

Policy on Relationships with Corporate Partners for the Sickle Cell Awareness Group of Ontario (SCAGO)

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Accountability: Sickle Cell Awareness Group of Ontario

Responsibility: Management

Approver: Sickle Cell Awareness Group of Ontario Board Members

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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 and knowledge of the patients 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 maintains the trust of our members and other stakeholders, and therefore it is crucial to protect our credibility and independence, and to avoid conflicts of interest and the appearance of undue influence. The purpose of this policy is to create a framework to guide SCAGO with regards to its relationships with corporate partners and other external stakeholders.

General Principles:

SCAGO is committed to the following principles:

1. We will never compromise our independence.
2. We will be transparent as to our roles.
3. We will be open about our policy on relationships with companies, communicate it accordingly, and make it available to those who might wish to view it.
4. We will publicly recognize our financial contributors.
5. We will set ground rules for contributions and sponsorships.

Guidelines:

1. Companies providing funding for SCAGO will be asked to provide unrestricted funding to SCAGO, in an amount that takes into consideration:
 - a. the company's historical involvement with SCAGO (if applicable);
 - b. the needs of SCAGO;
 - c. the importance of the company in the Canadian market; and
 - d. Strategic opportunities.
2. SCAGO's Board Members will decide which programs, events, publications, or other opportunities will be eligible for sponsorship. The Board also reserves the right to determine appropriate sponsors, the type of sponsorship, and the length or duration of sponsorship.
3. General information about SCAGO policies, programs, activities, publications, etc. should not be restricted to one company, and should be imparted in such a way as not to confer commercial advantage to any one company or companies.
4. SCAGO will seek to involve more than one company where feasible in each program, event, or publication. Priority will be given to those companies who accept to share a sponsorship, if the total amount of the sponsorship pledged matches or exceeds that of an exclusive sponsor. Exclusivity in sponsorship will be accepted only when all companies have had the possibility to express an interest and no two companies are willing to jointly sponsor.
5. All sponsorships will be by written agreement prior to implementation of the relationship, and signed copies will be kept by both parties.

6. Recognition in SCAGO programs, events, and publications will be given to companies and not products manufactured by these companies.
7. Sponsorship will only be accepted when SCAGO retains full editorial and decision-making control of the program, event, or publication.
8. The promotion of any company is acceptable only in defined circumstances, such as clearly-marked company tables/kiosks at SCAGO events or presentations within medical symposia. When such events occur, all companies in the particular Canadian market must be invited. Information distributed must be approved under the provisions of the Pharmaceutical Advertising Advisory Board, the RX & D Code or other appropriate industry standards, and the Health Protection Act.
9. In the written acknowledgments recognizing the sponsor(s) and/or written agreements, it will be specified that the program, event, or publication was made possible by an unrestricted grant from companies X, Y and Z. It will also be stated that the acceptance of any sponsorship grant does not in any way imply SCAGO's endorsement of any one company or its product(s).
10. SCAGO will not accept to reproduce in its publications any article produced by a company.
11. SCAGO will carefully evaluate the pertinence of participating in an event organized by one company (for example, a company-sponsored workshop). SCAGO will ensure that we do not do something with one company that we would not do with others. Before considering participation, SCAGO must ensure that the company event is educational or social in nature (i.e. not focused on selling a product), that participation would enhance SCAGO's ability to pursue our mission, and that participation would not create confusion about the respective roles of SCAGO and the company.
12. Any use of SCAGO's name, logo or other identifying marks by donors or sponsors in promotional or educational materials must have the advance express written consent of the President/CEO of SCAGO. Any use granted should be specific as to duration, publication, and medium.
13. In the event that a representative of a company is involved in an event as a volunteer, his/her professional affiliation must be transparent.
14. Requests or opportunities for sponsorship received by SCAGO's volunteers, board or staff should be channelled through the President/CEO. No individual volunteer or staff should enter into an agreement or make promises of recognition without appropriate approvals.

15. SCAGO volunteers, board or staff may have business meetings with company representatives at an appropriate level. It is acceptable to accept meal invitations to conduct such business; however, volunteers and staff should not accept other privileges such as gifts or invitations/tickets to sporting or entertainment events.
16. If SCAGO volunteers, board or staffs are invited to participate in company-sponsored activities on behalf of SCAGO, it must be clear that such individual is representing SCAGO. If an honorarium is offered, it should be paid to SCAGO except where stated that the honorarium is for the representative.
17. SCAGO volunteers, board or staff should not accept a speaking engagement at a promotional event (e.g. pharmaceutical product launch). No volunteer or staff member should endorse any one product in preference to others, or participate in a company-sponsored event that could reasonably be interpreted as an endorsement of that company or its products.
18. SCAGO volunteers, staff or board should not accept individual sponsorships from companies to attend meetings, conferences, or congresses. SCAGO should endeavour to solicit general funding for such events from all companies, and then determine itself those who will represent SCAGO and the event.