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- Advocate with provincial governments to obtain designation and provincial funding for comprehensive care clinics across the country.
 - Promote data collection to support optimal evidence-based care and treatment.
 - Encourage patient adherence to evidence-based treatment protocols.
 - Organize national blood drives as well as stem cell registry drives.
 - Foster a strong collaboration with *Hema Quebec* and *Canadian Blood Services* to help raise more awareness around the need for more phenotypic blood supply.
 - Include the blood drive and stem cell registry information and events on SCDAC/AAFC website.

Desired Outcomes 2013–2018

- All people with Sickle Cell Disease will have access to comprehensive care, delivered according to national standards of care.
- Major hospitals in every province will have comprehensive care clinics to cater to the needs of individuals with Sickle Cell Disease
- Comprehensive care clinics would have achieved accreditation in accordance with the national standards of care.
- A national report card would have been published reporting the results of accreditation.
- Within this time period, most if not all provinces will have designated provincial funding for the establishment of comprehensive care clinics.
- More comprehensive care clinics would have been established within the country.
- All comprehensive care clinics will have adequate resources, based on standards of care, to provide care, offer psychosocial support, and conduct outreach care and services.
- Qualified physicians would have been attracted to the field of hemoglobinopathies, with a focus on Sickle Cell Disease.
- Qualified nurses, physiotherapists, social workers, and other health care providers would have been attracted to the field of Hematology, with interest in Sickle Cell Disease.
- There would be an increase in the phenotypic blood supply for all individuals living with Sickle Cell Disease.
- Qualified nurses, physiotherapists, social workers and other health care providers would have been attracted to the field of Hematology, with interest in Sickle Cell Disease.
- There would be more Black communities participating in the One Match Stem Cell Registry.



National Role	Provincial /Member Organization Role
MARAB to develop standards of care (in collaboration with health care providers and CANHAEM)	Develop and maintain a relationship with hospital administrations and ministries of health
MARAB to develop accreditation process (in collaboration with health care providers)	Advocate to maintain or enhance resources in comprehensive care clinics
Support the professional development of health care providers (e.g. annual meetings of various disciplines, New Team Workshop etc.)	Maintain a close relationship with the staff in comprehensive care clinics
Support chapters in their advocacy efforts to maintain and enhance comprehensive care clinics	Communicate with members to better evaluate care provided in comprehensive care clinics
Support member organizations to obtain provincial designation and funding for comprehensive care clinics	Advocate to obtain provincial designation and funding for comprehensive care clinics
Seek positions on all important national blood system committees so as to have a strong voice on behalf of people with Sickle Cell Disease	Seek positions on provincial blood system committees so as to have a strong voice on behalf of people with Sickle Cell Disease
Maintain and renew the expertise of our national volunteers and staff (when applicable)	Foster knowledge and expertise on blood system issues in each chapter.
Establish a national blood drive and stem cell registry strategy in collaboration with CBS and Hema-Quebec	Encourage provincial blood drives and stem cell registry campaigns



NATIONAL ADVOCACY & AWARENESS

Goal

Raise awareness of Sick Cell Disease among individuals with the disease, their communities, and health care providers. Also promote uniform newborn screening and follow-up counselling across the country.

Objectives

- Make SCDAC/AAFC programs and services better known to all people with Sick Cell Disease.
- Promote better understanding of Sick Cell Disease among health care providers who may come into contact with people with Sick Cell Disease (eg. in emergency rooms), in order to optimize diagnosis and access to immediate comprehensive care.
- Establish partnership with and have SCDAC/AAFC educational materials at community centres across the country.
- Provide information to health care professionals so they can better treat the disease.
- Provide educational information through outreach efforts to those who are carriers of the sickle cell gene.
- Establish a genetic counselling mechanism to educate carriers of the sickle cell gene.
- Work with the provincial ministries of health to ensure newborns are screened for Sick Cell Disease.
- Provide follow-up counselling to parents of babies diagnosed with Sick Cell Disease and/or Sick Cell Trait.
- Build pockets of awareness among those close to individuals with Sick Cell Disease (extended families, neighbours, daycare workers, teachers, employers.)
- Partner with the media houses to effectively raise more public awareness of the disease.

Some Key Strategies

- Provide tools to educate extended families, neighbours, daycare workers, teachers, employers, community workers, and coaches about Sick Cell Disease.
- Develop efficient tools for hematologists and nurses in comprehensive care clinics to reach out to other health care providers.



- Provide *Lunch and Learn* opportunities in hospitals that are currently without comprehensive care.
- Launch a targeted outreach campaign aimed at those with Sickle Cell Trait.
- Develop and implement a cause-related marketing strategy for Sickle Cell Disease.
- Create public and media events on World Sickle Cell Day.
- Work with the appropriate provincial governmental bodies to ensure the establishment of newborn screening.
- In collaboration with health professionals, SCDAC/AAFC member organizations to establish follow-up screening programs for parents of babies diagnosed with Sickle Cell Disease and Sickle Cell Trait.
- Present a plan to the Minister of Immigration.

Desired Outcomes 2013–2018

- Every person with Sickle Cell Disease would be informed annually of the programs and services offered by the SCDAC/AAFC.
- Every person with SCD, who is known to comprehensive care clinics, would be counted in the National Registry.
- The number of people with SCD registered in comprehensive care clinics and satellite clinics would have increased.
- More individuals living with Sickle Cell Trait would have been identified and counted in the National Registry.
- Public awareness around Sickle Cell Disease would have greatly increased.
- Corporate and individual donations would have increased as a result of public awareness.
- The number of community partners would have increased.
- Mandatory newborn screening for Sickle Cell Disease would have become part of the ministry of health's requirement for all provinces.
- All newcomers to Canada would have access to information on Sickle Cell Disease. Access to information will help to raise more awareness among carriers, encourage testing, and reduce the number of children born with SCD.
- New immigrants living with SCD would be able to access immediate care and contact SCDAC/AAFC's local advocacy group for support.
- More individuals making informed pre-sickle cell birth decisions.

National Role	Provincial/Member Organization Role
Work with member organizations and	Involve the hematologists and nurses



the available comprehensive care clinics to develop a package of information that can be delivered annually to all individuals living with Sickle Cell Disease	working in comprehensive care clinics in reaching out to health care providers in hospitals with no comprehensive care program for Sickle Cell Disease (for example, involve them in establishing the <i>Lunch and Learn</i> program in these hospitals)
Maintain and develop tools for community education.	Participate in social club events (e.g. Lions, Kiwanis, Chamber of Commerce etc.) to raise awareness about Sickle Cell Disease
Establish a multidisciplinary working group focused on outreach	Publish articles on Sickle Cell Disease in local newspapers
Create a targeted outreach campaign aimed at identifying those with the trait. Collaborate with national community organizations such as the <i>Cote-de-Neiges Black Community Association</i> in Quebec, and the <i>Ontario Black History Society</i> in Ontario	Encourage collaboration between chapters and community associations. Use community events to propel Sickle Cell education
Create materials and provide support for public and media events on World Sickle Cell Day	Organize public and media events on World Sickle Cell Day
Collaborate with member organizations to ensure newborn screening is available in their provinces	Member organizations to lobby for newborn screening in their provinces
Establish follow-up programs for parents of babies with Sickle Cell Disease and Sickle Cell Trait that have been identified through newborn screening	Implement the SCDAC/AAFC follow-up programs created for parents of babies with Sickle Cell Disease and Sickle Cell Trait as identified through newborn screening
Collaborate with Immigration Canada to provide newcomers with sickle cell information	Support the national organization on this initiative



EDUCATION AND SUPPORT

Goal

- Provide effective delivery of information and support to patients and their families in both English and French.
- Identify at-risk communities and provide preventative information in both English and French.
- Mobilize a broad spectrum of partners to provide resources and support for every individual living with Sickle Cell Disease.

Objectives

- Determine the needs of and provide the support needed by children and adults living with Sickle Cell Disease by combining the collaborative efforts of the provincial chapters/member organizations, the national organization, and the comprehensive care clinics.
- Increase utilization of the existing educational and support programs of each member/provincial chapter.
- Increase the level of knowledge and understanding of managing Sickle Cell Disease among patients, their families, and educators.
- Create and deliver relevant educational materials in both paper and electronic forms.
- Establish an educational committee to coordinate the materials for SCDAC/AAFC.
- Establish programs and make them accessible to individuals living with Sickle Cell Disease.
- Create, maintain, and update the SCDAC/AAFC catalogue of educational materials.
- Develop new materials if and when needed.
- Support innovative learning environments such as webinars and other interactive networks.

Some Key Strategies

- Encourage the integration of educational programs into member organizations' social events.
- Encourage all patients to obtain provincial/member organization as well as SCDAC/AAFC membership.
- Enlist the support of all comprehensive care clinics in recruiting members.



- Remain current in the use of the internet and social media so as to better communicate information and allow members to be well-connected.
- Enhance evaluation and encourage timely feedback from provincial/member organizations post-program and/or service delivery.
- Identify the core programs and services to be offered nationally
- Improve collaboration and communication between provincial/member organizations and the national organization.
- Clarify the roles and responsibilities of the member organization and the national organization in the delivery of information, programs, and support.
- Establish a strong communication strategy to work as effectively with the French speaking members as with the English speaking members.
- Provide training for member organizations through webinars and other online tools.
- Improve skills in order to advocate and lobby effectively.

Desired Outcomes

- A defined set of core programs and services will be offered nationally.
- Every person with Sick Cell Disease registered in a comprehensive care clinic will be informed of the existence of the SCDAC/AAFC and its programs and services.

National Role	Provincial/Member Organization Role
Maintain and update SCDAC/AAFC's catalogue of educational materials in both English and French, and subsequently distribute these materials to the member organizations for their perusal	Increase utilization of existing educational and support programs. Chapters to submit new materials to SCDAC/AAFC for approval before printing. Chapters to use official SCDAC/AAFC materials
Collaborate with chapters and health care providers to determine the educational and support needs of people with Sick Cell Disorder	Collaborate with the national organization to determine the educational and support needs of people with Sick Cell Disease
Develop new materials and pilot workshops if and when needed, and distribute to all chapters	Develop pilot workshops if and when needed, and share results
Deliver paper documents to clinics and chapters	
Act as a clearinghouse for educational	Integrate educational programs and



documents for members	distribute educational materials at chapter events
Develop and maintain the national website and a presence on appropriate social networks	Provide peer support through social events, workshops, family weekends, and education days
Support chapters in developing provincial sections of the national website	Develop content for provincial sections of the national website
Publish a national news magazine to be available in both French and English	Publish provincial newsletters or communicate key information through the SCDAC/AAFC news magazine and the national website
Hold annual medical and scientific symposia	Provide parent-to-parent support and direct aid to members when possible
Evaluate program and service delivery	Evaluate and provide feedback to the national organization post-program and/or service delivery

ADVANCEMENT THROUGH COLLABORATION

Goal

To advance the objective of the SCDAC/AAFC by collaborating with other national patient organizations, organizations for rare red blood cell disorders, and ministries of health.

Objectives

- Gain valuable experience from networking with organizations with similar objectives and goals.
- Work closely with organizations such as CORD, NRBDO, Thalassemia Foundation, Health Charities of Canada Coalition (HCCC) and the Hemoglobinopathy nurses and medical doctors' groups in order to pursue a common goal for rare and red blood cell disorders.
- Develop and maintain a strong relationship with SCDA and Global Sickle Cell Network, Hemoglobinopathy Group of Canada, and any other organizational body that would cultivate a strong root for SCDAC/AAFC.



- Seek mentorship opportunities from established health charities such as HCCC, Parkinson Society and Cystic Fibrosis.
- Increase the stakeholder database with representation not only from the SCD communities, but also from society at large.

Some Key Strategies

- Meet with the leaders of the organizational bodies and discuss collaboration.
- Apply for and maintain membership with these bodies.
- Enlist the support of these bodies in developing programs and educational materials.
- Engage in joint projects with these bodies.
- Enlist the support of the appropriate bodies when approaching the provincial Ministry of Health on issues specific to each province.
- Improve collaboration and communication between these bodies and SCDAC/AAFC.

Desired Outcome

- SCDAC/AAFC would piggyback on these bodies in achieving some of its objects.
- SCDAC/AAFC would not work in isolation on many important projects common to red blood cell disorders.
- SCDAC/AAFC would be recognized by the ministries of health across the country.
- The resources and partnership provided by the different bodies would help to propel SCDAC/AAFC forward in its mission.
- Huge advancement would be achieved as a result of increased collaboration, input, and mentorship from outside the sickle cell communities.

National Role	Provincial/Member Organization Role
Collaboration with national bodies such as the <i>Canadian Organization for Rare Disorders (CORD)</i> , <i>Network of Rare Blood Disorders Organizations (NRBDO)</i> , <i>Health Charities of Canada Coalition</i> , <i>Thalassemia Foundation of Canada</i> and the <i>CANHAEM</i>	Ensure that member organizations understand the process of working closely with the Ministry of Education, and receive the modus operandi to achieve success in such endeavours.
Seek Mentorship opportunities with other established Canadian patient organizations	Pass down resources and support received from mentoring Canadian Organizations to SCDAC/AAFC member



	organizations
Collaborate with international bodies such as <i>Global Sickle Cell Network (GSCN)</i> , and <i>Sickle Cell Disease Association of America (SCDAA)</i>	SCDAC to pass down the resources and support received from international bodies to its member organizations and list such members on its website in a prominent location
Ensure that member organizations receive adequate support from these bodies at their provincial/chapter levels	Member organizations to work closely with the partner bodies in their provinces

FUNDRAISING AND ORGANIZATIONAL SUSTAINABILITY

Goal

Collaborate with health partners, sponsors, and donors to raise and allocate funds for the above objects.

Some Key Strategies

- Build support for the SCDAC/AAFC from members' social networks (families, friends, social clubs, religious groups, schools, local businesses etc.)
- Develop and implement integrated (chapter/national), planned giving appeals to members.
- Financially support one program per chapter.
- Collaborate with chapters to cultivate major giving opportunities among the members and their social networks.
- Disseminate the chapter fundraising initiatives (golf tournaments, bike-o-thons, special events, gala etc.)
- Collaborate with *Canadian Institute of Health Research (CIHR)/Small Health Organizations Partnership Program (SHOPP)*.
- Seek sponsors from the public and private sectors.
- Establish a fundraising committee to work on SCDAC/AAFC fundraising initiatives.

Desired Outcomes 2013–2018

- The pharmaceutical sector will continue to be a strong supporter of the SCDAC/AAFC.
- Health partners will become a significant source of funds for the chapters and the national organization.



- Annual giving from the expanded membership and their social networks will become a source of funds for the chapters and for the SCDAC/AAFC research program.
- Planned giving appeals targeted at the membership will be implemented.
- The national organization, chapters, and members will contribute annually a set amount to the national body.
- The national organization and member organizations will have the resources necessary to achieve the mission and the goals of the organization.
- The national organization and member organizations will maintain balanced budgets.
- The national organization will be able to sustain \$10,000 or more in a contingency fund.

National Roles	Provincial/Member Organization Roles
Maintain and build stronger collaboration with the pharmaceutical sector at the national level	Continue to work with the pharmaceutical sector to secure annual support for chapter/member organizations' programs and services
Develop and implement a social marketing strategy for Sickle Cell Disorders	Seek support from provincial governments and local businesses
Develop and implement integrated (chapter/national) planned giving appeals to members	Participate in (or lead, where capacity permits) an integrated chapter/national appeal to members to support chapter programs and services and the national research program
Create a national system to support chapter/member organization fundraising initiatives	Organize fundraising initiatives (golf tournaments, bike-o-thons, special events, galas etc.)
Collaborate with chapters/member organizations to cultivate major giving opportunities among their membership and their social networks	
Support provincial chapters on one program per year	Apply for support for educational programs



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