Recognizing June 19 as World Sickle Cell Day

June 19, 2014 - The Sickle Cell Awareness Group of Ontario (SCAGO), Sickle Cell Association of Ontario (SCAO), and the Thalassemia Foundation of Canada (TFO) have called for the recognition of June 19 as the World Sickle Cell Day in Ontario. The private member’s Bill 175\(^1\) introduced in the Legislature on March 19, 2014 seeks the proclamation of June 19 of every year as the day to recognize and promote awareness of Sickle Cell Disease in the province of Ontario.

The Sickle Cell Disease Association of Canada (SCDAC) also called for the recognition of June 19\(^{th}\) as National Sickle Cell Day in Canada as found in the private member’s Bill C-221\(^2\).

SCDIO, UN, WHO - Through the advocacy of the Sickle Cell Disease International Organisation (SCDIO), the support of the Republic of Congo and the Republic of Senegal, and the commitment in the scientific world, the African Union (in 2005), the United Nations Educational, Scientific and Cultural Organization (UNESCO) (in 2005), World Health Organization (WHO) (in 2006), and the United Nations (UN) (in 2008) Sickle Cell Disease was recognized as a public health priority. Consequently, June 19th of every year has been chosen to celebrate World Sickle Cell Day in order to raise awareness of the disease in the world\(^3\).

What is Sickle Cell Disease?

Sickle Cell Disease (SCD) is the most prevalent genetic disease worldwide. It is present on four continents: in sub-Saharan Africa and in the Maghrib, in Asia (Middle-East, Arabic peninsula, India), in the Americas, on the North (USA), centre (Guatemala, Caribbean islands), and on the South (Brazil, Surinam, Guiana), in Southern Europe (Southern Italy and Sicily, Greece, Turkey). Trans-continental, SCD is also trans-ethnic and affects black populations from African origin and Arabic, Indian, and Caucasian populations from Southern Europe.

Sickle Cell Disease is characterized by a mutation in the shape of the red blood cell from a smooth, circular shape to a crescent shape, which can result in the blockage of small blood vessels and the impairment of blood flow, thus leading to a reduction in red blood cell survival and subsequent anemia.

The life span of persons with severe SCD can be reduced by as much as 30 years.

It has been approximated that 5% of the world’s population carries the trait gene for Sickle Cell Disease, with the percentage of carriers of the gene being as high as 25% in some regions. It is
estimated that 1,000 babies are born world-wide every day with this severe and invalidating condition and that 50% of them will die before the age of 5 years.

The school may support students with Sickle Cell Disease on June 19th by:

- Displaying posters in schools
- Watching the awareness/educational video supplied by SCAGO
- Educating the students about Sickle Cell Disease

The school may support students with Sickle Cell Disease after June 19th by:

- Providing catch-up mechanisms for students with the disease when there is absenteeism from school due to illness
- Allowing frequent hydration and the resultant washroom breaks
- Ensuring water fountains are clean to reduce risk of infection
- Referring to The Teacher’s Guide from the Hospital for Sick Kids
- Ensuring that staff (teachers, social workers, etc.) attend sickle cell conferences and other educational sessions
- Seeking in-school presentations from SCAGO
- Including the IHCP in the students’ IEP
- Allowing and supporting them to function within their limits (especially during gym and other strenuous activities)

For more information on Sickle Cell Disease, visit:

1. [www.sicklecellanemia.ca](http://www.sicklecellanemia.ca)
2. [www.sicklecelldisease.ca](http://www.sicklecelldisease.ca)

For educational videos on various topics relating to Sickle Cell Disease, visit:

4. [https://www.youtube.com/user/scagovids](https://www.youtube.com/user/scagovids)

About the Sickle Cell Awareness Group of Ontario (SCAGO):
SCAGO is a multi-stakeholder group formed in 2005 to raise awareness, educate and facilitate better management and care of patients living with Sickle Cell Disease.
About the Sickle Cell Disease Association of Canada (SCDAC):
Established in 2012, SCDAC/AAFC is committed to increasing awareness about Sickle Cell Disease, enhancing methods of identification, diagnosis, and treatment towards improving the quality of life of affected individuals and their families.

To achieve our mission, SCDAC/AAFC supports the establishment of coordinated clinical services and research initiatives that will help with SCD treatments and efforts towards a cure.


http://www.unesco.org/new/en/unesco/events/allevents/?tx_browser_pi1%5BshowUid%5D=4087

Sincerely,

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