MIKE COLLE, MPP

Eglinton-Lawrence

Sickle Cell and Thalassemia Care Ontario, 2014
BACKGROUNDER

The *Sickle Cell and Thalassemia Care Ontario Act* would, if passed, establish a provincial body called Sickle Cell & Thalassemia Care Ontario, and proclaim June 19th to be Sickle Cell and Thalassemia Awareness Day in Ontario.

Sickle cell and thalassemic disorders are debilitating genetic diseases that can cause organ dysfunction, limit an individual's quality of life and shorten their lifespan. There are more and more children and adults in Ontario who have sickle cell or thalassemic disorders, although there are significant gaps in research about the prevalence of the disorders. It is estimated that 5 per cent of the world's population are carriers of genetic traits for sickle cell or thalassemic disorders.

Ontario has lead the way in recognizing the seriousness of sickle cell and thalassemic disorders. Ontario was the first province to establish screening programs to identify newborns who have sickle cell or other blood disorders. The next step is to provide provincial co-ordination of comprehensive healthcare. This is crucial for ensuring that individuals and families have lifelong access to quality healthcare, genetic counselling and social support.

Sickle Cell and Thalassemia Care Ontario is intended to improve the co-ordination of healthcare resources, promote awareness and education and advocate on behalf of individuals who have sickle cell or thalassemic disorders and their families.

In co-operation with healthcare professionals, hospitals, research institutions and advocacy groups, Sickle Cell and Thalassemia Care Ontario will develop provincial strategies for improving the co-ordination and quality of sickle cell and thalassemia healthcare.

Proclaiming June 19 as Sickle Cell and Thalassemia Awareness Day in Ontario increases awareness of these blood disorders and dedicates a day to support individuals who have sickle cell or thalassemic disorders and their families.

Sickle Cell Disorder (sickle-cell anemia or sickle-cell disease)

- Sickle cell disorder is a mutation in red blood cells where they are "sickle" shaped, which can cause blockages of blood flow and results in anemia.
- Sufferers experience crises of excruciating pain, progressive organ dysfunction, visual impairment, and premature death.
- Life spans of persons with severe sickle cell disease can be reduced by 30 years.
- Sickle cell disorders require lifelong care and interventions for preventable problems including management of pain medication, antibiotics, nutrition, folic acid supplementation and high fluid intake.
- Sickle cell disorder and the carrier gene are most common among people of sub-Saharan African, Indian, Saudi Arabian and Mediterranean origins.

- If two people who are sickle cell genetic carriers have a child there is a 1 in 4 chance the child will have sickle cell disorder and 2 in 4 chance they will be a carrier.

- A blood test called hemoglobin electrophoresis will determine a genetic trait or sickle cell disorder.

.

Thalassemic Disorders

- Thalassemia is a genetic blood disease where a person is unable to produce enough hemoglobin, which carries oxygen and is necessary for healthy red blood cells. The disorder also results in progressive organ dysfunction and premature death.

- Patients with severe thalassemia need regular blood transfusions and also iron-chelation therapy (to remove excess iron from the blood).

- Thalassemia is most common to people of Chinese, South Asian, Mediterranean, Middle Eastern and African origins.

- People from these regions are often carriers of thalassemic disorders and if two people who are genetic carriers have a child there is a 1 in 4 chance the newborn will have thalassemia major and a 2 in 4 chance the child will have thalassemia minor and also be a carrier.

- A special blood test called hemoglobin electrophoresis is needed to determine whether a person is a carrier.

Sickle Cell and Thalassemia in Canada and Ontario

- In Canada, the Sickle Cell Awareness Group of Ontario conducted a study which showed that 32 out of 40 African-Canadians carry the traits.

- Ontario is home to over 75% of Canadians living with sickle cell disorder, and the large majority of Canadians with thalassemic disorders.

Newborn Screening

- Ontario was the first province with newborn screening for hemoglobinopathies (including sickle cell disease) since 2006.

- Newborn testing for genetic traits is optional.

For additional information, please contact:

Dustin Cohen
Office of Mike Colle, MPP Eglinton Lawrence
Tel: 416-212-6326 Mobile: 647-523-3159
dcohen@liberal.ola.org