Provincial Mental Health and Social Support Hub for Sickle Cell Disease

Bridging the Health Equity Gap for Sickle Cell Disease in Ontario

Pre-Budget Submission to the Government of Ontario

December 2021

Prepared by:
Lanre Tunji-Ajayi, M.S.M
President/CEO,
Sickle Cell Awareness Group of Ontario
235-415 Oakdale Rd,
North York, ON. M3N 1W7

www.sicklecellanemia.ca

What is Sickle Cell Disease (SCD)?

- SCD is the most common genetically inherited disease in Canada.
- It is a severe, congenital disorder of the red blood cells, affecting individuals from diverse ethnic backgrounds – Mediterranean, African, Caribbean, Middle East, South America, and South Asia.
- More than 6000 Canadians and 3500 Ontarians (Kim et al) are affected, and that number is increasing annually in large part due to migration from countries with high disease prevalence, as well as natural increase within Canada from parents who carry SCD genetic traits.
- Individuals living with SCD experience chronic fatigue and episodic pain crises. Without proper, ongoing care, these individuals experience major health complications including organ failure, even at a young age.
- They also have compromised immune systems and are highly susceptible to infection. As such, they are at a higher risk of contracting dangerous communicable illnesses, such as COVID-19, and experiencing poorer outcomes compared to their peers who do not have SCD.

COVID-19 has demonstrated the critical need for targeted mental health and social supports for people living with SCD in Ontario

- The COVID-19 pandemic and the associated social distancing measures have further demonstrated the critical need for mental health and social supports for people living with Sickle Cell Disease in Ontario.
    - Lack of access to support networks and care services during the pandemic, or sole reliance on virtual alternatives, exposed the significant mental health burden that many individuals with SCD bear.
    - There is a high prevalence of anxiety and depression reported in SCD patients compared with the general population (Jenerette C et al, Comer W et al).
    - Research also shows that patients with SCD and depression experience less favorable medical outcomes than patients without depression (Belgrave FZ et al, Molock SD et al).
    - Individuals living with chronic pain, such as that experienced by those with SCD, is strongly associated with depression and other psychological disorders (Currie SR et al, Arnow BA et al, and Ohayon MM et al).
- Compounding this further is that in Ontario and across the country, SCD predominantly affects individuals who identify as Black.

- The persistent health disparities experienced by racialized communities creates significant barriers to health equity for Ontario's Black community, particularly those individuals with SCD who depend substantially on access to Ontario's health and social services and even more so for those who live outside of the Greater Toronto Area/ large urban areas.

***Recommendation*: Investing in a provincial mental health and social support hub for SCD will help save lives and improve health outcomes**

- The Sickle Cell Awareness Group of Ontario is advocating for ***a provincial mental health and social support hub*** providing both virtual and in-person programming for individuals living with sickle-cell disease (SCD) in Ontario.
- Improving mental health outcomes and social supports for Ontarians with SCD will reduce the number and frequency of costly and frequently preventable emergency visits and in-patient admissions experienced by SCD patients - freeing up much-needed hospital beds space and in-patient care resources.
- The proposed hub will offer a range of supports designed for those living with SCD, including individual counselling, fitness and wellness classes, and peer-to-peer support groups. The hub will offer both in-person and virtual supports, allowing patients from all across the province to easily access the resources available.
- SCAGO recommends that the physical hub be located in a non-clinical setting in the Greater Toronto Area, which has Ontario's highest proportion of individuals living with SCD who have the option to access in-person programs.
- The proposed hub would require ***a provincial investment of $4.5 million over 4 years*** to cover start-up and capital costs, specialized staffing, as well as programming and operations.

About the Sickle Cell Awareness Group of Ontario

- The Sickle Cell Awareness Group of Ontario (SCAGO) is a leading charitable patient support and advocacy organization providing evidence-based support to families with children, adolescents, and adults, with SCD across the four regions of the province.

References

Kim, E., Graves, E., Tunji-Ajayi, L. & Pendergrast, J. (2018). How Many Sickle Cell Disease Patients Are There in Ontario? Results of a Query of Health Services Administrative Databases. Retrieved from: https://sicklecellanemia.ca/how-many-sickle-cell-disease-patients-are-there-in-ontario

Currie SR, Wang J. Chronic back pain and major depression in the general Canadian population. Pain. 2004;107(1-2):54-60. [PubMed] [Google Scholar].

Arnow BA, Hunkeler EM, Blasey CM, et al. . Comorbid depression, chronic pain, and disability in primary care. Psychosom Med. 2006;68(2):262-268. [PubMed] [Google Scholar].

Ohayon MM, Schatzberg AF. Using chronic pain to predict depressive morbidity in the general population. Arch Gen Psychiatry. 2003;60(1):39-47. [PubMed] [Google Scholar].

Jenerette C, Funk M, Murdaugh C. Sickle cell disease: a stigmatizing condition that may lead to depression. Issues Ment Health Nurs. 2005;26(10):1081-1101. [PubMed] [Google Scholar].

Belgrave FZ, Molock SD. The role of depression in hospital admissions and emergency treatment of patients with sickle cell disease. J Natl Med Assoc. 1991;83(9):777-781. [PMC free article] [PubMed] [Google Scholar].