Why We Swab: Development of a Library of Stories in Stem Cell Donation

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Background

- Many patients with blood diseases need a stem cell transplant as part of their treatment; however, the majority do not have a suitable matching donor in their family and require an alternative donor such as an unrelated donor. 
- Storytelling is an important tool to convey information. Stories are powerful in their ability to disseminate information in a meaningful way, through engaging the reader’s emotions and thoughts. 
- The use of stories about real people allows readers to empathize with the experience of engaging one person to another.

Results – Story Examples

<table>
<thead>
<tr>
<th>Family Member and Caregiver Stories</th>
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<td>Stories from family members and caregivers demonstrate the widespread impact someone can have when they sign up as a stem cell donor.</td>
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<th>Donor-Recipient Stories</th>
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<td>Stories which showcase stem cell recipients and their unrelated donors together are especially powerful.</td>
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<th>Social Media Engagement</th>
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<td>The story of Mike (unrelated donor) and How (stem cell recipient) delivers two different perspectives on the same stem cell donation experience.</td>
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Patient and Recipient Stories

- We highlight diverse storytellers to address the need for more ethnically diverse individuals to sign up as stem cell donors.
- At present, 7 ethnically diverse storytellers have shared their stories with us: 
  - Monica (left-most) – Filipina
  - Libby (below) – awardi
  - Ren (middle-left) – Indigenous
  - Carl (top-left) – Indigenous, European
  - Bess (right) – half-Finnish, half-Indian
  - Libby (not shown) – JRT Sikh Punjabi
  - Melissa (bottom-left) – Indigenous

Social Media Engagement

- In the first four weeks following launch on 23/09/2019 fifteen story segments were published in the Why We Swab Facebook and Instagram accounts.
- Social media insight features were used to evaluate social media post reach and engagement.
- Facebook:
  - Accrued 417 page likes
  - Reached an audience of 59,932 people
  - Had 11,537 engagements (i.e. likes, comments, and saves)
- Instagram:
  - Accrued 133 followers
  - Reached an audience of 1,588 people
  - Had 247 engagements (i.e. likes, comments, and saves)

Conclusion

- We describe the launch of Why We Swab, a library of stories in stem cell donation developed to support the education and recruitment of unrelated stem cell donors.
- The initiative will connect with additional storytellers and aim to publish new stories at least once per month.

References


Acknowledgements

We are grateful to all stem cell donation program members and participants to include their stories in our library, as well as all members of the Why We Swab Committee. We thank the donor recruiters who participated in the needs assessment surveys, as well as all recruiters across Canada for the work they have contributed. We are thankful to all social media companies for their support, especially to Facebook for their assistance in sharing our digital library of stories.

We also thank all donors and family members who shared their stories with us. We are particularly grateful for the generous funding from the Stem Cell Network of Canada which made it possible for us to continue our work.

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<th>Methods</th>
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<td>- Why We Swab is an initiative that aims to write and report stories about Canadian recipients and stem cell donors and recipients; patients searching for a match; family members; and transplant staff.</td>
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<td>- The stories are told at an audience of potential stem cell donors.</td>
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<td>- Stories are told in a first-person narrative and published alongside the storyteller’s photo.</td>
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<td>- Some stories feature several parts that are subsequently published over several days, constituting a story series.</td>
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<td>- A committee of donor recruiters was formed to find storytellers, conduct interviews, and write and publish stories across social media (including Facebook, Instagram, and Twitter).</td>
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<td>- A process to create stories was developed:</td>
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<td>1. Identify storytellers and secure their informed consent.</td>
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<td>2. Conduct interviews (in person, phone call, or written) and request media (e.g., photos).</td>
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<td>3. Transcribe interview.</td>
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<td>4. Collect interview notes (person, phone call, or written) and request media (e.g., photos).</td>
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<td>5. Publish story online.</td>
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<td>6. Publish story online.</td>
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Figure:

- Image 2: A committee of donor recruiters was formed to find storytellers, conduct interviews, and write and publish stories across social media (including Facebook, Instagram, and Twitter). 
- Image 3: A process to create stories was developed: 
  1. Identify storytellers and secure their informed consent. 
  2. Conduct interviews (in person, phone call, or written) and request media (e.g., photos). 
  3. Transcribe interview. 
  4. Obtain final approval from the storyteller. 
  5. Publish story online. 
  6. Publish story online.