

TRUSTEE CONFERENCE REPORT

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Name of Conference: Canadian Congress of Black Parliamentarians (CCBP)

Sponsoring Organization:

Theme (if any):

Conference Dates: August 7-9 2024

Location: Ottawa, ON

Workshops/Seminars/Presentations/Keynote Speeches Attended:

I am pleased that I had the opportunity to attend the conference for the second year in a row. We gathered in the spirit of discussing how to improve the lives of Black Canadians.

The discussions took place against the backdrop of the many challenges faced by Canadians from all backgrounds. The many discussions that I participated in confirmed how important it is for all of us as Canadians to come together to find workable solutions that are impacting us.

One of the highlights for me was lending support to the sponsorship of Bill S-280 by Independent Senator The Honourable Marie-Francoise Megie. The Bill is, An Act Respecting A National Framework On Sickle Cell Disease.

Bill S-280 would require the Minister of Health to develop a national framework on sickle cell disease (SCD) that meets certain requirements. Please see contents of the framework below.

National framework

2 (1) The Minister of Health must develop a national framework on sickle cell disease.

Content

(2) The national framework must

- (a) include measures to address the training, education and diagnostic and treatment tool needs of health care professionals relating to sickle cell disease;**
- (b) provide for the creation of a national research network to advance research, improve data collection and establish a national registry on sickle cell disease;**

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(c) set evidence-based national standards for the diagnosis and treatment of sickle cell disease;

(d) include measures to ensure equitable access to neonatal screening, to diagnosis and to the provision of results for affected individuals and organizations;

(e) include measures to support public awareness campaigns on sickle cell disease; and

(f) include an analysis respecting the implementation of a tax credit for individuals with sickle cell disease and their caregivers.

Consultations

(3) For the purpose of developing the national framework, the Minister of Health must consult with

(a) the minister responsible for diversity, inclusion and persons with disabilities, the minister responsible for families, children and social development and any other minister who, in the Minister's opinion, has relevant responsibilities;

(b) representatives of the provincial and territorial governments, including those responsible for health, persons with disabilities, mental health and addictions;

(c) relevant stakeholders, including self-advocates, caregivers, support persons, service providers, representatives of the medical and research communities, and organizations that the Minister considers to have relevant expertise and experience relating to sickle cell disease; and

(d) any other person or entity that the Minister considers appropriate.