

## Clinical Process Instruction Manual

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### Donor Information Inquiry – Disclosure Policy and Process

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#### Policy:

Ontario Health (Trillium Gift of Life Network [TGLN]) is permitted to only disclose personal information [PI], including personal health information [PHI], it collects for the purposes of supporting organ and tissue donation and transplantation. Additionally, Ontario Health (TGLN) is limited to disclosing PI to only those individuals or entities as set out in the *Gift of Life Act*, such as designated facilities and physicians or as otherwise permitted by the *Act* (e.g., under data-sharing agreements for purposes relating to organ donation and transplantation). The privacy provisions of the *Gift of Life Act* do not outline provisions for sharing PI with the next-of-kin (NOK) and/or patient's substitute of potential and actual organ and tissue donors. However, TGLN may share limited donation outcome information related to donated organs and/or tissue with those individuals who facilitate donation by affirming and/or consenting to donating organs and/or tissues of their loved ones. Donation outcome information is ancillary to a decision about the donation, as permitted in section 5(4.1) of the *Act*. The purpose of sharing this information is to instill confidence and trust in the organ and tissue donation and transplantation system and provide some amount of closure and comfort to those individuals as outlined above.

This policy applies to the disclosure of donor outcome information following donor case management and requests for other items classified as PHI, for example photos of the donor prior to donation. This may also include disclosure as part TGLN's family aftercare processes and/or upon request for information from individuals including NOK and/or patient's substitute following the immediate donation process.

TGLN will readily provide donation outcome information to the patient's substitute documented on the consent form and/or Donor Management System [DMS], in accordance with Donor and Family Aftercare processes. Individuals who participated in the donation process (e.g. completed Donor Medical and Social History Questionnaire) who request limited donation outcome information may be provided with information in accordance with this and other relevant Clinical Process Instructions (CPIs).

Note: Please defer to practice guidelines for details/extent of information shared with the patient's substitute following consented and not recovered cases, and other outcomes. The Organ and Tissue Donation Coordinator (OTDC) and Provincial Resource Centre [PRC] staff are encouraged to answer any general inquiries that may arise from families after the donation process.

#### Process:

1. Upon inquiry from an interested party, the TGLN staff member will take the name, relationship and contact information of the requestor, along with the donor information and the reason for the inquiry.
2. For inquiries about donation outcomes within the post-case period, approximately one week from the tissue or organ recovery event, the outcome will be managed through the PRC, Tissue

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Coordinators, or OTDCs. Inquiries received from interested parties after the post-case period will be directed and managed by Donor Family Services.

3. Any inquiry, and resulting action by TGLN staff should be noted in the clinical notes in the DMS by clinical staff. Family Service staff will document in the DMS section identified for Donor Family Services communication.
4. The TGLN staff member will review the case record for documentation to confirm the individual making the inquiry. Information on the outcome/disposition of the donated organs or tissues are generally limited to individuals in the Gift of Life Act consent hierarchy, and may also include:
  - Any individuals necessary or auxiliary to those who participated in the consent process, or portion of the donation process, including those who participated in providing information for the Donor Medical and Social History Questionnaire; and
  - Any individual who would have been involved or ought to have been involved, in the consent process as part of the consent hierarchy, and was not known or readily available at the time of consent.

TGLN may provide the above individuals with limited donation outcome information as part of its donor family support aftercare program or upon request from the individual.

TGLN may disclose limited donation outcome information to the individuals as described above. Donation information is limited to the organs and/or tissue recovered and transplanted, or those tissues donated if they were accepted for ocular transplantation, when known, life-stage of organ recipient (e.g. youth, young adult, adult) and general description of recipient ailment (e.g. heart disease, diabetes, etc.)

5. Requests for a copy of the Consent to Donate Organs and/or Tissue Form and the Donor Medical and Social History Questionnaire may be provided, where requested, if the individual requesting information completed the form. Any PI or notes documented on these forms collected from anyone other than the requestor will be redacted prior to sharing with the individual. Requests for the consent form or medical social history by the individual(s) completing that form will be escalated to the Manager of Tissue or Organ to enable assignment of any needed redacted information by PRC staff. At any time, concerns or questions can be advanced to the Privacy Manager by the Manager on-call [MOC] or Manager advised of the request.
6. Other donor information may only be disclosed as permitted by the *Gift of Life Act*. Requests should be discussed with MOC and/or Privacy Manager.



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#### Records:

Record Name	Form No. (if applicable)	Record Holder	Record Location	Record Retention Time (as a minimum)
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No records

#### References:

- Disclosure of Donor and Recipient Personal Information to External Stakeholders during Offering, Acceptance and Recovery Process Instruction Clinical CPI-9-1306
- Donor Medical and Social History – Organ or Combined Organ & Tissue Process Instruction CPI-9-207
- Next-of-Kin Reporting for Medical Unsuitability Process Instruction CPI-9-710