

# Top of the World Stem Cell Drive: A Case Study in Rural Stem Cell Donor Recruitment

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## ABSTRACT

Many patients with blood diseases require a stem cell or bone marrow transplant as part of their treatment, and they need a donor who is a genetic match for a transplant. Canadians aged 17-35 can register as potential stem cell donors at stem cell drives, where they swab their cheeks to provide a tissue sample. Patients are more likely to match to a donor in their own ethnic group, and there is currently a special need for Canadian Aboriginal donors, as this demographic is underrepresented on Canada's stem cell donor database. At the University of British Columbia, third-year medical students are required to complete an elective in a rural community in British Columbia or in the territories of Canada. This presents an ideal opportunity to engage rural Canadians, including Canadian Aboriginals, to participate in the stem cell donor database. This dispatch outlines a pilot rural stem cell drive, and discusses general strategies for the implementation of rural stem cell drives.

**KEYWORDS:** *donor recruitment, stem cell drive, aboriginal; health advocacy, rural engagement*

## INTRODUCTION

For Drayson, a six-year-old Aboriginal boy from Manitoba with a rare blood disease, finding a genetic match for a stem cell transplant will be an uphill battle. Drayson has been diagnosed with Fanconi anemia, a rare, inherited bone marrow failure syndrome that is usually associated with congenital anomalies.<sup>1</sup> It often progresses to pancytopenia and predisposes the patient to cancers including leukemia, myelodysplastic syndrome, and liver tumours.<sup>1</sup> He is just one of over twenty Canadian Aboriginals who are actively searching for a stem cell donor and cannot find a match anywhere in the world.<sup>2</sup>

Many patients with blood diseases require a stem cell transplant as part of their treatment. This process usually requires destruction of the patient's immune system with radiation or chemotherapy followed by transplantation of new blood machinery in the form of hematopoietic stem cells. These stem cells can be obtained from either bone marrow or from blood, and they must closely match the human leukocyte antigen (HLA) markers of the patient. Over 70 per cent of the time, patients cannot find a genetic match within their family, and they must rely on unrelated donors.<sup>3</sup>

Canada's stem cell donor database is used to match potential donors to patients in need, and it includes over 340 thousand Canadians willing to consider donating their stem cells. Individuals aged 17-35 can register to join this database online or at stem cell drives, where they provide consent and swab their cheeks to provide a tissue sample. Young male donors are preferred, as the selection of donors with these characteristics is associated with

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Figure 1. Inuvik, Northwest Territories.

improved patient outcomes.<sup>4</sup> Including Canada's, there are 71 registries in the world, allowing transplant coordinators to search through 22 million potential stem cell donors from across the world to find a genetic match for their patients.

Drayson's story highlights the special need for Canadian Aboriginal donors. Patients are more likely to match to a donor in their own ethnic group,<sup>5</sup> and Canadian Aboriginals have a genetic makeup that is unique to Canada. These factors make it unlikely for patients from this demographic to find a genetic match outside of Canada, despite the large number of donors worldwide. Moreover, Aboriginals currently represent less than 1% of Canada's stem cell donor database, with younger males—the most needed donors—only making up about 25% of this limited registrant pool.<sup>2</sup>

## PILOTING A RURAL STEM CELL DRIVE

At the University of British Columbia, third-year medical students complete a rural medicine elective in a community in British Columbia or in the territories of Canada. This past summer, I was placed in Inuvik, Northwest Territories (Figure 1), and I set out to



Figure 2. Rural Stem Cell Drive Setup: featuring posters, information pamphlets, swab kits, consent forms, and required office supplies. Photo was taken during rural stem cell drive pilot in Inuvik, Northwest Territories, August 2013, at NorthMART Community Store.

engage the community of Inuvik with the stem cell network by hosting a stem cell drive.

As founder of the UBC Medicine Stem Cell Club, I already had a number of tools available to facilitate this drive. Our club equips members with training to run stem cell drives independently, and it is accredited, supported, and equipped by OneMatch Stem Cell and Marrow Network to operate stem cell drives.

I first submitted a proposal to a Quality and Risk Management Administrator at the Beaufort-Delta Health and Social Services, the health authority servicing Beaufort Delta Region in the Northwest Territories. I was given permission, with the caveat that my drive needed insurance coverage. OneMatch arranged to provide the insurance.

My next task was to secure a location—a high traffic, easily accessible area—where I could get permission to set up a table and could invite people walking past to consider registering as potential stem cell donors. I approached several venues, and I was allowed to set up a table in the NorthMART Community Store, near the food court (an ideal venue to reach out to 17-35-year-old males) (Figure 2).

I used social media to advertise for the drive, by posting on Inuvik's events page on Facebook. Inuvik has a remarkable online presence, which is something that I did not initially expect, given its small size. My marketing campaign highlighted Drayson's story, and targeted young, male, and Aboriginal residents of Inuvik (Figure 3).

## RESULTS AND DISCUSSION

The pilot rural stem cell drive took place over approximately 20 hours during the final week of the rural elective. It successfully recruited 44 individuals under age 35 to be potential stem cell donors, including 26 Aboriginal males.

There were a number of challenges which needed to be overcome when coordinating rural drives. First, supplies, including OneMatch swab kits, needed to be transported to the site of the drive. Arranging shipment of supplies to rural locations

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can take time and requires planning in advance. Second, rural electives at UBC are just one month long. This does not provide much time to obtain permission from the local health authority and from OneMatch, to arrange supply shipment, and to run the drive itself. During my pilot drive in Inuvik, it took two weeks to secure the approval and supplies needed to run a drive, highlighting the need to plan ahead.


Finally, to achieve informed consent, it is necessary to impart registrants with basic knowledge about the stem cell donation process, including potential risks. In any public setting, it is particularly important to present information clearly and accessibly so that participants will have a clear understanding of what they are being asked to do and why this is significant.

## CONCLUSION

In all, this pilot demonstrated that combining stem cell drives with medical student rural electives is feasible and can facilitate rural community participation in Canada's stem cell donor database. Rural stem cell drives provide an opportunity to engage individuals from key ethnic groups to become potential stem cell donors, including Inuit, First Nations, and Metis Aboriginals of Canada.

The principles of coordinating a rural stem cell drive (Appendix 1), as piloted this past summer in Inuvik, can be extrapolated to any rural community. An important facet of medical student training in Canada is to become a health advocate. This includes identifying opportunities for health promotion and disease prevention in the communities served and responding appropriately.<sup>6</sup> Through coordinating rural stem cell drives, medical students can improve their health advocacy skill set and ultimately become better physicians.

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APPENDIX 1

**Checklist: For Use When Planning to Coordinate a Rural Stem Cell Drive**

1. In Advance of the Rural Experience
  - a. Contact OneMatch (and/or the UBC Medicine Stem Cell Club) about your interest.
  - b. Request permission from Local Health Authority. Note that this step is not mandatory, but that it is good practice, particularly when acting as a representative or affiliate of the medical school.
2. Soon After Arrival
  - a. Find and secure location for drive: community centre, event/festival, high school (grade 12 class), or any high traffic area where you can interact with the most needed demographics: young, healthy, and ethnically diverse males.
  - b. Connect with OneMatch (and/or the UBC Medicine Stem Cell Club) to arrange shipping of needed supplies and to secure insurance for the event.
  - c. Advertise! Most small towns have social media. Some have local radio stations. Inuvik had a television channel exclusively for local advertising.
3. Coordinating a Rural Stem Cell Drive
  - a. Run the swab drive (see references<sup>6</sup> for a list of swab drive procedures and requirements).
  - b. Arrange for the shipment of completed swab kits to OneMatch headquarters, with their guidance.

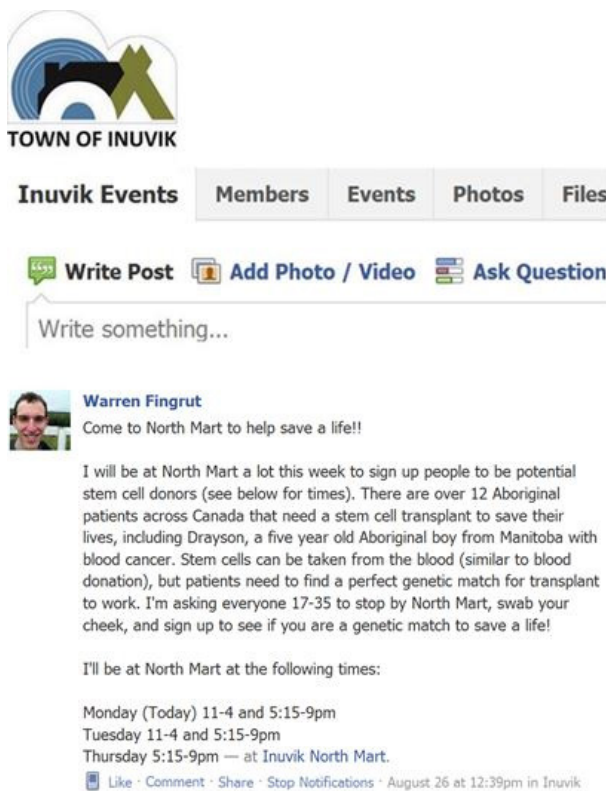


Figure 3. Sample Advertising Campaign Resources for a Rural Stem Cell Drive. Left: Social Media Campaign. Right: Printed Poster Targeting Aboriginal Demographic