Canada Celebrates World Sickle Cell Day.

World Sickle Cell Day Message From

Sickle Cell Disease Association of Canada/Association d'Anémie Falciforme du Canada (SCDAC/AAFC)

About World Sickle Cell Day

The World Health Organization (2006) and the United Nations (2008) have recognized sickle cell disease (SCD) as a global public health priority and in order to raise awareness of the disease, designated the 19th day of June every year as World Sickle Cell Day (WSCD). According to the World Health Organization (WHO) estimates, sickle-cell anemia affects nearly 100 million people throughout the world, with over 300 000 children born every year with the condition. Tragically, the majority of these individuals will die in childhood due to lack of basic care, and those who survive into adulthood are too often face a life of chronic disability and premature death unless disease-modifying therapy can be provided. The WHO therefore urges countries

affected by SCD to establish health programs at the national level and promote access to medical services for people affected by the disease[1]

[1]Ref: http://www.un.org/press/en/2008/ga10803.doc.htm

SCD in Canada

SCDAC/AAFC recognizes SCD as an increasingly important medical issue in Canada, with an estimated 5000 Canadians affected and over 100 children born with the condition annually; further increases in the affected patient population result from immigration. Amongst individuals with ethnic roots in regions of the world traditionally affected by malaria, the prevalence of the gene for sickle cell disease may be as high as I in 4. Individuals who carry this gene have an asymptomatic condition known as sickle cell trait and very often are not aware of the risk they carry of having a child affected with sickle cell disease. Without routine screening and awareness among the general public, the number of individuals in Canada with sickle cell disease will continue to increase, placing a significant burden both on families and the medical system as a whole.

Furthermore, the quality of care provided to sickle cell patients in Canada is still sorely lacking, with patients first stigmatized and branded as "drug seekers" when presenting for medical treatment for vaso-occlusive pain crises, and then denied access to the comprehensive care which could prevent those crises. SCDAC/AAFC, is doing its part to reduce this stigma, improve quality of care and knowledge translation among care providers, and establish national standards for the treatment of sickle cell disease in Canada.

We believe that the first step to addressing the burden of sickle cell disease is to increase awareness and understanding of this condition, and as such the SCDAC has sought for a national bill to recognize June 19 as National Sickle Cell Awareness Day in Canada. On December 8th 2015, on behalf of the SCDAC, Bill S-211 - An Act respecting National Sickle Cell Awareness Day - was introduced by Senator Jane Cordy. As of this press release, this bill has passed 1st reading and is currently in 2nd reading.

http://liberalsenateforum.ca/bills/s-211-national-sickle-cell-awareness-day-act/

SCDAC/AAFC also believes that early diagnosis of babies with SCD will improve health outcomes of the affected and as such continues to push for universal newborn screening (NBS) across the country. With 66.7% achievement rate, we urge the provinces of Alberta, Newfoundland & Labrador, Manitoba and Saskatchewan, and the Northwest Territories to join the other Canadian provinces and territories and include SCD in their NBS programs.

About SCDAC/AAFC

SCDAC/AAFC is committed to increasing awareness of SCD and enhancing methods of identification, diagnosis, and treatment with the goal of improving the quality of life of affected individuals and their families.

One of the most important treatments of sickle cell disease is the transfusion of carefully matched red blood cells. To increase the supply of this rare type of blood, SCDAC is marking the 2016 World Sickle Cell Day (WSCD) by championing blood donation drives amongst highly-desirable ethnic groups across the country. The targeted donation day is June 18th, with the following locations highlighted:

Blood Drive locations supported by SCDAC/AAFC on June 18th:

Alberta	Edmonton	8249-114 Street
Nova Scotia	Halifax	7071 Bayers Road
Ontario	Hamilton	Hamilton Blood Clinic. 35 Stone Church Rd. Ancaster, ON
	Mississauga	Heartland Town Centre Permanent location. 765 Britannia Rd. W.
	Ottawa	1575 Carling Ave.
	Downtown Toronto	Canadian Blood Services @ Bay & Bloor. 2nd floor by the Movie theatre. 55 Bloor St. W- Manulife Centre

Saskatchewan	Saskatoon	325 – 20 Street East

We encourage you to register to donate blood at: secretary@sicklecelldisease.ca

SCDAC/AAFC urges you to support the WSCD initiative by donating blood on June 18th and encouraging friends, families, neighbours, co-workers to donate blood. Don't forget to tweet @sicklecellca using #EachReachSix

"Many times, as a practicing hematologist, I have seen patients with sickle cell disease on the brink of death brought back to full health through the careful use of blood transfusions; for countless others, the use of regular blood transfusion support is all that stands between them and a devastating stroke. On the other hand, if anything other than the most carefully selected units of blood are transfused to patients with sickle cell disease, disastrous complications can arise. For this reason, it is critical that individuals of ethnic backgrounds similar to those of most patients with sickle cell disease (particularly those of West Central African origin) come out to donate blood. Previous restrictions at Canadian Blood Services have recently eased. There used to be a long list of African countries that were excluded because of the sensitivity of the HIV test; as the test got better, the list got a lot shorter....so more people from those countries that previously were deferred can now donate" provided Dr. Jacob Pendergrast, Clinical Hematologist and Transfusion Specialist, University Health Network.

What is SCD?

SCD or sickle cell anemia is a hereditary genetic disease characterized by the presence of abnormal crescent-shaped red blood cells. People with SCD have abnormal hemoglobin (called hemoglobin S or sickle haemoglobin) in their red blood cells. Hemoglobin is a protein in red blood cells that carries oxygen throughout the body. The lack of tissue oxygen can cause attacks of sudden, excruciating and severe pain, called pain crises. These pain attacks can occur without warning, with pain level often described as higher than childbirth labour pain and cancer related pain.

The red cell sickling and poor oxygen delivery can also cause organ damage. Over a lifetime, SCD can harm a person's spleen, brain, eyes, lungs, liver, heart, kidneys, joints, bones, or skin. It

can cause stroke in even children as young as two years old! At the present time, hematopoietic stem cell transplantation is the only cure for SCD.

Canadians affected by sickle cell disorders include Canadian-born and immigrants with diverse ethnic backgrounds - African, Caribbean, Mediterranean, Middle East, South America, South Asia etc.

Once again, SCDAC uses this medium to wish all a most impactful World Sickle Cell Day.

Sincerely yours,

Mrs. Lanre Tunji-Ajayi
President & Executive Director
Sickle Cell Disease Association of Canada/ Association d'Anémie Falciforme du Canada (SCDAC/AAFC)
PH: 416-951-6981
E-mail: president@sicklecelldisease.ca
Copy: secretary@sicklecelldisease.ca