

## **Sickle Cell Disease Awareness Day and Thalassemia Awareness Day Act Passes Second Reading**

March 2, 2021

TORONTO — A Private Member's Bill co-sponsored by Andrea Khanjin, MPP for Barrie-Innisfil, and Rudy Cuzzetto, MPP for Mississauga-Lakeshore, will proceed to public hearings, as it passed second reading in the Ontario Legislative Assembly today, and was referred to the Standing Committee on Regulations and Private Bills.

Bill 255, the [\*Sickle Cell Disease Awareness Day and Thalassemia Awareness Day Act\*](#), would, if passed, proclaim June 19 as Sickle Cell Disease Awareness Day, and May 8 as Thalassemia Awareness Day.

"I am so thankful that I had the opportunity to meet with Lanre – Founder of the *Sickle Cell Awareness Group of Ontario* – when I was first elected, to learn more about how much of an impact this disease causes for so many people in our communities," said Khanjin. "To raise awareness on how important this issue is, in 2018 I hosted an event at Queens Park where people from across Ontario came to attend; and this Private Member's Bill is a major step to recognize people that live with these diseases, and the supports that are available to them."

"I'm pleased that Bill 255 has passed second reading," said Cuzzetto. "Sickle cell disease and thalassemia are the most common inherited blood disorders in the world, and yet awareness, research, and treatments lag far behind many other chronic illnesses. Recognizing these days in Ontario is a small but important step forward towards greater awareness of these conditions in our schools, workplaces, and hospitals across the province, and ultimately towards improving the lives of Ontarians living with sickle cell disease or thalassemia, and their families."

Sickle cell disease and thalassemia are inherited red blood cell disorders. As debilitating genetic diseases, they can cause severe chronic pain, organ dysfunction, bacterial infections, and many other serious complications. The lifespan of individuals with these disorders can be reduced by as much as 30 years.

June 19 is recognized annually as World Sickle Cell Day by organizations such as the World Health Organization, African Union, and the United Nations, including the United Nations Educational, Scientific and Cultural Organization. May 8 is recognized annually

as World Thalassaemia Day throughout the world and by the Thalassaemia International Federation.

“I’m looking forward to public hearings on this bill,” said Khanjin.

Once a date is set for Bill 255 to be debated at the Standing Committee on Regulations and Private Bills, members of the public will have an opportunity to attend (virtually), and to make presentations on the bill.

### Quick Facts

- Approximately five per cent of the world’s population are healthy carriers of the genes for sickle cell disease, with the percentage as high as 25 per cent in some regions.
- Although Ontario now offers universal newborn screening for these disorders, important gaps remain in our understanding and knowledge about their exact prevalence in our province.
- It is estimated that 3,500 people in the province of Ontario, and 6,000 in Canada, are living with sickle cell disorder. Over 150,000 people in Ontario are also estimated to carry the sickle cell gene.
- It is estimated that there are 1,200 thalassaemia patients in Canada, with more than 75 per cent living in Ontario. Toronto is home to the largest centre for thalassaemia comprehensive care in North America.

### Additional Resources

- [Sickle Cell Awareness Group of Ontario](#)
- [Thalassaemia Foundation of Canada](#)
- [Thalassaemia International Federation](#)

## What People Are Saying

“Globally, Sickle Cell Disease (SCD) and Thalassemia are the most common genetic blood disorders affecting millions of people. Preventable complications suffered by individuals affected by these disorders include damage to vital organs of the body and premature death. In the words of Sunday Afolabi, in whose memory the Sickle Cell Awareness Group of Ontario (SCAGO) was established, ‘I look forward to a day when no one will ever have to suffer from the debilitating complications of SCD’. The province of Ontario recognizing June 19 as World Sickle Cell Awareness Day, and May 8th as the International Thalassemia Awareness Day is a step in that direction as we work towards equitable care for individuals and families affected by sickle cell and thalassemic disorders. We thank MPP. Andrea Khanjin, MPP. Rudy Cuzzetto and every Member of the Provincial Parliament for supporting the Ontario sickle cell and thalassemia communities.”

**Lanre Tunji, Ajayi, Founder, Sickle Cell Awareness Group of Ontario**

“Thalassemia and sickle cell anemia are chronic, severe, and complex conditions that require multidisciplinary care delivered through comprehensive monitoring and treatment programs across Ontario similar to the province-wide care programs successfully established decades ago for cancer and other patient groups. We, at the Thalassemia Foundation of Canada, believe that increased awareness is a fundamental initial step that will drive forward the necessary positive changes and improvements desperately needed by patients. We are utterly appreciative of the Honorable Andrea Khanjin and the Honorable Rudy Cuzzetto and the distinguished Members of the Legislative Assembly of Ontario for standing with our patients and their families in acknowledging May 8th International Thalassemia Day and June 19th World Sickle Cell Awareness Day as awareness days in Ontario.”

**Riyad Elbard, President, Thalassemia Foundation of Canada**

“Sickle cell disease, the world’s most common genetic disease, is finally starting to receive the recognition it deserves, by both the medical profession, the pharmaceutical industry, and health care policy writers. As the first country in the world to officially endorse June 19th as World Sickle Cell Disease Day, Canada has an important leadership role to play as we enter an exciting new era of patient care, and cure.”

**Dr. Jacob Pendergrast, University Health Network, Toronto**

"The clinical team at the Children’s Hospital of Eastern Ontario are excited by this important initiative, which should hopefully result in long-term improvements to the care for this under-recognized population. Patients with Sickle cell disease have a daily

struggle with the complications of their disease with only one Health Canada approved treatment available to minimize these complications. Many patients with thalassemia are dependent on blood transfusions to survive and need daily medications to limit the complications of iron overload. The Awareness Bill put forward by Andrea Khanjin and Rudy Cuzzetto will be a small but important step towards improving the visibility and support that is sorely needed for the children and adults with these life-shortening disorders."

**Dr. Robert Klaassen, Children's Hospital of Eastern Ontario, Ottawa**

"I am looking forward to the day where due to society's extensive knowledge of SCD, stigma will be eradicated and the people living with the disease will no longer be discriminated against due to their health status and as such will be able to live life to the fullest of its extent."

**Marie-Pascale Poku, Chair, Patient Advisory and Advocacy Council, Sickle Cell Awareness Group of Ontario**

"Individuals living with sickle cell disease and thalassemia deserve our deep respect and support. These are common genetic blood disorders. All citizens require a good understanding of the inheritance patterns and carrier screening. By formally recognizing June 19th as World Sickle Cell Day and May 8th as World Thalassemia Day, we can expand awareness in our communities."

**Dr. Madeleine Verhovsek, McMaster Medical Centre, Hamilton**

"Thank you, MPP. Andrea Khanjin and MPP. Rudy Cuzzetto for helping to push this initiative forward."

**Dr. Ziad Solh, London Health Science Centre, London**

"Improving public, professional and government awareness of the burdens of sickle cell disease and thalassemia and the need for better access to diagnosis, comprehensive clinical care, community supports and therapies is life sustaining."

**John Adams, Community Advocate, Toronto**

"To have such a bill enacted to proclaim Sickle Cell and Thalassemia Awareness Day is the beginning of a new era. How many times have I spoken to families from different ethnicities only to find they were not aware of Thalassemia and the impact it may have on their lives and their loved ones. Most importantly to plan and to prepare for what is in store for them like days that are needed to be off work in order to bring their children in for transfusions. The evenings preparing for the subcutaneous injection that is delivered in their loved ones body, for a period of 10 to 12 hours. There are many more

considerations, for example mental health, different level of care and most importantly the will and determination of both parents and Thalassemia patients to live a normal and successful life. In my 32 years of raising twins both with Thalassemia, both with different needs, different treatments and care, I have seen both spectrums, one who is positive very successful and determined not to be stigmatized by this disease. The other more passive, less ambitious, struggling with compliance, lacking intelligence and requiring government assistance to no avail, as no one understands this disease and how it impacts these precious children and young adults. With a legislated act, I see a brighter future for these kids, I see professionals working together to educate and inform people. I see people making decisions that are theirs to make. Thank you MPP Rudy Cuzzetto and MPP Andrea Khanjin."

**Mary Alfano, Community Advocate, Mississauga**

"If we all stay humble and kind we can recognize the struggles everyone faces with empathy, while allowing space to create viable solutions and safe spaces for all of us."

**Shanicka Edward, Founder, Shak's World, Barrie**

"Empower Simcoe thinks everyone should have the opportunity to lead a meaningful life. Gaps in the Health Care system are challenging for individuals with sickle cell. Any opportunity to close these gaps would benefit the population and society at large."

**Claudine Cousins, CEO, Empower Simcoe, Barrie**

"Sickle cell anemia is a common genetic disorder that has been personally experienced by loved ones for me. Tosyn Bucknor, publicly known as Tosyn, is a friend from a very young age, and who I watch as she lived through the many painful crises ... of being a sickle cell carrier. She lived her life and lit up the world in everything she chose to do; a lawyer, an on-air personality, but most of all, a really great friend – a sister, a daughter that Canada will choose to recognize June 19th at this point in time – not just as a form of recognition, but to actually raise and increase awareness around this disease is a great step. Thank you in memory of the many Tosyn Bucknors across the world, living here in Canada by birth Canadian, or by adoption. We say thank you."

**Titi Akinsanmi, Local Entrepreneur and Data Privacy Professional, Innisfil**

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