

Draft Date: November 10th 2014

Policy of the Sickle Cell Awareness Group of Ontario (SCAGO) to guide Regions and Chapters¹

Accountability: Sickle Cell Awareness Group of Ontario

Responsibility: Management and Board

Approver: Sickle Cell Awareness Group of Ontario Board Members

Approval date:

Last Revision date:
July 14, 2016

Review:
as necessary

Overview:

The Sickle Cell Awareness Group of Ontario (herein referred to as “SCAGO”) is a provincial association, formed to advocate for and support individuals with sickle cell disease. SCAGO advocates and lobby in a coordinated fashion on key issues to secure and maintain patient access to comprehensive care while empowering the patients and educating the medical and the allied health professionals that treat them.

The goals of the organization are to promote the health of our citizens, reduce pain and suffering, and help people to live as nearly normal lives as possible and to raise the level of awareness (education) and knowledge of the patients, medical and allied health professionals as the general community on the subject of sickle cell disease

We also need to inform the individuals living with sickle cell disease in the following key issues:

- Importance of clinical trials and patients involvement
- Importance of patient registries to facilitate access to quality care and existing and emerging therapies
- Improved access to drug therapies
- Treatment guidelines
- Educational guidelines to maintain same level of education across Canada
- Management of the disease

It is imperative that SCAGO is efficiently and properly represented, maintains the trust of our members and other stakeholders, and protects its credibility. The purpose of this policy is to create a framework to guide regions and chapters under the banner of SCAGO.

Guidelines:

1. Sickle Cell Awareness Group of Ontario herein referred to as SCAGO may set up chapters in different regions of the province.
2. SCAGO may also set up clubs, groups and programs in schools, hospitals, community health centres, community centres and in religious establishments to further its mission of Awareness and Education
3. Individuals applying for a chapter must submit a letter of intent and resume; volunteered with SCAGO for a minimum of 1-2 years, be in good standing (membership to date) and go through a screening process including an interview process
4. Chapter coordinator must have strong leadership skills and possess managerial and people's skills
5. Chapter coordinator must not have criminal record nor file for bankruptcy or proposal.
6. Chapter coordinator must understand the mission and vision of SCAGO and be true to it
7. Chapter coordinator must not be a member of any other sickle cell association in the province of Ontario nor have interest in setting up a parallel sickle cell association or program.
8. Chapter or coordinator must understand the strategic direction of SCAGO and be clear on its by-law and policies. A chapter or sub group may not create different bylaw but employ SCAGO's guiding rules.
9. A chapter may have sub-committees but not a board of directors
10. A chapter coordinator may be appointed by the SCAGO's management or board after careful screening
11. Chapter coordinator may not misrepresent but uphold the integrity of SCAGO in all dealings
12. SCAGO's president or executive director must be a co-signer in all chapter or sub-group documentations.
13. Chapter coordinator must submit quarterly reports to the executive lead of SCAGO. Failure to do so without adequate reasons and prior notice may result in disciplinary measures
14. Chapter coordinator must attend all training and retreats of SCAGO. Where unable to attend, a cogent reason must be provided to the president of the association
15. SCAGO must be visible at all its events.
16. Prior to embarking on any program, a proposal in respect to the program of interest must be presented in writing to the board for approval.
17. An event or program under the banner of SCAGO will remain a SCAGO event
18. Authorization must be sought for all events/programs before taking place.
19. Bi-yearly meeting must be held between SCAGO and chapter head

- 20. SCAGO’s name, logo or other identifying marks must be approved in writing by the Executive Director or Lead of SCAGO before it goes on flyers and other promotional materials.
- 21. A third party may not be invited to a SCAGO’s event/program without approval from the executive director or lead of SCAGO. An approval must be provided in writing.
- 22. SCAGO’s president or the executive director must be privy to, approve and co-sign all funding requests.
- 23. Funds raised by the chapters must be deposited with the CFO/treasurer of the association. No parallel bank account may be established by the chapters.
- 24. SCAGO does not encourage financial remunerations but gift cards for presenters at its events

Current programs available for chapters or sub groups

- Learning for Life™ Education Sessions
- Lunch & Learn Education Sessions
- Youth Group/ Young Adult Group
- SCAGO’s Peer Support Group
- SCAGO’ Parents Support Group
- SCAGO Sub- Group /chapter (city or region based)
- Emergency Funding
- Students/School Group

Name of Chapter coordinator: -----

City and region where the chapter will be established: -----

Signature of representative:-----

Date:-----

President, SCAGO:-----

Signature :-----

N:B: Carefully review the guidelines and only sign if agreed to the policy. Thank you