



SCAGO

Sickle Cell Awareness Group of Ontario

May 13, 2020

York Region
17250 Yonge Street
Newmarket, ON L3Y 6Z1

Dear City Clerk's Office:

I would like to take this opportunity to introduce myself as the Communications and Marketing Manager for the Sickle Cell Awareness Group of Ontario (SCAGO).

Sickle Cell Awareness Group of Ontario also known as SCAGO is a member organization under the national umbrella of the Sickle Cell Disease Association of Canada.

It was established in 2005 to:

- Improve treatment and care received by patients living with SCD by providing better education about the disease to the medical and allied health professionals.
- Educate the community on SCD and sickle cell trait with the expected outcome of reducing the number of children born with the disease.
- Support those living with the disease by providing access to peer support group meetings, scholarships, learning for life seminars and advocating on their behalves with the Ontario Ministry of Health.

Sickle Cell Disease (SCD) or Sickle Cell Anaemia is a hereditary genetic disease characterized by the presence of abnormal crescent-shaped red blood cells. It affects Canadians of Asian, African, Mediterranean, Middle Eastern and Caribbean heritage. In 2005, it was estimated that over 2000 Ontarians are living with sickle cell disease and up to one in four from some specific cultural background carries the sickle cell trait. Most recent reports show that the incidence of SCD in Ontario is 1 in 2800 births (2015).

World Sickle Cell Day is observed on June 19 and has been recognized by the United Nation since 2008. On November 22, 2017, the Canadian government passed Bill S-211, enacting June 19th every year as "National Sickle Cell Awareness Day". World Sickle Cell Day was created to encourage global awareness and action to bring awareness through information, activities and concern. Globally, SCD has been recognized as a huge public health problem and "one of the world's foremost genetic diseases" (World Health Organization). According, to WHO

there are nearly 100 million people throughout the world affected by SCD and 300 million people who carry the SCD trait.

We are requesting the York Region to declare a Proclamation to recognize World Sickle Cell Day on June 19, 2020. Our missions below are aligned with the aim of a proclamation:

- Increase public awareness of sickle cell disease
- The great importance of education on SCD and the importance of genetic testing. This *may* reduce the # of new births.
- Improved awareness will assist in patients realizing there is a community across Ontario
- To give hope, inspiration and empowerment to the individuals living with sickle cell disease.

We were very fortunate, in 2017, 2018 and 2019 to partner with the CN Tower, Exhibition Princess Gates, Niagara Falls, the City of Toronto, the City of Markham, City of Newmarket, City of Brampton, City of Mississauga, City of London, and many others to illuminate their landmarks. We found that there was a lot of people talking on social media platforms about the disease and requesting more information to help. We were also astounded by the amount of SCD patients who reached out to tell us the ways this initiative made them feel empowered and able to share their experiences with friends and co-workers. As we continue to find new ways to raise awareness and to dispel the stereotypes surrounding SCD, we push to recognize SCD patients who continue to live with the disease, as well as those who have lost their lives.

We would like to request that on June 19, 2020, the York Region declare a proclamation to recognize World Sickle Day.

Thank you for taking the time to read this proclamation request. If you have any further questions, please don't hesitate to message me. I look forward to hearing from you.

Best Regards,

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Organization's Information

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