

60 020
Stem Cell Registry
Transplant Centre Reference Manual

Section 10 – Recipient Updates Post-Transplant

Effective Date:	2020-06-29
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Approval Signatures	Date
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Approved by Manager, Quality Assurance <i>[Signature]</i>	2020-04-03

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Revision History

Version	Amdt.	Detail	Effective Date
1	0	CR 17603: New document created from UBMTTC0101 as per corporate LINK project	2020-06-29

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OVERVIEW

An important part of the donation process is the collection of recipient information post-transplant. Such information is essential to monitor the overall effectiveness of the Canadian Blood Services Stem Cell Registry (stem cell registry) program, to provide required data to the World Marrow Donor Association (WMDA), and to compile survival and engraftment data essential to analysis of best practices. Some post-transplant information may be provided to the donor.

The stem cell registry will request a recipient update at 3 months and 1 year post-transplant for statistical purposes and may include a request for an update for the donor at that time. Transplant centres are encouraged to inform the stem cell registry as soon as possible if there is a recipient death, of the inability to obtain an update, or if the recipient has declined to consent to release information to the donor.

In accordance with international regulations where applicable, stem cell registry donors and recipients may exchange anonymous correspondence anytime post-transplant. All correspondence will be screened by the stem cell registry to maintain confidentiality. Any information that may identify the age, sex, name, or location of the donor or recipient will not be permitted and/or forwarded. The stem cell registry does not allow the exchange of gifts or photographs.

The donor and recipient will be permitted to exchange their personal information (name, address, etc) only if both parties agree, and after the wait period as deemed by each international registry or Canadian transplant centre has been observed. The wait period for stem cell registry donors is one year post-transplant.

The exchange of maternal personal information with a cord stem cell transplant recipient is not permitted.

Due to the varying regulations of international registries, the possibility exists that some recipients and donors will not be permitted to exchange anonymous correspondence or personal information, regardless of the stem cell registry's guidelines.

PROCESS

<p>10.1. Recipient Update/ Reporting of Recipient Death</p>	<p>10.1.1. Receive request from the stem cell registry.</p> <p>10.1.2. Complete the <i>Patient Update Post-Transplant</i> or <i>Patient Update Post Transplant HPC-CBU</i> form and send to stem cell registry.</p> <p>10.1.3 Update patient profile in Stem Cells National Systems Solution (SCNSS) in case of recipient death.</p>
<p>10.2. Donor-Recipient Anonymous Correspondence</p>	<p>10.2.1. Counsel the recipient/family not to include personal information such as their age, sex, name, or location in the card or letter for a donor.</p> <p>10.2.2. Send correspondence to stem cell registry.</p>
<p>10.3. Requests for Exchange of Personal Information</p>	<p>10.3.1. Receive request to establish direct contact between donor and recipient or recipient’s family if recipient has passed away.</p> <p>10.3.2. Contact the recipient or immediate family member.</p> <p>10.3.3. Advise the recipient or immediate family member to review the risks and benefits of the exchange.</p> <p>10.3.4. Provide recipient or recipient’s family the following forms to be completed:</p> <ul style="list-style-type: none"> • <i>Consent to Release Personal Information to Donor</i> • <i>Consent to Release Family Contact Information.</i> <p>10.3.5. Inform stem cell registry that consent has been declined, if applicable.</p> <p>10.3.6. Send completed consent form to stem cell registry.</p> <p>10.3.7. Receive donor’s information from stem cell registry.</p> <p>10.3.8. Send donor’s information to the recipient, or the recipient’s family.</p>

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ASSOCIATED DOCUMENTS:

F801605, *Patient Update Post-Transplant*

F801604, *Consent to Release Personal Information to Donor*

F801613, *Consent to Release Family Contact Information*

F801618, *Patient Update Post Transplant HPC-CBU*

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