Building a Community of Practice to Support Stem Cell Donor Recruitment in Canada

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Elsa Nega, Mother of 2 in Canada Needs Life-Saving Marrow Transplant

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Because Elsa Nega is an Ethiopian, her chances of finding a donor on the international registry is slim and so her family is appealing to Ethiopians worldwide to help save her life by joining the registry at Match4Elsa.com
Non-Caucasian people are underrepresented on Canada’s donor registry.
22 campuses across Canada
10,000 donors to date (60% are non-Caucasian)

www.stemcellclub.ca
Community of Practice

“A group of people who share a concern or a passion for something they do, and learn how to do it better as they interact regularly”
Questions for the expert panel

How can I best

• cultivate a community of practice?
• secure buy-in from stem cell drive leaders?
• support knowledge exchange and collaboration?
Overall Impact on the Registry (as of January 2017)

<table>
<thead>
<tr>
<th>Registrants listed to OneMatch[^a,||]</th>
<th>Total Registrants</th>
<th>Total Males 17-35[^*]</th>
<th>Total non-Caucasian Males ages 17-35[^*,|^[]</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>404,941</td>
<td>83,825</td>
<td>35,491</td>
</tr>
<tr>
<td>Registrants Recruited by Stem Cell Club[[]</td>
<td>6,585</td>
<td>2,877</td>
<td>1,255</td>
</tr>
<tr>
<td>Percentage of all donors on OneMatch who were recruited by Stem Cell Club[[]</td>
<td>1.63%</td>
<td>3.43%</td>
<td>3.53%</td>
</tr>
</tbody>
</table>

\[^a\] Data presented reflects only drives at which detailed outcomes were recorded (~75% of stem cell drives).
\[^*\] Non-Caucasian males included those who self-identified at time of recruitment as any ethnicity other than Caucasian.
\[^\[\]\] Aboriginal males include registrants who self-identified at time of recruitment as Metis, Inuit, or First Nations.
\[^\[\|\|\] Data provided by OneMatch Stem Cell and Marrow Network of the Canadian Blood Services.
\[^\[\|\] As of January 30, 2017
Canada’s Stem Cell Donor Database Needs Improvement!

There is a special need for Aboriginal Peoples, who make up less than 1% of Canada’s database.
Targeted Recruitment of Aboriginal Males

A significant proportion of Aboriginal males on the OneMatch registry have been recruited at drives spearheaded by Stem Cell Club.

<table>
<thead>
<tr>
<th>Registrants listed to OneMatch</th>
<th>Total Aboriginal Males ages 17-35*\†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registrants Recruited by Stem Cell Club</td>
<td>79</td>
</tr>
<tr>
<td>Percentage of all donors on OneMatch who were recruited by Stem Cell Club</td>
<td>7.50%</td>
</tr>
</tbody>
</table>
### Match Rates as of September 1, 2016

<table>
<thead>
<tr>
<th>Total Registrants</th>
<th>Available for Matching</th>
<th>Selected for Verification Typing</th>
<th>Selected for Workup</th>
<th>Donated Stem Cells</th>
</tr>
</thead>
<tbody>
<tr>
<td>5,243</td>
<td>3,700</td>
<td>419</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Status of registrants recruited by Stem Cell Club following registration

<table>
<thead>
<tr>
<th>Registrant Status</th>
<th># of Registrants</th>
<th>Percentage of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registrant available for matching</td>
<td>3,700</td>
<td>70.57%</td>
</tr>
<tr>
<td>Unknown</td>
<td>942</td>
<td>17.97%</td>
</tr>
<tr>
<td>Labelling error at event - label replaced - cannot trace to original barcode</td>
<td>771</td>
<td>14.71%</td>
</tr>
<tr>
<td>Potential - testing not yet completed</td>
<td>171</td>
<td>3.26%</td>
</tr>
<tr>
<td>Unavailable</td>
<td>601</td>
<td>11.46%</td>
</tr>
<tr>
<td>Not able to contact registrant for followup on initial registration information</td>
<td>442</td>
<td>8.43%</td>
</tr>
<tr>
<td>Registrant deferred at enrollment</td>
<td>102</td>
<td>1.95%</td>
</tr>
<tr>
<td>Registrant declined to proceed when contacted for followup on initial registration</td>
<td>22</td>
<td>0.42%</td>
</tr>
<tr>
<td>Registrant unavailable due to personal reasons</td>
<td>20</td>
<td>0.38%</td>
</tr>
<tr>
<td>Donor temporarily unavailable for matching</td>
<td>7</td>
<td>0.13%</td>
</tr>
<tr>
<td>Duplicate registrant</td>
<td>6</td>
<td>0.12%</td>
</tr>
<tr>
<td>Registrant emigrated</td>
<td>1</td>
<td>0.02%</td>
</tr>
<tr>
<td>Registrant deceased</td>
<td>1</td>
<td>0.02%</td>
</tr>
<tr>
<td>Total</td>
<td>5,243</td>
<td>100%</td>
</tr>
</tbody>
</table>

Number of registrants listed on registry, not listed, and unknown
We recruit potential donors at Stem Cell Drives

Stem Cell Drive Stations

- Prescreening
- Informed Consent
- Registration
- Swabbing
- Reconciliation

At Every Station: Confidentiality, Privacy, Quality Control
The Stem Cell Drive
Stem Cell Club Toolkit

We have developed a number of resources to promote the success of our drives:

• Stem cell drive model
• Promotional resources
• Informed consent process
• Stem cell donation procedure diagrams
• Approach for redirecting non-optimal donors
• Checklists

These resources are highlighted in our training

All of these resources are available on our website, www.stemcellclub.ca
The Stem Cell Drive: A Model for Stem Cell Donor Recruitment

Prescreening
- Approach the next needed stem cell donors according to the literature on young and ethnically-diverse males.
- Discuss with potential registrants:
  1. Brief overview of stem cells and motivation for more registrants in the network.
  2. Stem cell donation principles: DNA typing and matching and diseases treated by a transplant.
- Redirect ineligible and non-optimal donors to help in other ways (e.g., blood donation, cord blood donation, donor plasma donation, spreading awareness).

Informed Consent
- Hand registrants a information sheet.
- Explain the procedure diagrams for peripheral blood stem cell and bone marrow donation.
- Educate registrants about:
  1. Peripherial Blood Stem Cell Donation and Bone Marrow Stem Cell Donation.
  2. What happens if you say no?
  3. Donor and patient anonymity.
  4. The registrant's right to withdraw.

Registration
- Guide registrants to complete the registration form which includes:
  1. Contact and demographic information.
  2. Health screening questionnaire.
  3. A consent form to sign.
- Ensure the forms are completed.

Swabbing
- Perform an informed consent discussion by adding:
  1. Contact and demographic information.
  2. Health screening questionnaire.
  3. A consent form to sign.
- Affix barcode stickers onto each swab kit component.
- Complete a final verification of informed consent and answer any final questions.

Reconciliation
- Complete a final verification of informed consent and answer any final questions.
- Complete a final error check of all swab kit components, including the registration form and correct sticker placement.
- Deliver final information:
  1. Registrants need to update their health/contact information as applicable.
  2. Registrants will remain on the registry until age 60.
  3. Registrants may be contacted if there are any questions about their registration form.
- Process swab kits and prepare them for shipping.
Stem Cell Club Promotional Resources

• Capitalizing on the creativity of club members
Our informed consent process spans across the stations, meeting WMDA suggested procedures.

Information to be provided to registrant:

- Principles of haematopoietic stem cell donation
- Procedures relating to haematopoietic stem cell donation
- Risks and possible side effects of haematopoietic stem cell donation
- Health restrictions for volunteer donors
- Infectious diseases (HIV, hepatites) and the implications of transmission of such disease from donor to patient
- Collection, storage and usage of data including details of data that is passed to transplant centres/other Registries
- Confidentiality of personal data of both patient and volunteer donor
- Anonymity of both patient and volunteer donor
- Donation for any potential recipient worldwide
- Responsibility of volunteer to advise Registry of changes in circumstances (health, address, contact numbers)
- Rights of withdrawal from the Registry
- Nonremuneration of donation

Adapted from Rosenmayr et al. (2003)
Stem Cell Club’s Stem Cell Donation Procedure Diagrams

**Stem Cell Donation from Blood**

**Prior to Donation**
- The donor receives daily doses of a growth factor, starting one week prior to donation.
- This increases the amount of stem cells in the blood.

**Day of Donation**
1. Blood is drawn through a needle.
2. Stem cells are separated from the rest of your blood (takes 4-6 hours).
3. Remaining blood is returned back into your body through another needle.

**Stem Cell Donation from Bone Marrow**

Performed under anesthesia. Hollow needles withdraw stem cells from bone marrow of pelvic bones.

Bone Marrow donation is less common than stem cell donation from blood.

Realistic diagrams, featuring young and ethnically-diverse males as donors.
Additional Examples

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More Indigenous donors are needed!
Redirecting ineligible/non-optimal donors to help in other ways

Over 35?
- “As people age, their stem cells age too”
- “Studies have shown that patients have a better chance of surviving when the donor is younger”

Female?
- “Studies have shown that when the donor is male, the patient has less chance of complications”
- “Female donors experience more side effects than males”
- “Today, three out of four stem cell donors chosen to help save a life are male”
- Encourage women to donate umbilical cord stem cells from baby if they plan to have a child (where available)

Poor health?
- “Donors need to be healthy, not just to protect the patient but also to protect themselves”
- Refer the registrant to the website wiki.wmda.info for disease-specific information regarding medical suitability

Unwilling to donate to anyone in need?
- Explain that donation is anonymous for both patient and donor
- Registrants must be willing to donate to anyone in need, anywhere in the world

Lacking healthcare coverage?
- “Provincial health insurance coverage is required at time of donation to cover the cost of stem cell collection”
- Registrants who will remain in Canada and obtain provincial healthcare coverage may register
- Registrants from another country can search for a registry in their home country on bmdw.org
Stem Cell Drive Checklists

- Recruiters are instructed with and guided to adhere to our station-specific best-practices checklists

### 1. Stem Cell Drive Setup
- Before the drive
  - Complete pre-event form and send to registry
  - Location scouting
  - Power outlets identified
  - Ice safety and first aid plan
  - Ice plan
  - Arranging access to tables and chairs needed
- Supply plan
- Table white, registration forms, informational pamphlets, informed consent diagrams, stationary and required office supplies
- Insurance, resuscitation, and stopping paperwork
- Volunteer Recruiter recruitment, sign-up and training
- Promotions
  - Social media posts, etc.

### 2. Prescreening
- Do you have a minute to save a life?
- Explain the principles of stem cell donation
- What are stem cells?
- What is the purpose of the stem cell drive?
- What is the tissue sample biopsy for?
- Why is a biopsy (tissue sampling) used to match to patients in need?
- How are the patients we help generally treated with stem cells and marrow donation?
- How could the results be critical to the life of a patient located anywhere in the world?

### 3. Redirect Donors to Help in Other Ways
- Key messages which apply to everyone
  - “Thank you for your service and dedication. You can contribute to the care of ill patients, even if you are not able to donate.”

### 4. Informed Consent
- Head registers on an information pamphlet
- Discuss about procedures
- Peripherals Blood Transplant
- Stem cells involve a minimal health risk to increase stem cells in a blood
- Stem cells are cells that can be used to repair all soft tissue
- Stem marrow transplants
- Put on sleeve
- Ice procedure
- Hours until side of lip
- Explain anatomy of both patient and volunteer donors
- Explain donor rights to withdraw at any time

### 5. Registration
- Check for errors:
  - Data (correct date and contact format)
  - Check that registra’s eligibility is not expired for today’s date
  - Check if consent signed (correct date and format)
  - Explain confidentiality of personal data (for both registrant and patient)
- Refer to consent form for details of data collection, storage, usage
- Explain health information is shared with other registries to help find matches for patients across the world

### 6. Swabbing
- Check with the registrant to see if they understand.
- Ask them:
  - “What happens if you are a match?”
  - “What are the risks involved in donating stem cells?”
  - “What happens if you say no?”
- Affix unique barcode labels onto
  - Swabs
  - Swab Kit Envelope
  - Consent Form
- Guide registrants through swabbing
- Place swab in bag for 30 seconds, no squeezing
- Seal completed swab kit
- Send registrant to reconciliation staff member

### 7. Reconciliation
- Ask if there are any systematic errors, missing cases, referring previous station, and trouble shooting or notify supervisor as applicable
- Ask the registrant: “Do you have unanswered questions?”
- Error check the registrant’s form, including:
  - Legible? Date? Missing questions?
  - Barcode labels properly affixed
- Provide information to registrant:
  - Length of time will remain on the registry
  - The registry may contact you by telephone if they have any questions about your registration
  - Update the registry with any changes to health or address
  - Ask the registrant to consider signing up to donate blood
  - Final paperwork:
    - For each swab kit
      - Vials unique barcode label from each swab kit onto tracking log
      - Log sheet demographics on outcomes form
      - Follow-up is not a registry officer or clinic, record registrant name and phone number on registrant data sheet

### 8. Takedown of Drive and Post-event
- Route leaves with slips and paper into clear plastic bag
- Complete reconciliation log
- Complete shipping receipt if needed
- Assemble the box of completed swab kits as follows:
  - The box, there should be a plastic bag with:
    - Blood sample kits
    - Reconstituting kit
- On the box:
  - Shipping label if applicable
  - Confidentiality slip
  - Per Intravenous Use label
  - Shipping Number
t  - Confidentiality slip
  - Confidentiality slip
- Return supplies to storage
- Complete post-event report
- If swabs kits are lost any 24 hours in registry office, registry to use registrant data sheet to notify reconciled registrants that their data has been compromised