



Sickle Cell Disease
Association of Atlantic Canada
Association d'anémie falciforme
du Canada atlantique

Annual Report SCDAAC/AAFCA Activities from January to December 2020

Goal #1: Governance

Develop Board, Volunteers and Governance Document

Progress: It was agreed that each province in Atlantic Canada (NS, NB, PEI, NL) be represented on the Board. New individuals were evaluated and accepted to the Board totalling to 9 Board members. Committees were formed including fundraising, governance, nomination, and outreach and awareness. Additionally, policies were developed to guide the roles and the committees, the policies include governance, nomination, outreach and awareness, and a volunteer manual. Persons volunteered to lead the committees.

Goal #2: Advocacy

Establishing a clinic for adults with Sickle Cell Disease (SCD)

Progress: SCDAAC in collaboration with Thalassemia Foundation of Canada in advocating for a clinic for adults with SCD. SCDAAC had number of planning meetings with the President of the TFC sent a joint letter to Hon Minister Randy Delorey in September. An updated letter was sent to the Honourable Minister Leo Glavine after he was appointed as the new minister. In this letter, the minister was informed that the number of SCD patients has been increasing as a result of the newborn screening, immigration, and people relocating to NS for various reasons including work and school. As a result, there is the need for a comprehensive adult care clinic in the province. A meeting with minister was requested to discuss the need for adult clinic for SCD and thalassemia.

The Canadian Haemoglobinopathy Association, the Network of Rare Blood Disorders, the Canadian Organizations for Rare Blood Disease, Honourable David M. Wells, Senator of Newfoundland and Labrador; and Honourable Jane Cordy, Senator of Nova Scotia have sent letters in support our request to the Minister of Health and Wellness. We sent two reminders and have still not received any response, however, some the organizations that provided letters of support received response.

Next Step:

SCDAAC and TFC are in the process a communication strategy because it has been difficult to meet with the minister. First, we will reach out to local and national community informing that NS is not meeting the national standard for care as CANHAEM's national standard. Some of these organizations include Dalhousie - Researcher for Public Health



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– Drs. Ingrid and Dryden, HAAC, Game Changers 902, Black Physicians of Canada, the South Asian Allyship Organization, UACWA, and so on. Their input in moving forward would be crucial to achieve our goal of establishing a clinic for adults with SCD.

2. SCDAAC also advocated for individuals who needed supports and assistance while they were hospitalized, many of whom were new to NS and weren't sure how the healthcare system operates, and need long-term advocacy in multiple areas. (Illustrating again the need for comprehensive care as outlined in the 'Consensus Statement' – with proactive care and follow up, ER visits and hospital stays are reduced significantly)

Goal #3: Awareness and Education

1. Host Sickle Cell Disease Association national conference in Halifax June 18 – 20
Conference was cancelled due to COVID-19
2. SCDAAC used social media (Facebook, twitter and WhatsApp group) to engage and reach out to the community. These forums are used to share educational material, webinars, information, and support
3. SCDAAC shared information and links of many webinars hosted by SCD organizations across Canada regarding SCD treatments, SCD and COVID-19.
4. SCDAAC hosts a website; many families and adults with SCD have been able to connect with the Association.
5. SCDAAC obtained a standing banner, water bottles and pens with the new name and logo

Goal #4: Fundraising and Sustainability

Progress:

SCDAAC submitted funding proposals to:

1. Community Health Boards to support SCD patients (children) attend Brigadoon Camp. This camp provides specialised programs for children with chronic health conditions. An email has been received that one of CHBs provided partial funding.
Next step: the amount won't be enough to support families. There is a need to request for additional funding.
2. Government of Canada's Emergency Community Support Fund Canadian through Red Cross and Government of Canada – Round 1
Funding was received and SCDAAC provided laptops or tablets, grocery gift cards, and personal protective equipment.



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3. Government of Canada's Emergency Community Support Fund Canadian through Red Cross and Government of Canada – Round 2
Funding request was approved
4. Supporting Black Canadian Communities Initiative

A correspondence was received indicating that funding decisions have been made at this time and communicating the funding decisions for equipment projects in March 2021.

Next step:

Follow up funding requests where SCDAAC has not received a response; sign funding agreements and move forward with the implementation of the proposed projects.

<https://sicklecellatlanticcanada.ca/>