligations between spouses

<sup>179</sup> Ontario Provincial Advisory Committee on New Predictive Genetic Technologies, *supra* note 68 at 75 (recommendation 26(a)).

<sup>180</sup> *Loi n° 2004-800 du 6 août 2004 relative à la bioéthique*, J.O., 7 June 2004, 14040, art. L.1131-1. It is worth noting that the unique regime outlined in the *Loi relative à la bioéthique* has not been put into use as of the time of writing. The Conseil d’État must first prepare an implementation decree. See Claudine Bergoignan Esper, “En génétique, quelques propos sur l’information médicale à caractère familial” (2007) 84 *Médecine & droit* 80 at 80.

and parents and children are limited to financial support obligations<sup>181</sup> and as such are unlikely to give rise to a duty to communicate genetic information.

Duties of care between family members in this context will therefore rely on common law rules, where they are established using the neighbour principle: a duty of care extends to “persons who are so closely and directly affected by my actions that I ought reasonably to have them in contemplation as being so affected when I am directing my mind to the acts or omissions which are called in question.”<sup>182</sup> The requirements for this test are proximity (is there a sufficiently close relationship between me and the category of people to which the person affected belongs?) and reasonable foreseeability (is it reasonably foreseeable that this category of people will be affected by my actions or omissions?). An updated formulation of the test has been adopted in Canada, as follows: (1) whether the circumstances disclose a reasonable and foreseeable harm and proximity sufficient to establish a *prima facie* duty of care—proximity factors arising from the relationship between the parties—and (2) whether there exist residual policy considerations which justify denying liability.<sup>183</sup>

Between relatives who share a genetic code, or family members who share a close relationship, there would appear to be, *de facto*, sufficient proximity between the parties for a duty of care to arise. Not only are genetic relatives close in relationship by virtue of their shared biology, it is also reasonably foreseeable that genetic relatives would be affected by a failure to inform them of the presence of a genetic risk within the family. Exceptions to this occur where the existence of genetic relatives, or the importance of the information for them, is unknown. The latter exception is likely to be rare, as guidelines for genetics professionals increasingly advise discussing the importance of genetic information for potentially affected relatives with patients.<sup>184</sup>

Problems may arise however at the second stage of the analysis: whether there are policy reasons to negate the duty of care. In *Winnipeg v. G.*<sup>185</sup> and *Dobson v. Dobson*,<sup>186</sup> two cases involving the obligations of pregnant women toward their unborn children, the Supreme Court of Canada supported the following, *inter alia*, as legitimate policy reasons to negate the duty of care: difficulty of drawing a line between appropriate and inappropriate behavior;<sup>187</sup> concerns about restricting the autonomy and privacy of pregnant women;<sup>188</sup> and concern over family disharmony resulting from prenatal causes of action.<sup>189</sup> Concerns over the potential negative effects on family relationships in the context of communication of genetic information are common.<sup>190</sup> Similarly, difficulty drawing the line between appropriate and inappropriate behaviour is challenging where the family context and relationships play a significant role in the communication of genetic information. Finally, concern over the autonomy and privacy rights of individuals is also likely to be a relevant policy concern in the eyes of common law courts.

In Canadian common law, there is an increased duty of care on the part of parents with respect to their minor children since parents have fiduciary obligations to act in their children’s best interests.<sup>191</sup> However, there is no consensus on whether children should be made aware of their genetic risk or undergo genetic testing for adult onset conditions. Moreover, parents acting as fiduciaries with respect to their children’s interests are given discretion to decide what is in their children’s best interests, particularly when the “right” course of action is less than clear.<sup>192</sup> Where there is no clear consensus on the

<sup>181</sup> *Family Law Act*, *supra* note 14, ss. 30–32.

<sup>182</sup> *Donoghue v. Stevenson*, [1932] A.C. 562 at 580.

<sup>183</sup> *Cooper v. Hobart*, [2001] 3 S.C.R. 537.

<sup>184</sup> American Society of Clinical Oncology, *supra* note 127; Human Genetics Society of Australasia, *supra* note 127; Laura E. Forrest *et al.*, “Communicating”, *supra* note 75; Knoppers, *supra* note 3; Offit, *supra* note 128.

<sup>185</sup> *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)*, [1997] 3 S.C.R. 925, 152 D.L.R. (4th) 193 [*Winnipeg*].

<sup>186</sup> *Dobson (Litigation Guardian of) v. Dobson*, [1999] 2 S.C.R. 753, 174 D.L.R. (4th) 1 [*Dobson*].

<sup>187</sup> *Winnipeg*, *supra* note 185.

<sup>188</sup> *Ibid.*; *Dobson*, *supra* note 186.

<sup>189</sup> *Dobson*, *ibid.*

<sup>190</sup> Gilbar, *supra* note 11.

<sup>191</sup> *M.(K.) v. M.(H.)* [1992] 3 S.C.R. 6, 98 D.L.R. (4th) 289.

<sup>192</sup> *Ibid.*

merits of communicating genetic information with children and on genetic testing for adult-onset conditions in children, it is unlikely that a breach of this duty would be found.

*Injury* - Injury in a case of a failure to communicate genetic information could be the onset of a disease associated with surveillance and prevention measures, such as hereditary non-polyposis colorectal cancer (HNPCC) or breast cancer, the onset of a non-preventable disease, such as Huntington's disease, death associated with one of these diseases, or the birth of a child affected by a genetic mutation or genetic disease. The injury could also be associated with the lost chance to plan one's life with knowledge of the future onset of a debilitating disease.

There are issues in Canadian common law with claims for an injury associated with the birth of a child. Such injuries are known as wrongful birth (a claim by parents against a physician for failure to inform parents that their unborn fetus was affected by disease or disability, where the parents would have aborted or avoided conceiving had they known this information), wrongful life (a claim by a diseased or disabled child against a physician or hospital for having been born affected by disease or disability), and wrongful pregnancy (a claim by parents against a physician or hospital, typically for a failed sterilization procedure that led to the birth of a healthy child).

Wrongful birth has been recognized by Canadian courts,<sup>193</sup> notwithstanding the fact that these cases may be problematic as creating a duty on the part of physicians to advise women to abort their unborn children and as devaluing disabled children's lives.<sup>194</sup> With the advent of reproductive technologies such as pre-implantation genetic diagnosis—which can enable individuals who are aware of their risk of having a child affected by genetic disease to prevent such a birth—the difficult issue of abortion may not be raised in a claim for wrongful birth. Rather, the issue may become the lost chance to undergo preventive reproductive procedures where, had parents been aware of their genetic risk; they would have undergone such procedures prior to conception. These cases may create an entirely new category of claims: wrongful conception. This unprecedented type of claim may share characteristics with claims for wrongful birth and for wrongful pregnancy. However, such cases would not avoid the problem of seeing courts handing down rulings that ascribed less value to the lives of children affected with genetic disease than to those of children born free of them.

Claims for wrongful life have been divided into two categories, one of which has been recognized by Canadian courts. Courts have recognized claims for wrongful life where a child was born with abnormalities that were caused by a physician's wrongful act or omission, but denied claims where "but for" the wrongful act of a physician, the child would not have been born at all.<sup>195</sup> Cases involving serious hereditary disease are likely to fall into the second category as the injury in such cases is caused by the existence of a genetic mutation and not by a wrongful act or omission.<sup>196</sup> Where a physician fails to inform the mother or parents of the possibility of having a child affected with genetic disease, he or she causes or allows the child to be conceived or born where parents would otherwise have avoided pregnancy or sought an abortion.

Wrongful pregnancy has been rejected by one court in Ontario<sup>197</sup> as well as in the U.K.<sup>198</sup> on the ground that courts cannot deem the birth of a healthy child to have constituted an injury to the child's parents. Here again, a claim for wrongful conception may arise where a couple claims that they would have taken precautions to avoid pregnancy had they been aware of the risk of having an affected child. In sum, wrongful birth, wrongful life, and wrongful pregnancy claims are problematic at the level of injury assessment in Canadian common law. Other injury claims become problematic at the level of causation.

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<sup>193</sup> *Arndt v. Smith*, [1997] 2 S.C.R. 539, 148 D.L.R. (4th) 48.

<sup>194</sup> These were the reasons given for a rejection of such a claim in the U.K. case of *McKay v. Essex Area Health Authority*, [1982] Q.B. 1166.

<sup>195</sup> *Lacroix (Guardian of) v. Dominique* (2001), 202 D.L.R. (4th) 121; but see *Bovingdon v. Hergott* (2008), 88 O.R. (3d) 641, 290 D.L.R. (4th) 126 [*Bovingdon*] where the division of claims for wrongful life into two categories was rejected as unhelpful and the claim was decided on a civil liability analysis.

<sup>196</sup> *Bovingdon*, *ibid.*

<sup>197</sup> *Kealey v. Berezowski* (1996), 30 O.R. (3rd) 37, 136 D.L.R. (4th) 708.

<sup>198</sup> *McFarlane v. Tayside Health Board*, [1999] 3 W.L.R. 1301.

*Causation* - In common law, causation is established where, on a balance of probabilities, there is a direct and foreseeable link between the fault and the injury.<sup>199</sup> The test for directness is commonly articulated as the “but for” test that asks: but for the fault, would the injury have happened? The common law also sometimes asks whether the damage was a reasonably foreseeable consequence of the faulty act. Ultimately, causation can be determined based on a common sense evaluation of the facts of a case.<sup>200</sup>

Establishing causation between the failure to inform genetic relatives of the presence of a genetic mutation in the family and injuries such as the development of a genetic disease, death from genetic disease, or the birth of a child affected by genetic disease, is a formidable challenge. Here, the failure to communicate is not the *cause* of the injury. The injury is caused by the genetic mutation that an individual either has or does not have from the moment of conception. This is distinguishable from cases involving a duty to warn one’s sexual partner of infection with a sexually transmitted disease where the infected partner is, in a sense, an agent of the disease. In such cases, the infected person creates the risk, whereas in genetics cases the risk is already present (or absent).<sup>201</sup>

The loss of a chance to prevent the onset of genetic disease or the birth of an affected child may be one route around causation problems. In such cases, the court must determine what might have happened had there been no failure to communicate genetic information. In cases involving a disease that has 100% penetrance and whose onset cannot be prevented, such as Huntington’s disease, the disease will manifest regardless of prior knowledge of genetic risk. There is therefore no loss of chance to prevent disease onset in the Huntington’s context, although there might be a claim for a loss of chance to plan one’s life according to the knowledge of imminent disease onset. In cases involving complex genetic conditions such as HNPCC or breast cancer, there is often a chance that undertaking prevention and surveillance measures could prevent disease onset. In the U.K., a court has rejected causation based on loss of chance where it could not be proven that with proper treatment the chance of avoiding injury was greater than 50%.<sup>202</sup> Thus, there must be more than a 50% chance that the injury would not have occurred if communication of genetic risk had taken place.

### 3. *Liability in Quebec civil law*

In Quebec civil law, fault, injury, and causation are the required elements for a finding of civil liability. Statutory care obligations such as those found in the Civil Code of Quebec (CCQ) go to the determination of fault, which is where this analysis begins.

*Fault* - In the civil law, there is no test for the duty of care. According to 1457 CCQ, a duty of care is owed to everyone. Fault is the violation of the duty to not cause injury to another. The standard is whether a reasonably prudent and diligent person in the same circumstances would have committed the act. Because the standard is that of the reasonable person, it is a socially determined norm and it can change over time.<sup>203</sup> As we have argued elsewhere, intra-familial communication of genetic information is a highly complex and context-based process. Often, decisions not to communicate are based on careful deliberations about what is in the best interests of family members and of the family as a whole.<sup>204</sup> Moreover, as discussed above, the few laws and policies that do discuss the process of communication or that encourage intra-familial communication explicitly preclude the imposition of civil liability for a failure to communicate genetic information within the family. For these reasons, making out a fault for non-communication based on a reasonable person standard would be a challenge as social norms would be unlikely to find this a fault.

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<sup>199</sup> *Barnett v. Chelsea & Kensington Hospital*, [1968] 1 All E.R. 1068.

<sup>200</sup> *Snell v. Farrell*, [1990] 2 S.C.R. 311, 72 D.L.R. (4th) 289.

<sup>201</sup> Clayton, *supra* note 8 at 377.

<sup>202</sup> *Gregg v. Scott*, [2005] 2 A.C. 176 (H.L.).

<sup>203</sup> Jean-Louis Baudouin & Patrice Deslauriers, *La Responsabilité Civile: Principes généraux*, 7th ed. (Cowansville, Québec: Yvon Blais, 2007) at 153.

<sup>204</sup> Nycum, Knoppers & Avard, *supra* note 4.

It is important to consider whether the breach of statutory obligations between family members may constitute a fault. As compared to the Ontario *Family Law Act*, the CCQ creates a broader spectrum of obligations. In Quebec, spouses “owe each other respect, succor, fidelity and assistance.”<sup>205</sup> These terms are not defined and case law does not clarify them, but it is arguable that they create broader obligations than mere financial support.<sup>206</sup> One could argue that the obligations of respect, succor, and assistance include the obligation to ensure that one’s spouse is fully informed of one’s genetic status, of the potential impact of that status on health and care needs, and of the potential impact on prospective or born children of the union. Moreover, “spouses together take in hand the moral and material direction of the family, exercise parental authority and assume the tasks resulting therefrom.”<sup>207</sup> It could be argued that spouses cannot take on these tasks together when one spouse is aware of genetic risk information while the other is not.

As for obligations between parents and children, in Quebec “every child, regardless of age, owes respect to his father and mother.”<sup>208</sup> Might this obligation of respect also form the basis of an argument in favour of an obligation to inform parents of genetic risk? Children also possess certain rights, beyond the right to alimentary support, from their parents or guardians. Children have the “right to the protection, security and attention that his parents or the persons acting in their stead are able to give to him.”<sup>209</sup> Moreover, “[e]very decision concerning a child shall be taken in light of the child’s interests and the respect of his rights. Consideration is given, in addition to the moral, intellectual, emotional, and physical needs of the child, to the child’s age, health, personality, and family environment, and to the other aspects of his situation.”<sup>210</sup> A similar right for children is created in the *Quebec Charter of Human Rights and Freedoms (Quebec Charter)*, where it states that “[e]very child has a right to the protection, security and attention that his parents or the persons acting in their stead are capable of providing.”<sup>211</sup> These broad rights may create a duty on the part of parents and guardians to communicate genetic information with their children. However, the list of considerations that must be taken into account in coming to such a decision to communicate could act to justify a decision not to communicate, in the child’s best interests.

Another relevant statutory duty that would apply to a larger group of genetic relatives is found in the *Quebec Charter*. Section 2(2) creates a duty to rescue: “Every person must come to the aid of anyone whose life is in peril, either personally or calling for aid, by giving him the necessary and immediate physical assistance, unless it involves danger to himself or a third person, or he has another valid reason.”<sup>212</sup> This duty to rescue may create a positive duty to communicate serious genetic risk with those who may be potentially affected, regardless of their degree of relation. In the present context, it may be that concern for other family members or family harmony could be valid justifications for a decision not to communicate under this article of the *Quebec Charter*.

*Injury* - The assessment of injury in the civil law is similar to the determination in the common law, as discussed above. In civil law, injuries may be “bodily, moral or material”<sup>213</sup> and as such they could include loss of income, cost of care, pain and suffering, and loss of ability. All of these are associated with the development of a genetic disease, with death from genetic disease, or with the birth of a child affected with genetic disease or having a genetic mutation. Loss of chance to prevent these injuries may also be considered an injury in the civil law.

In the civil law, the wrongful birth of a healthy child has been compensated.<sup>214</sup> The Quebec Court of Appeal found that, in Quebec, public policy is not opposed to the birth of a healthy child constitut-

<sup>205</sup> Art. 392 C.C.Q.

<sup>206</sup> See e.g. Alain Roy, “Le contrat en contexte d’intimité” (2001-2002) 47 McGill L.J. 855 at 879 where the author argues that the obligation of fidelity is included in this article.

<sup>207</sup> Art. 394 C.C.Q.

<sup>208</sup> Art. 597 C.C.Q.

<sup>209</sup> Art. 32 C.C.Q.

<sup>210</sup> Art. 33 C.C.Q.

<sup>211</sup> *Charter of Human Rights and Freedoms*, R.S.Q. c. C-12 at s. 39.

<sup>212</sup> *Ibid.* at s. 2(2).

<sup>213</sup> Art. 1457 C.C.Q.

<sup>214</sup> *Cooke v. Suite*, [1995] R.J.Q. 2765.

ing an injury, that the right to plan family size is an important one, and that the benefits associated with the birth of a healthy child do not annul the damage suffered in losing the right to plan family size.<sup>215</sup> Moreover, a Quebec court has also recognized a claim for wrongful pregnancy and the wrongful birth of a child affected with a heritable condition in a case involving a failed sterilization procedure.<sup>216</sup> A claim for the wrongful birth of a child affected with genetic disease or a genetic mutation may therefore be easier to make out in the context of non-communication of genetic information.

Loss of chance goes to causation in the common law but in civil law it is also a consideration at the level of injury. The Supreme Court of Canada has compensated a victim for the trauma of knowledge that a chance was lost but not for the injury whose prevention the lost chance was claimed for.<sup>217</sup> In this case, the Court ruled that the lost chance was itself the injury, but did not go to the larger injury, death from cancer. If, on a causation analysis, it cannot be proven on a balance of probabilities that the lost chance caused an injury such as the onset of disease or death, in Quebec, the loss of chance to prevent the larger injury may itself be considered an injury.

*Causation* - In Quebec, causation is established if it can be shown on a balance of probabilities that the injury is a direct and immediate consequence of the faulty act.<sup>218</sup> Although several approaches to determining causation have been used by Quebec courts, the most common is adequate causation—an approach that separates the true cause from conditions that allowed the injury to take place.<sup>219</sup> It is an objective test that asks what cause truly led to the injury.<sup>220</sup> The civil law also attaches importance in the determination of causation to reasonable foreseeability that the injury would result from the faulty act, and to breaks in the chain of causation.<sup>221</sup>

The challenges to a finding of causation that arise in the common law of negligence are at issue in the civil law causation analysis as well. Given that genetic mutations are present from birth, establishing a causal link between the failure to communicate genetic information and the development of genetic disease is challenging. It may be reasonably foreseeable that not communicating genetic information could lead to the development of genetic disease that is preventable. However, the lack of such communication is not an adequate cause of the development of genetic disease. The adequate cause is rather the presence of a genetic mutation.

#### CONCLUSION

This article has discussed some of the many possible foundations for finding an intra-familial obligation to communicate genetic information. In defining the genetic family for the purposes of determining to whom a communication obligation may be owed, a biosocial approach that gives wide berth both to recognized interests and to social relationships will subsume biological and social relationships within the definition of family. However, it will also allow the exclusion of those family members with whom there is no relationship whatsoever. When defining and characterizing genetic information, it is important to consider whether family history information should be included in the category. It is also meaningful to ask whether such information should be treated like other medical information or whether it warrants a unique and distinct category.

Communication obligations could arise by virtue of the special obligations that go along with membership in a family. Those perforce will vary in accordance with perceptions of who is a genetic family member. Notions of individual autonomy may work to preclude communication obligations, whereas relational autonomy may facilitate recognition of communication obligations by acknowledging that decision-making takes place in the context of relationships. Theories of ownership and control that recognize genetic information as shared between family members can affect perceived

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<sup>215</sup> *Ibid.*

<sup>216</sup> *Engstrom v. Courteau*, [1986] R.J.Q. 3048.

<sup>217</sup> *Laferrrière v. Lawson*, [1989] R.J.Q. 27.

<sup>218</sup> Art. 1607 C.C.Q.

<sup>219</sup> Baudouin & Deslauriers, *supra* note 203203 at 629.

<sup>220</sup> *Ibid.*

<sup>221</sup> *Ibid.* at 625.

communication obligations and facilitate communication. When it comes to the limits of health care provider obligations, it may be that there are stronger obligations between family members than between health professionals and the relatives of their patients since there is no duty of confidentiality between family members mitigating communication obligations. Finally, although individual privacy rights are well protected in Canada, it is arguable that these rights do not reach inside families to protect the private information of one family member from other members.

Although it has been argued here that a legal obligation to communicate genetic information within families would be difficult to make out under Canadian common law and Quebec civil law rules, there are nonetheless several international and national normative documents that articulate an intra-familial obligation to communicate genetic information. These articulations could provide support for a court of law looking to find a legal obligation in this context. It is therefore important for policy makers to address this issue and provide sound guidance on whether there is or is not a legal obligation to communicate genetic information within families. Legislation that creates a legal obligation is ill-advised as it would likely cause difficulties for families given the context specificity of decision-making around intra-familial communication. Moreover, to the best of our knowledge, no other nation in the world has created a legislative regime that would impose this kind of obligation. In fact, the one nation that we know has taken up intra-familial communication of genetic information in a legislative regime, France, explicitly precludes the imposition of liability for a failure to communicate but provides a mechanism that facilitates such communication. Rather, such a regime should acknowledge perceived obligations and provide mechanisms for individuals and families to meet these obligations in a manner and setting that are appropriate for each family context.