



**SCAGO**  
Sickle Cell Awareness Group of Ontario

# **Strategic Plan**

## **2016-2021**

[www.sicklecellanemia.ca](http://www.sicklecellanemia.ca)

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# SCAGO

Sickle Cell Awareness Group of Ontario

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## ORGANIZATIONAL BACKGROUND

Sickle Cell Awareness Group of Ontario (SCAGO), previously known as Seed of Life Philanthropic Organization, was founded in 2005 in honour of Sunday Afolabi, the brother of the past president and founder of SCAGO Lanre Tunji -Ajayi.

Late Sunday Afolabi held a successful Engineering career prior to his death in 1999 when he later succumbed to the complications of Sickle Cell Disease (SCD).

In response to this loss, SCAGO was established to raise awareness and educate the public on sickle cell disease. SCAGO supports and contributes immensely to improve quality of life of individuals living with sickle cell disease across the province. SCAGO continues to advance care and treatment by supporting research and advocating with the government on behalf its constituents. SCAGO also liaises with community agencies and stake holders to bring more awareness to this disease.

As a non-profit charitable organization, SCAGO functions through a Board of Directors and volunteer management team that work effectively to support the sickle cell community in Ontario. In addition, SCAGO continues to procure and maintain the partnership of several key stakeholders within the community.

The organization holds annual general meeting and six boards of directors meeting yearly.



## Foreword from the President, Ms. Dotty Nicholas

### What is strategy?

Strategy is a guide to inform allocation of scarce resources towards intended social impact. As such, it is our goal to achieve the tightest fit between actions undertaken, resources expended and intended impact.

Intended impact, while more challenging to define, is more useful for decision making. At SCAGO, our intended impact statement is a reflection of what we intend to achieve and we are very grateful to those who spent numerous hours to ensure the success of the drafting of this strategic plan.

Thank you  
Dotty Nicholas  
President, Sickle Cell Awareness Group of Ontario

### Strategic Plan Drafting Team

1. Ms. Dotty Nicholas
2. Ms. Doreen Alexander
3. Ms. Moji Ogunsola
4. Ms. Ade Oyemade
5. Mr. Tosan-Atele Williams
6. Dr. Madeleine Verhovsek
7. Ms. Lanre Tunji-Ajayi

### Intended Impact of the Sickle Cell Awareness Group of Ontario:

“By 2021, Sickle Cell Awareness Group of Ontario would have served 1,500 patients and families with sickle cell disease in Ontario and ensures that they have access to comprehensive care and treatment as well as tangible interest in research initiatives consistent with other chronic diseases”.

As a result of our services, patients and families will experience less isolation, more stability, and improved knowledge of taking responsibility of their disease and thereby reduced complications.

As a result of our advocacy work, key decision makers will be aware of the impact of their decisions on the families that we serve, and will have access to progressive policy options.



## ORGANIZATIONAL VISION

Optimizing the lives of individuals and families living with Sickle Cell Disease

## ORGANIZATIONAL MISSION

To deliver optimal service that improves quality of life for patients and families

## ORGANIZATIONAL VALUES

**S:** Support patient and family centered approach to the planning & delivery of our services.

**C:** Committed to improve our services to our constituents.

**A:** Accountable for our services, resources and behaviours.

**G:** Gain recognition as the provincial voice for sickle cell disease

**O:** Openness and transparency in our services



## BOARD OF DIRECTORS

Name	Position
Ms. Dotty Nicholas	President
Mr. Ben Bere	Vice President
Mr. Neal Samson	Secretary
Moji Ogunsanya	Treasurer
Dr. Madeline Verhovsek	Board member
Tosan Atele-Williams	Board member
Ms. Doreen Alexander	Board Member
Mr. Ricardo Peguiro	Board Member

Advisory Committee	Occupation
Mr. John Adams	Chair, Canadian Organization for Rare Disorders
Dr. Olaniyi Ajisafe	Executive Director, Safe Care Medical Services
Mr. Nathan Downer	Reporter, CP24 Television
Rev. Audley James	Pastor, Revival Time Tabernacle Ministries
Dr. Melanie Kirby-Allen	Pediatric Sickle Cell Specialist, Sick Kids Hospital
Dr. Anne McLeod	Hematologist, Sunnybrook Hospital & Health Science Centre
Dr. Jacob Pendergrast	Hematologist, University Health Network: Toronto General Hospital
Dr. Ian Quirt	Retired Hematologist, UHN :Toronto General Hospital
Mr. Timothy Tunji-Ajayi	CEO, All Naturals Cosmetics Inc.
Ms. Lanre Tunji-Ajayi	President/CEO, Sickle Cell Disease Association of Canada

## Committees

### Board

Membership

Nominating

### Board/Management

Finance

Policy/Procedures

### Management

Chapter Planting

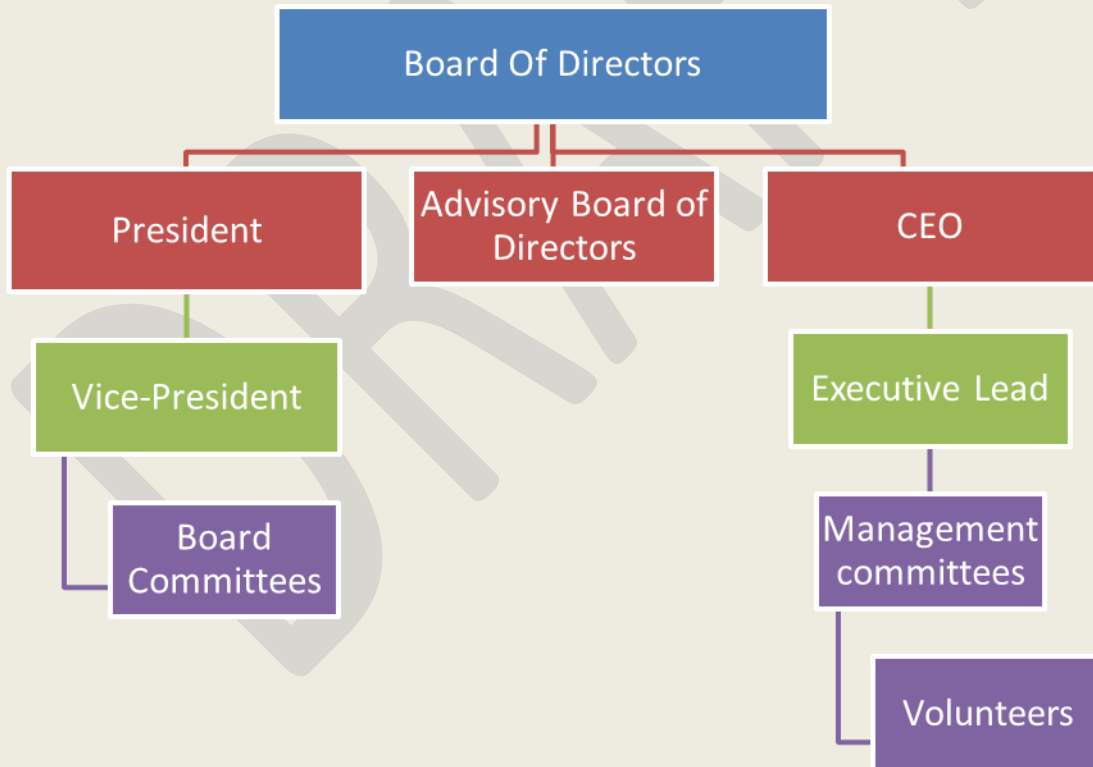


# SCAGO

Sickle Cell Awareness Group of Ontario

Communication
Education
Fundraising and Marketing
Health & Research
Outreach and Awareness
Support: Adult, Parent and Youth
Volunteer Committee

## ORGANIZATION STRUCTURE



### Strategic Pillars/Direction



# SCAGO

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Pillars are the guiding tools to support SCAGO's work. Given our patient and families centered approach, our pillars are geared towards improving the quality of life of those affected by sickle cell disease.

## Quality of Life Experience

### **Executor of Patients & Families Engagement**

Engage individual and families living with SCD in the planning and executing of complication preventative strategies required to optimize care

### **Innovator of a connected model of service**

Collaborate with hospitals and related agencies to design and implement initiatives to help improve access to services and education

### **Promoter of Applicable Research Strategies**

Support research to improve care and treatment





## STRATEGIC GOALS RELATED TO OUR VISION, MISSION AND VALUES

#	Goals	Objectives
1	Research	Promote and support research to improve treatment and ultimately find a cure for Sickle Cell Disease
2.	Care and Treatment	Achieve comprehensive care for individuals with SCD in Ontario by: <ul style="list-style-type: none"><li>a) Establishing a sickle cell Centre where programs and services can be provided to patients and families</li><li>b) Advocating with MOHLTC on behalf of patients and their families</li><li>c) Assuring and improving the quality of health care delivery to patients across the province by supporting the development and implementation of standard of care guidelines</li><li>d) Disseminating “best practice” guidelines for quality improvement.</li><li>e) Ensuring safe and adequate supply of phenotypic blood.</li></ul>
3.	Advocacy and Awareness	<b>Advocacy:</b> <ul style="list-style-type: none"><li>a) Continue to develop strategies to engage the Ministry of Health and Long Term Care around the development and implementation of evidence based practice tools required to support and prevent sickle cell complications in individual and families living with sickle cell disease</li><li>b) •Engage the Ministry of Health and Long Term Care on the importance of education on carrier status</li><li>c) Ensure sickle cell disease is visible to policy makers by holding bi-annual Action Day Ontario</li></ul>



		<ul style="list-style-type: none"> <li>d) Continue to advocate for the provision of healthcare resources/funding and access to care for individuals and families living with SCD</li> <li>e) Align SCAGO work with the Sickle Cell Disease Association of Canada mission and vision, to have a united front to support individual and families living with sickle cell disease in Ontario</li> </ul> <p><b>Awareness:</b></p> <ul style="list-style-type: none"> <li>a) Engage individuals and families living with sickle cell disease in the planning and implementation of complication preventative strategies required to optimize care</li> <li>b) Collaborate with Ontario hospitals to design and implement SCD initiatives to help improve awareness and access to treatment, and education</li> <li>c) Create awareness amongst health care professionals regarding the needs and experiences of families living with sickle cell disease.</li> <li>d) Promote public awareness of SCD</li> <li>e) Mobilize public support for the appropriate care of individuals with SCD.</li> <li>f) Create public awareness of the need to fund scientific and clinical advances in SCD.</li> <li>g) Disseminate positive images and information about SCD.</li> <li>h) Promote sickle cell trait counselling.</li> <li>i) Create chapters in different regions of the province as necessary.</li> </ul>
4.	Education and Support	<ul style="list-style-type: none"> <li>a) Develop multi- approach education interactive strategies and tools required to support knowledge transfer among the community hospitals professionals, public and individuals/ families with sickle cell disease</li> </ul>



		<ul style="list-style-type: none"><li>b) Lead and facilitate the development of a rich information-sharing environment to support care providers in the province</li><li>c) Engage schools to include SCD in their teaching curriculum and support plan. Be a primary source of information that provides valuable resources to patients and their families in Ontario.</li></ul>
5.	Advancement Through Collaboration	<ul style="list-style-type: none"><li>a) Under the banner of the National Association- the Sickle Cell Disease Association of Canada (SCDAC/AAFC); collaborate with other provincial sickle cell organizations and other agencies such as the Association of Ontario Health Centres (AOHC) Anemia Institute for Research &amp; Education, Canadian Organization for Rare Disorders (CORD), Network of Rare Blood Disorders Organizations (NRBDO), and the Thalassemia Foundation of Canada, as well as international bodies such as Global Sickle Cell Network (GSCN) to advance the interest of people with hemoglobinopathies.</li><li>b) Work with the Ministry of Health and Long Term Care (MOHLTC) to procure resources and establish policies in the best interest of SCD patients.</li><li>c) Establish a strong relationship with the Public Health Agencies in Ontario.</li><li>d) Network and seek membership opportunities with well-established health charities within Ontario.</li></ul>

## MEDIA RELATIONS



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In order to increase public awareness, education and support the community living with SCD SCAGO has extended its outreach methods to include ongoing media appearances and publication features. The following is a list of media outlets and stakeholders that have been utilized and are actively engaged in SCAGO's mission to heighten public awareness.

- Rogers Television
- Planet Africa Television
- Global Television: Featured in their community calendar listing of events and announcements.
- CTV community – Featured in their calendar listing of events and announcements
- Newspapers and Magazines – , Share Magazine, Ottawa Sun, Pride Magazine, Miles Magazine
- Radio Stations - 680 News, 1010 FM, CHRY 105.1 FM , 98.7FM

## **PARTNERSHIP / STAKEHOLDERS**

- Hospital for Sick Children
- Toronto General Hospital
- Brampton Civic Hospital (William Osler Health Center)
- Ottawa Hospital
- Children Hospital of Eastern Ontario
- McMaster Medical Centre
- Rouge Valley Health Center (Centenary Site)
- Pfizer Canada
- Apotex/Apopharma Canada
- Novartis Canada
- Public Libraries
- Sickle Cell Association of Ontario
- Camp Jumoke
- Sickle Cell Disease Association of Canada
- Thalassemia Foundation of Canada
- Parent Support Group Of Ottawa
- Canadian Blood Services
- National Rare Blood Disorder Organization
- Canadian Organization for Rare Disorder
- Faith Based Organizations
- Black Health Alliance



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- Public Schools, Community Colleges, and Universities
- Physicians' Offices
- Toronto District Health Council
- School Board
- Peel Public Health
- Association of Health Centres

## ESTIMATED COST OF EXECUTING SCAGO STRATEGIC DIRECTION

The following is a comprehensive list of requirements for the effective implementation of the SCAGO strategic direction outlined.

#	Action	Estimated Cost
1	Workshops & Seminars	\$15,000/year
2	Adult Program Coordinator	\$5,000/year
3		
4	Office Administration	\$10,000/year
5	Banners and Brochures	\$2,500/year
6	Aggressive Use of Ontario-wide Promotional Outlets, specifically Transit Buses & Subways, Billboards	\$10,000/year
7	Tele and Video Conferences	\$1,000/year
8	Other miscellaneous	\$5,000
9	The establishment of a Sickle Cell Center	\$200,000



## EVALUATION

As an organization, we believe in measurable success and accountability. In order to ensure and effectively monitor the efficiency of the aforementioned strategic plans, SCAGO will implement the following:

- Questionnaires will be formatted and distributed to program participants at various outreach locations in order to evaluate the success of the program.
- Evaluation forms will be made available online for members of the community to easily access and provide valuable feedback.
- Medical and allied health professionals will be evaluated at the end of each conference and seminar.
- Interviews will be conducted via telephone to receive feedback from patients and their families.
- Online surveys will be conducted as necessary



## QUANTIFIABLE DELIVERABLES

#	ACTIVITIES	EXPECTED RESULTS	PERFORMANCE INDICATORS	TARGET DATES	EVALUATION METHODS
1	Sickle cell awareness and outreach in the community	100,000 individuals and families educated to get tested for sickle cell disease	<ul style="list-style-type: none"> <li>i. Families and individuals learnt how and where to get tested.</li> <li>ii. Learnt what sickle cell trait means</li> <li>iii. Making informed procreation choices.</li> </ul>	December 2021	Feedback Questionnaires
2	One to one genetic counseling for individuals and families with sickle cell trait	50 individuals/ families with sickle cell trait counseled per year	<ul style="list-style-type: none"> <li>i. Families and individuals making informed choices</li> <li>ii. Reduction in the number of babies born with SCD</li> </ul>	December 2021	Feedback questionnaires Early Diagnosis and detection
3	Support Group for parents of children or individuals with SCD(Parenting)	<ul style="list-style-type: none"> <li>i. Increased coping skills of parents raising a child or living with an adult child with SCD</li> <li>ii. Improved management of SCD</li> </ul>	50 parent support group meetings (10 meetings per year x5 years)	Ongoing	Self-reporting during parent support group meetings; questionnaire feedback and online surveys
4	Youth (13-18 years)	20 group activities	<ul style="list-style-type: none"> <li>i. Social and relationship building</li> <li>ii. Mentorship</li> <li>iii. Self-esteem building</li> </ul>	December 2021	Increased participation in youth meetings; self-reporting of better coping skills; improved quality of life; feedback from questionnaire; reduced ER visits
	Adult Peer Support Group	50 adults on average to attend periodic peer	<ul style="list-style-type: none"> <li>i. Coping skills sharing</li> <li>ii. Improved management of disease</li> </ul>	On-going in the GTA.	<ul style="list-style-type: none"> <li>i. Increased participation and attendance</li> </ul>



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	18+	support meetings	<ul style="list-style-type: none"> <li>iii. Sense of belonging and not feeling alone.</li> <li>iv. Improved psycho-social health</li> <li>v. Decrease ER visits</li> <li>vi. Consistency in keeping medical appointment</li> </ul>	To be started in H-W by 2017	<ul style="list-style-type: none"> <li>ii. Self-reporting of better coping skills via online surveys and questionnaires</li> </ul>
5	Professional workshops and forums	50 workshops and forums and seminars over 5 years	<p>1500 patients/ families attend learning for Life sessions over 5 years</p> <p>Health care professionals attending and participating in seminars, webinars, workshops as well as Lunch and Learns in hospitals</p>	December 2021	Questionnaires, online survey and self-reporting
6	Research	<ul style="list-style-type: none"> <li>i. 250-300 or more patients and families /year show interest in clinical trials and research initiatives</li> <li>ii. 100 or more patients and their families attend each research forums</li> <li>iii. Facilitate and conduct research that improves service delivery and patients quality of life</li> </ul>	<ul style="list-style-type: none"> <li>i. Disseminated 10 or more key research initiatives/year to stakeholders through our websites, newsletters, and social media</li> <li>ii. Raised \$10,000 or more for research initiatives annually</li> </ul>	Yearly evaluations	Questionnaires, online surveys and interviews.
7	Liaise with other Community	50 or more events in 5	Increase awareness about Sickle Cell	December	Surveys and





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	Agencies	years	Disease	2021	questionnaires
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