

Permanent Donor Deferral Policy

Background Rationale to have the questions relaxed/removed



Permanent donor deferral policy affects the supply of phenotypic blood extremely needed by individuals living with Sickle Cell Disease

Blood Donation-Geographic Deferrals:

Canadian Blood Services tests donors for HIV by checking for both antibodies to HIV and for the virus itself in the blood. Testing for the virus itself allows for earlier detection but is not always reliable in people who harbour rare or unusual strains of the virus. According to Canadian Blood Services, people who have lived in certain regions of Africa, who may have been exposed to new strains of the virus that causes HIV/AIDS are not eligible to donate blood. People who have received a blood transfusion while visiting there or who have had sex with someone that has lived there, are also not permitted to donate blood. This is not based on race or ethnicity but based on the possibility that these new strains may not always be detectable by available tests. When this rule was introduced in the 1990s the concern was mostly over HIV-1 Group O. Although tests can now detect this strain, even newer strains which tend to emerge in these same countries (eg., Group N and P) may still go undetected. Countries included in the region of concern are: Cameroon, Central African Republic, Chad, Congo, Equatorial Guinea, Gabon, Niger and Nigeria.

http://www.blood.ca/CentreApps/Internet/UW_V502_MainEngine.nsf/9749ca80b75a038585256aa20060d703/c8ed195dc27d2dde85256ab000563ecc?OpenDocument¹

Canada

The majority of blood donors are Caucasians while many of the individuals living with Sickle Cell Disease in Canada are of ethnic heritage, mostly of African and Caribbean background and especially of West-African descent.

Brief synopsis on Sickle Cell Disease

Sickle Cell Disease is a term used for a group of conditions in which the pathology is due to the presence of hemoglobin S. Homozygous S sickle cell disease, results from the inheritance of a sickle cell gene from both parents. Other genotypes of sickle cell disease result from the inheritance of one hemoglobin S and another abnormal hemoglobin, such as Hemoglobin C, causing SC sickle cell disease, or a β -Thalassemic gene mutation, causing Hemoglobin S β^+ or S β^0 sickle cell disease. Sickle cell disease is characterized by continuous red blood cell hemolysis, resulting in anemia, and intermittent episodes of blood vessel occlusion, causing pain and sometimes damage to bones and major organs such as the brain, lungs, liver, spleen, or kidneys. There is also increased susceptibility to infection and blood clots. The severity of the disease varies from patient to patient. Some patients have relatively few symptoms, while others develop progressive and irreversible organ failure. Being a carrier of the sickle cell gene (eg., inheriting Hemoglobin S from one parent and normal haemoglobin, or Hemoglobin A, from another parent) causes no symptoms under most circumstances and in fact provides some protection from malaria infections. For this reason, people whose ancestors are from areas where malaria has historically been active, particularly Africa and the Middle East, are more likely to carry the sickle cell gene.

Phenotypically-Matched Blood & Sickle Cell Disease

Patients with sickle cell disease are at high risk of developing antibodies to red blood cells following transfusion. This is thought to be primarily due to differences in proteins and carbohydrates on the surface of red blood cells from typical blood donors (often Caucasians) and those with sickle cell disease (often of African descent). Once antibodies develop it becomes more difficult to find compatible blood. Also, because these antibodies can become undetectable over time, a patient who has developed antibodies may inadvertently receive an incompatible red blood cell transfusion, particularly if they have been transfused at more than one hospital. When this happens, the transfused red blood cells are destroyed, causing worsening of the anemia, and often triggering a painful sickle cell crisis. For this reason, when selecting blood to transfuse to patients with sickle cell disease many hospitals now try to provide red blood cells that are matched not only for the antibodies a patient *has* made, but for antibodies that the patient *could* make. This kind of blood is called phenotypically-matched blood. In addition to being useful to patients with sickle cell disease, it is also sometimes needed when transfusing other patients who have made antibodies.

The best source of phenotypically matched blood for a patient with sickle cell disease is a donor who is also of African descent. As the population of patients with sickle cell disease in Canada increases, and as both their life expectancy and the number of indications for chronic transfusion support also increases, the demand for phenotypically matched blood can only grow. For this reason, it is important that as many African-Canadians as possible make donations to Canadian Blood Services or Hema Québec, the two blood suppliers in this country.

Case Study:

A typical blood donation drive event within the African-Canadian community

In 2008, the Sickle Cell Awareness Group of Ontario formerly known as Seed of Life, co-hosted a blood donation drive at Queensway Cathedral church, Ontario, Canada

Prior to this event, members of the organization went out to various churches and community groups -to encourage them to donate blood. The organization targeted many African and Caribbean groups. A large number of individuals with African background, especially those of Nigerian background, came en-mass to donate blood on the appointed blood donation day.

Amazingly, over 50 willing African-Canadian donors were turned down at this location. The reason for this was that individuals from selected African countries, namely Cameroon, Central African Republic, Chad, Congo, Equatorial Guinea, Gabon, Niger and Nigeria are permanently banned from donating blood in Canada due to concern that they are at increased risk of carrying rare strains of HIV. This, we soon realized became an obstacle that we have to constantly deal with as we found out that majority of the people from the groups we are educating and encouraging to donate blood “were born in or have lived in certain Central and West African countries since 1977”. Despite the fact that many of these willing donors were otherwise healthy, the organization has had to change its focus and start to canvass for blood donation within the Caribbean countries instead. However, we should not refuse African blood and studying a country as Nigeria would show why we believe that Health Canada and CBS should relax the indefinite deferral questions posed to these ethnic nations.

Nigerian Canadians & Sickle Cell Disease

- Of the approximately 275 000 children born each year world-wide with sickle cell disease, approximately 85% are born in Africa (Modell, Bulletin of the World Health Organization 2008;86:480–487)
- With a population of 170 million people, Nigeria is the 7th most populous country in the world and by far the most populous country in Africa <https://www.cia.gov/>, accessed Mar 3 2012)
- Of the approximately 20 000 Canadians of Nigerian descent, over 13 000 live in Ontario, 10 000 of them in the Greater Toronto Area ² (<http://www.statcan.gc.ca>, accessed Mar 3 2012)
- The majority of Nigerian Canadians emigrated to this country 25 to 40 years ago
- Canadian Blood Services has documented approximately 1000 patients with sickle cell disease living in Central Ontario who have required a transfusion ³.
- Patients with sickle cell disease comprise a large proportion of requests received by Canadian Blood Services for phenotypically-matched blood: approximately 1500 requests are received per year from the Hospital for Sick Children, and 3000 requests are received by the University Health Network (Canadian Blood Services, personal communication)

Repercussions

Banning potential blood donors of West African descent prevents thousands of people, many of whom are likely to be strongly motivated by having friends and relations affected by sickle cell disease, from donating blood which is likely to be phenotypically matched for patients in need. This is despite their living in Canada for many years in good health and the availability of new tests which can detect HIV-1 Group O, the strain which initially justified the ban on individuals from West Central Africa.

In November 2009, Héma Québec (HQ) initiated discussions with Health Canada to remove the questions below

- ✓ Were born in or have lived in certain Central and West African countries since 1977
- ✓ Have received blood/blood products derived from blood from these countries since 1977
- ✓ Have had sexual contact with anyone who was born in or have lived in these countries since 1977 ⁴

This is to be able to meet the increasing demand for phenotypically matched blood for patients with Sickle Cell Disease (SCD). Due to concern that there may be other novel strains of the HIV virus emerging in these same countries, Health Canada has proposed retaining these questions, but modifying them so that they only apply to individuals who have experienced the above risk factors within the previous 12 months only. This would allow time for antibodies to any new strains of HIV to become detectable, which available testing can then see. Individuals who have had sexual contact with someone with the above risk factors would need to also demonstrate that their sexual partner has been in Canada for the past 12 months and has had a negative HIV antibody test.

Sickle Cell Awareness Group of Ontario (SCAGO) – Our Stand

- ✓ The current life-time blood donor deferral on patients from West Central Africa is excessive and prevents many willing and healthy donors living in Canada from donating blood which is in short supply for patients with sickle cell disease

- ✓ The proposed modification of the deferral criteria from lifetime to 12 months is a reasonable compromise which should allow for increased number of donations by this group without increasing the theoretical risk of HIV transmission

Sickle Cell Association of Ontario (SCAO)- Our Stand

There are people dedicated to helping individuals living with sickle cell, by donating blood, but are turned away for reasons we feel are very arbitrary. So we request that you consider re-evaluating your criteria and propose some solutions which will increase the blood supply, while maintaining the safety of the Canadian blood banks

Sickle Cell Anemia Association of Quebec (AAFQ, Association d'anémie falciforme du Québec)

- ✓ The current life-time blood donor deferral on patients from West Central Africa, and the persons that had been intimate with them, is excessive and prevents many willing and healthy donors living in Canada from donating blood which is in short supply for patients with sickle cell disease
- ✓ The proposed modification of the deferral criteria from lifetime to 12 months is the compromise reached with Hema-Quebec, which should allow for increased number of donations by this group without increasing the theoretical risk of HIV or malaria transmission
- ✓ For the same goal, the current donor deferral on women with an hemoglobin level under 12,5 g should be lowered to 12 g, in order to keep encouraging women to participate in blood drives⁵

Source:

Canadian Blood Services – www.blood.ca 1

2006 Census of Population Data 2

Canadian Blood Services- HIV 0 Slides 3

Héma Québec 4

16th COPI, Hema-Quebec campaign towards ethnic groups of influence over potential blood donors, March 17th 2011⁵

P.S: Contents of this letter was discussed with Dr. Jacob Pendergrast- Member, Expert Advisory Committee for Blood Regulation, which reports to Health Canada