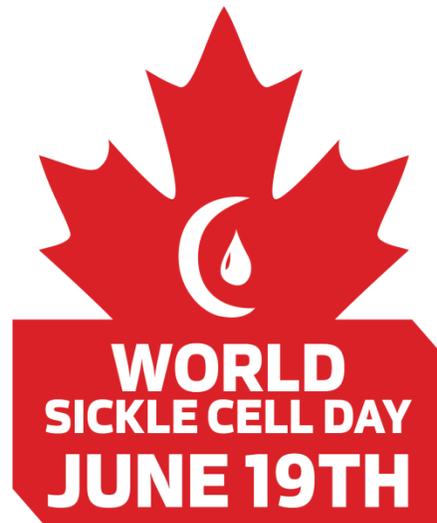


Canada Celebrates World Sickle Cell Day

World Sickle Cell Day Message



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 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 disease¹

¹Ref: <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 1 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.

SCD in Schools

Children and youths with sickle cell disease attend Ontario Schools. An important part of school inclusiveness is recognizing the importance of offering care to young people with long-standing illness, particularly since a major part of childhood is spent in attending school.

We are grateful to your school board for working closely with the Sickle Cell Awareness Group of Ontario (SCAGO) to ensure that students with SCD receive adequate support to excel in their academic endeavours

For more information on supporting students with SCD; kindly go to the links below

Link: <http://www.sicklecellanemia.ca/education.php>

June 19th Video Link: https://www.youtube.com/watch?v=8O_oWWD0zFU

School Flyer: <http://sicklecellanemia.ca/pulsepro/pulsepro/data/files/School-WSCD-June%2019th-flyer.jpg>

About SCAGO

SCAGO, established in 2005, is committed to increasing awareness of SCD and optimizing the lives of individuals living with the disease. It recently got the city of Markham and the town of Ajax to proclaim June 19th as World Sickle Cell Day.

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, SCAGO uses this medium to wish all a most impactful World Sickle Cell Day.

Sincerely yours,

A handwritten signature in black ink, appearing to read 'Tanya Williams', is shown on a light-colored background.

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