

Organ Transplantation Privacy Rights

Authored on behalf of **Ontario East Transplant Support Group**

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Introduction

This memorandum explores the area of law concerning the privacy rights of organ donors and recipients should they or their families wish to contact one another. The primary issues this memorandum focuses on include:

1. What is the relevant Ontario legislation regarding organ transplant privacy?
2. What is the customary practice of transplant organizations in Ontario regarding the privacy of organ donors and recipients?
3. What is the legislation and customary practice in other provinces?
4. What is the legislation and customary practice in other countries?

What is the relevant Ontario legislation regarding organ transplants?

All personal health information received by a health facility is considered property of the Ministry of Health and Long-Term Care and is treated in accordance with the *Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, Chapter F. 31, and the *Personal Health Information Protection Act*, S.O. 2004.

The Trillium Gift of Life Network Act, R.S.O. 1990, c. H.20[*The Act*], as modified by the *Human Tissue Gift Amendment Act (Trillium Gift of Life Network)*, 2000, is the most relevant legislation in Ontario regarding tissue transplants. *The Act* sets limitations on the extent to which health information in relation to tissue donations or transplants can be accessed. First of all, section 8.2(3) of *The Act* ensures that all designated health facilities dealing with activities related to tissue donations or transplants are subject to a confidentiality agreement to ensure that personal health information is only collected, used or disclosed in accordance with *The Act*. The subsections within section 8.19 outline a number of restrictions in this regard. Only the Minister of Health and Long-Term Care or other member of the Executive Council [the Minister], General Manager and the Trillium Gift of Life Network [the Network] may directly or indirectly collect personal information about individuals in relation to tissue donations or transplants. Accordingly, individuals who have donated or received tissues are prevented from accessing records of their respective receiver or donor without going through the Minister, General Manager or the Network.

With respect to disclosure of personal information maintained in health facilities, a designated facility shall only disclose health information to the above referenced individuals when it is necessary for a purpose related to tissue donations or transplants. If the person making the disclosure is of the opinion that disclosure is not necessary for a purpose related to tissue donations or transplants, the request for disclosure is denied. When the request is considered necessary and appropriate,

The Act only permits disclosure to a designated facility, an employee of the Ministry, a physician or a person or class of persons prescribed by the Minister.

However, this does not entirely preclude individuals from receiving information about their respective tissue donor or receiver. Sections 8.20 and 8.21 of *The Act* outline the process of contact and information disclosure between people other than the Network, Minister or General Manager. Individuals may enter into agreements with the Network, Minister or General Manager to collect, use or disclose personal information regarding the tissue donation or transplant. However, the agreements to disclose information are limited by certain mechanisms established to maintain privacy in accordance with the *Freedom of Information and Protection of Privacy Act* and the *Personal Health Information Protection Act*. Names and identifying information are removed so that privacy of involved individuals remains protected. Furthermore, section 29(a) of the *Personal Health Information Protection Act* requires that the individual about whom the information relates provides consent for the release of the personal information, regardless of the fact that identifying information will be removed prior to disclosure. As specified in section 18(1) of the *Personal Health Information Protection Act*, the consent must be knowledgeable, relate to the information, and not be obtained through deception or coercion. For consent to be knowledgeable, the individual must be aware of the purpose for the disclosure.

To summarize, while individuals cannot directly access information about a tissue donor or receiver, they may access non-identifying information through an agreement with the Minister, General Manager or the Network. The information will only be disclosed if the individual about whom the information relates provides explicit consent.

What is the customary practice of the Trillium Gift of Life Network in Ontario?

Donation is a confidential and anonymous process. Following a transplant, the Trillium Gift of Life Network contacts the donor to thank them and inform them of the outcome. The Network may facilitate anonymous correspondence between donor and recipient. The Network is prohibited from providing any information to a recipient or donor that would identify any individual involved, so correspondence is screened with any identifying information removed. General information such as the gender and life stage (i.e., child, adult) of the implicated individuals may be shared. The Network does not permit meetings between implicated individuals, even if both parties request and consent to the meeting.

What is the legislation and customary practice in other provinces?

Each province has enacted its own legislation for purposes of regulating organ and tissue transplantation. There appears to be little variation from province-

to-province in confidentiality regulations relating to this process. Additionally, the organizations responsible for facilitating donations have nearly identical practices for enabling communication between involved parties. This is not surprising as organ donation is an interprovincial activity requiring some uniformity of practice.

In British Columbia, the relevant legislation regarding tissue organ donation is the *Human Tissue Gift Act*, [RSBC 1996] c. 211, s. 12(1) states that except if legally required, a person must not disclose or give to any other person any information or document by which the identity of any person (a) who has given or refused to give consent, (b) with respect to whom a consent has been given, or (c) into whose body tissue had been given, is being, or may be transplanted, may become known publicly.

BC Transplant is responsible for facilitating all contact between donor family and recipients in the province. Either the donor family or the recipient may initiate this communication. Sample letters can be found on their website. An anonymous letter is first written by one of the parties and then sent to BC Transplant. They then edit out any remaining identifying features and then forward the letters along to the intended receiver. Copies of these letters are always retained.

In Alberta, the relevant legislation regarding tissue organ donation is the *Human Tissue and Organ Donation Act*, S.A. 2006, c. H-14.5. Identity of donors and recipients is strictly restricted under section 12(2). The Human Organ Procurement and Exchange (HOPE Program) is responsible for facilitating all contact between donor family and recipients. Their procedures are similar to BC Transplant's in that they allow either party to initiate communication and edit the letters as needed before mailing them to the intended receiver. Under no circumstance will they allow the parties to directly contact each other.

Although Saskatchewan has enacted legislation for organ transplantation under the *Human Tissue Gift Act*, R.S.S. 1978, c. H-15, the topic of confidentiality for these procedures appears to fall under the *Health Information Protection Act*, S.S. 1999, c. H-0.021. The program responsible for facilitating communication between parties is the Saskatchewan Transplant Program. Their procedures for this do not appear to differ in any substantial way from those of the HOPE Program.

In Manitoba, organ donation is a confidential act governed by the *Human Tissue Gift Act*, C.C.S.M. c. H180. After a donation has occurred, the family is contacted by telephone and informed which organs were recovered. They will also receive from the Donor Coordinator a letter giving general information about the recipient(s) of the organs. The Manitoba Transplant Program facilitates communication between involved parties. Their procedures also appear not to differ from those of the HOPE Program.

In Nova Scotia, the governing legislation on organ donation is the *Human Tissue Gift Act*, R.S.N.S. 1989, c. 215. Section 12 of the *Act* states that no information can be released in regard to who has consented to donation or transplantation.

There is no provision for the release of information with consent. However, donors can contact one another anonymously through the Nova Scotia Provincial Organ and Tissue Donation Program. The donor coordinators remove all indentifying information prior to providing the correspondence to the other party.

The Nova Scotia Provincial Organ and Tissue Donation Program has sought legal advice regarding changing the legislation and developing a way for the parties to meet if they choose to. This would be developed through a Donor Family Support Working Group, however, it is at the early stages and may not proceed forward.

Prince Edward Island has made specific provisions for the release of information regarding the donor, whether deceased or living, and the recipient in section 13(2) of the *Human Tissue Donation Act*, R.S.P.E.I. 1988, c. H-12.1. The provision states that upon consent of the individual, or their family if the individual is deceased, information relating to that individual may be released. However, organ donation in PEI is coordinated through the province of Nova Scotia. Therefore, any contact between parties is carried out in the same manner as that in Nova Scotia.

Newfoundland and Labrador has similar legislation to Nova Scotia. Section 19 of the *Human Tissue Act*, S.N.L. 1999, c. H-15 also provides that no information can be released in regards to organ donations or transplants. However, the Organ Procurement and Exchange of Newfoundland and Labrador does encourage anonymous correspondence between the parties through their organization. Like Nova Scotia, they review the letter or card to ensure it is proper and anonymous prior to forwarding it on to the intended recipient.

The *Human Tissue Gift Act*, S.N.B. 2004, c. H-12.5 governs organ donation in New Brunswick but does not contain a clause regarding the release of donor or recipient information specifically. Issues dealing with the release of information from a public body, including Regional Health Authorities, appear to be governed by the *Protection of Personal Information Act*, S.N.B. 1998, c. P-19.1.

The New Brunswick Organ/Tissue Procurement Program facilitates and encourages anonymous contact between parties by acting as a go between and they encourage recipients to send letters of thanks through their organization. The program omits any indentifying information and sends the card on to the donor family or donor recipient.

To date, there has been little success in establishing contact with Quebec, but given our findings across the country, it is expected that Quebec's system would not differ significantly from any of the other provinces.

What is the legislation and customary practice in other countries?

Looking at other English-speaking, common law countries, there is a very similar trend among them. The United States, United Kingdom and Australia do not have legislation explicitly barring organ donors and their families from contacting the recipients or vice versa. Just like Ontario, there is a customary practice among hospitals and organ transplant groups to allow for some limited contact between both parties. Unlike Ontario, the international organizations do allow both sides to meet face-to-face if they wish to.

United States

In the United States, there is no federal legislation directly dealing with the specific issue of donors and recipients contacting one another. However, two pieces of legislation indirectly deal with this issue. The first is the *Health Insurance Portability and Accountability Act of 1996*, 45 C.F.R. §§ 160-164 (HIPAA). The HIPAA is an Act created by the U.S. to improve the health care insurance system in their country. Of particular relevance to this memo is section 164 of the HIPAA, which created the “Privacy Rule” in 2003. The Privacy Rule was created in part to protect the privacy of individually identifiable health information. The Rule applies to health plans, health care providers and health care clearinghouses and limits the disclosure of information any of these organizations can provide to only the most essential information. Any information that identifies the individual or provides a reasonable basis to identify the individual may not be disclosed. This includes the patient’s name, address, birth date and Social Security Number. In general, all of this means that information about organ donation and transplantation would generally be off-limits unless the donor or recipient chose to waive their rights under the HIPAA.

Even before the HIPAA and Privacy Rule came into effect, it was the customary hospital policy to avoid direct disclosure of donor/recipient information to the other party. This has been due to an underlying concern that parties may have unrealistic expectations of the other party, which may lead to hurt feelings or a fear that one party may attempt to establish contact beyond the other’s comfort zone. Instead, similar to the Trillium network in Ontario, the general practice of transplant organizations is to provide some basic, non-personally identifying information to the donor family and to the recipient (commonly including hometown or home state, gender, age, and either the need for the transplant or the cause of death of the donor). If either party wants to send a letter or card to the other, the organization will pass it along but will remove any personally identifiable information.

In addition, there is the second piece of legislation that specifically binds organ transplant groups: the *Federal Privacy Act*, 5 USC § 552a (FPA). This Act only applies to federal agencies, and concerning organ transplants it applies to the United Network for Organ Sharing (UNOS), so it does not bind individual hospitals, although the latter is still covered by the HIPAA. UNOS has a federal contract to operate the national transplant network and has detailed records on every donor, recipient and candidate in the U.S. since 1987. However, the FPA says they cannot disclose any personally identifiable information publicly without a release from the people directly involved, a court order, a request from the member organization

where the records originated, and/or a specific request from the government agency with whom they contract.

Both pieces of legislation raise barriers for organ donors trying to contact recipients, but neither one bars it. Currently, most organizations tend to continue with the customary practice of letting parties reach each other through anonymous letters, but in addition most organizations will allow (or often facilitate) an initial phone call or meeting between the parties if both independently state the wish to do so. That is often the result of a process involving several previous letters or other contacts. Usually after that first direct contact, the organization would let the people involved decide if they want to have further visits or calls on their own. The general goal is to try to ensure that when disclosure occurs it is usually in a way that allows the people involved to be emotionally prepared. The organizations are aware that the two parties may meet through accident or by doing research and it is not illegal to do so, but it is discouraged, because it goes against this general goal.

United Kingdom

The United Kingdom's system has much less legislation than that of the United States regarding privacy. The *Human Tissue Act 2004*, the U.K. legislation regarding organ donation, does not state anything about privacy. Rather, the U.K.'s customary practice is very similar to that of the United States and Ontario. Like most other organ donation systems, theirs is based on the principle of anonymity. In addition, the U.K.'s National Health System (NHS) has a strong principle of patient confidentiality that the Organ Donation and Transplantation Directorate works to uphold. The Directorate has a donor transplant coordinator (DTC) that works with the family of the donor and a recipient transplant coordinator (RTC) that works with the patient and their family. The DTC and RTC will work with one another, but neither the donor's family nor the recipient meet one another. The donor families will receive limited information as to where the donor's organs went, but personal details are not disclosed.

It is also suggested that donor families might like to write to the recipients and transplant recipients are asked if they would like to do the same for the donor and their family. These letters or cards must be made anonymous so that no personal information is passed on. They always go through the transplant coordinators and they are checked to ensure information remains private. Over time, should relationships grow between these individuals, they may arrange to meet one another. There are rare cases when the donor's family and recipient meet outside of the organization without any involvement from organ transplant organizations. Just like in the United State, whether it occurred by random chance or through research, there is nothing wrong or illegal about doing so, but it is not a preferred method by the organizations.

Australia

The most noticeable difference between the Australian and UK systems is that unlike the UK, which has a national system, Australia is similar to the Canadian model where each state has its own organization. The largest organization, LifeGift – which handles organ donation in Australia’s two most populous states among other territories – has a very explicit policy that is very similar to the UK. In New South Wales and Victoria, there are donor coordinators who give the donor’s family information regarding which organs and tissues were transplanted, but not who the recipient is. Transplantation agencies do allow recipients and donor families to write letters to one another via the organization with identifying information removed by the coordinators.

In addition, personal information about donors in Australia is stored on the Australian Organ Donor Register. The information on the register may only be accessed by authorized personnel approved by a committee formed from representatives from Medicare Australia, the Department of Health and Ageing and state organ donation agencies.

Conclusion

The findings of this memorandum indicate that there is a near-universal standard of practice for how organizations handle with the privacy rights of donors, recipients and their families. There does not appear to be any legislation explicitly allowing or disallowing one party from contacting the other. However, it is generally agreed that both sides should make initial contact through their province’s organ transplant organization in order to ensure all parties are able to schedule meetings within their comfort zone.

In addition, there has been no indication that there are signs that this form of contact will be reformed in Ontario in the future, similar to recent adoption reform. The only controversy over organ donation in Ontario in the last few years has been about whether there should be presumed consent. It appears that most, if not all, parties in the industry are satisfied with the current arrangement. However as mentioned previously, there is a reform movement in its infancy in Nova Scotia. They are looking into whether their province should have a system similar to that of the US and UK, where both parties would be able to meet face-to-face if they agreed to it.

Although there is no prohibition on contact, people will want to be cautious because people are entitled to their personal space and privacy. If individuals do not wish to be contacted it could potentially lead to action on the part of the individual to make the conduct cease. As a result, the person making the conduct may find themselves in a situation they would have wanted to avoid.