

Anatomy of a Stem Cell Drive: An Evidence-Based Approach to Stem Cell Drive Organization

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abstract

Patients in need of a stem cell transplant often rely on unrelated donors. Canadians can register as donors online or at a stem cell drive by providing consent and a tissue sample for typing. To the knowledge of this author, no guidelines have been published to recommend a process for stem cell donor recruitment at drives. This article outlines an evidence-based approach to stem cell drive organization with five core components: prescreening, informed consent, registration, swabbing, and reconciliation. This approach offers guidance to medical students who coordinate stem cell drives and encourages them to act as health advocates for Canadians who need a stem cell transplant.

introduction

Patients with a variety of blood cancers and metabolic diseases may require a stem cell transplant as part of their treatment.¹ However, 70% of patients do not have a suitable genetic match in their family.² Canada's stem cell donor database, OneMatch Stem Cell and Marrow Network, is used to match potential unrelated donors to patients worldwide. Individuals aged 17-35 years can register online or at a stem cell drive where they provide consent and a tissue sample (buccal-swab) for Human Leukocyte Antigen (HLA) allele typing. However, due to the overwhelming number of possible HLA allele combinations, it remains challenging to secure a compatible stem cell donor for many patients: currently, over 1000 Canadians are unable to find a match anywhere in the world.³

To address the need for stem cell donor registrants, I founded the UBC Stem Cell Club in 2011. As of June 2014, the club has coordinated 21 stem cell drives in a variety of settings including drives on six university campuses across BC, in the community, and in rural areas.^{4,6} Altogether, we have recruited over 2300 donors, representing 2.5% of all registrants recruited across Canada between 2012 and 2014.⁴ We have gained considerable experience operating stem cell drives, and we are accredited by OneMatch to run drives independently.

To the knowledge of this author, no guidelines have been published to recommend a process for stem cell donor recruitment at drives. In this article, I outline an approach to stem cell drive organization, which is applied to every UBC Stem Cell Club drive. This approach features evidence-based strategies to identify the most-needed stem cell donors and to minimize donor ambivalence and withdrawal from the registry. Our drives include five necessary stations: pre-screening, informed consent, registration, swabbing, and reconciliation (see Table 1). These stations are not necessarily physically separate from each other; rather, they represent the path that a registrant takes to sign up to be a potential stem cell donor at a drive.

pre-screening

The first station of a stem cell drive is the pre-screening station. Here, volunteers interact with people walking by, inform them about the stem cell drive, and screen for stem cell donor eligibility. To register as a donor, individuals must be willing to swab their cheeks to provide a DNA sample and to sign a consent form to join the registry. Additionally, individuals must also meet a number of health and demographic criteria. OneMatch requires donors to be aged 17-35 years.³

Registrants must be at least 17 years old as this is the age required to provide consent. Individuals older than age 35 are not eligible to register as studies have shown that a younger donor age is associated with improved outcomes, including increased survival rates, in the transplant recipient.⁵ This evidence has guided OneMatch to focus recruitment efforts toward younger donors.³ Individuals registering to be stem cell donors also need to be in good general health. This requirement seeks to protect volunteer donors from the risk of damage to their own health and to protect recipients from transmissible diseases.⁷ Registrants also need to have

Ineligible registrants should be redirected to help in other ways; they could be encouraged to donate blood if able, to ask their peers, friends, and family to consider registering as stem cell donors, and to volunteer at stem cell drives.

Table 1: Five Stations necessary for a stem cell drive

Station	Purpose
1. Prescreening	Recruits individuals to consider registering as potential donors Ensures donor eligibility Targets the most-needed donors
2. Informed consent	Ensures that donors are informed about: <ul style="list-style-type: none"> • Stem cell donation principles and procedures • Risks and side effects of donation • Anonymity, confidentiality, and right to withdraw from the registry
3. Registration	Guides registrants to complete necessary paperwork Answers registrant questions
4. Swabbing	Guides registrants to swab their cheeks for a tissue sample Assembles and seals completed swab kits
5. Reconciliation	Delivers final information Assesses informed consent Checks for errors Processes kits for shipment and drive outcome reporting

provincial health care coverage: if a registrant is selected as a match to donate their stem cells, the registrant's health care coverage pays for the medical workup and the procedure itself. International students and visitors from other countries should be encouraged to register as donors on their home country databases. Finally, stem cell donors must be willing to donate to anyone in need worldwide.⁹ Donors cannot direct their donation to a patient of their choice. Ineligible registrants should be redirected to help in other ways; they could be encouraged to donate blood if able, to ask their peers, friends, and family to consider registering as stem cell donors, and to volunteer at stem cell drives.

In addition to confirming that potential registrants meet minimum eligibility criteria to sign up, volunteers at the pre-screening station should actively target the most-needed stem cell donors: donors that are young, male, and ethnically diverse. As discussed above, younger donors are associated with improved outcomes, including recipient survival.⁵ Younger donors are also on the registry longer and are more likely to be in good health. Male donors are preferred as they are associated with decreased incidence of one significant transplant complication: chronic graft-versus-host disease.⁵ Recruitment of ethnically-diverse donors is important as patients are more likely to find a genetic match from donors within their own ethnic community.⁸

informed consent

Interested potential donors who meet the minimum eligibility requirements outlined above should be directed to an informed consent station. Informed consent is a moral, ethical, and legal requirement to become a stem cell donor. In addition to studies have shown that individuals are more likely to be ambivalent towards donating if they feel less informed or have unanswered questions at the time of recruitment.¹⁰ Such individuals are more likely to withdraw from the registry if asked to proceed with the donation.¹¹ Informed consent includes notifying the registrant of all relevant procedures, as well as possible risks of donation, right to withdraw, and confidentiality and anonymity of the program.¹²

In addition to confirming that potential registrants meet minimum eligibility criteria to sign up, volunteers at the pre-screening station should actively target the most-needed stem cell donors: donors that are young, male, and ethnically diverse.

registration

To sign up as a stem cell donor in Canada, registrants must complete a form that asks for demographic information (including ethnic background), contact information, and medical history. Registrants then sign their consent to join the registry. At this station, volunteers should be available to guide registrants through forms and answer any questions that may arise. It is important that registrants provide detailed contact information, including alternate contacts, so they can be contacted if they are a match.¹³



Figure 1: Registrants swab their cheeks with a cotton swab to provide a DNA sample. Four cheek swabs are collected from the registrant, each from a different area of the mouth. Swabs are flagged with a unique registrant barcode.

Stem cell drives directly improve the Canadian stem cell donor database, an important global health resource that helps patients worldwide.

swabbing

Following registration, registrants should proceed to a swabbing station. Here, four separate cotton swabs are used to obtain four buccal cell samples (see Figure 1). Drive volunteers affix bar code labels to the registrants' paperwork and cotton swabs. Registrants are guided to swab their own cheeks. Volunteers should then help registrants package their swabs into a swab kit, staple the paperwork and swab kit together, and direct the registrant to the reconciliation station.

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reconciliation

The final station of a stem cell drive is reconciliation. Here, registrants should be given another opportunity to ask questions. Drive organizers should inform registrants that they will remain on the registry until age 60. Registrants may also be called by OneMatch staff to confirm any details on their paperwork. They should be told that they are responsible for updating their address if necessary. This allows OneMatch to contact them if they are found to be a suitable match. The last step of the stem cell drive is error checking with the registrant. Errors can prevent completed swab kits from being entered into Canada's stem cell donor database. The process of redoing registration paperwork and/or cheek swabs can delay processing and testing; this can result in a delay for a patient and a matched donor. Finally, kits are processed and recorded for shipping and drive outcomes are tallied.

conclusion: stem cell drives and health advocacy

Stem cell drives directly improve the Canadian stem cell donor database, an important global health resource that helps patients worldwide. Coordinating or volunteering at drives represents a meaningful avenue for individuals to act as health advocates for over 1000 Canadians who are in need of a transplant but cannot find a match. The five-station approach to stem cell drive organization outlined here represents a model for effective stem cell donor recruitment.

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