



GUIDELINES AND POLICIES FOR THE

RESEARCH ADVISORY COMMITTEE (RAC)

Of the

SCDAC/AAFC

1

The Sick Cell Disease Association of Canada strives to improve the health and quality of life for all people with sickle cell disease and to find a cure

**March
2015**

We will provide support, and work to increase knowledge, awareness and understanding among members of the sickle cell disease community including health care professionals

**Updated
Feb. 2017**

We will create greater public awareness of sickle cell disease and of our organization



The Research Advisory Committee:

The Research Advisory Committee will establish the research priorities of the SCDAC/AAFC, its strategic research partnership and run the research program in the most effective way possible. SCDAC/AAFC's research agenda will not be limited to fellowships, basic research, clinical research, research by young investigators but also include social and psychosocial research initiatives. Hence RAC should include psychologists, social workers, and nurses in addition to academic clinicians. The research agenda designed by RAC must be best suited to the persons and processes served by the organization.

TERMS OF REFERENCE

PURPOSE: The purpose of this committee is to advise the SCDAC /AAFC Board of Directors on its research programs so as to maximize its impact.

OBJECTIVES:

- Help the SCDAC/AAFC establish research priorities and policies;
- Help the SCDAC/AAFC run its research programs in the most effective way possible;
- Help the SCDAC/AAFC establish strategic research partnerships;
- Support the Research Peer Review Committee of the SCDAC/AAFC.

2

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DUTIES AND RESPONSIBILITIES:

- Advise the SCDAC/AAFC on research priorities within the field of hemoglobinopathy that will allow the SCDAC/AAFC research programs to have maximal impact;
- Advise the SCDAC/AAFC on the types of research programs (e.g. fellowships, basic research, clinical research, research by young investigators, qualitative research...) that are best suited to the persons and processes served by the organization;
- Establish and regularly review the terms of reference and operating parameters for the Peer Review Committee;
- Advise the SCDAC/AAFC about the membership of the Peer Review Committee;
- Advise the SCDAC/AAFC on ways to improve the application and granting process;
- Advise the SCDAC/AAFC on ways to better publicize the existence of its research programs and the results of the research conducted;
- Guide the SCDAC/AAFC in exploring and establishing strategic partnerships that will be beneficial to both parties;
- Provide any other advice that will benefit the SCDAC/AAFC research programs, including ways to resolve conflicts that may arise from the Peer Review Committee, its operation or recommendations;
- Proactively raise issues of importance, and conflict of interest concerning research;
- Commit and dedicate to SCDAC/AAFC's research agenda;
- Report annually to the national Board of Directors on the status state of SCDAC/AAFC research programs.

3

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OTHER DUTIES AND RESPONSIBILITIES:

The Committee will:

- a. undertake timely, extensive review of materials from time to time;
- b. establish policies and guidelines as deemed fit;
- c. establish the grant application document;
- d. participate in meetings/teleconferences as called by the Chair/Support Chair;
- e. submit feedbacks and updates to the Chair/Support Chair.

The Chairperson will:

- a. chair the meetings and delegate responsibilities;
- b. review the agenda and minutes for each meeting;
- c. provide written feedback to RPRC on funding recommendations submitted by RPRC;
- d. report to the Board via the president on the final research priorities to support;
- e. the supporting chair will step in to the role of the chair should the chair refuse or unable to fulfil duties effectively and in the same token, the chair may assign another support chair should the support chair be inefficient.

4

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MEMBERSHIP AND TERMS OF OFFICE:

The Committee must be ready, able and willing (RAW) to ensure SCDAC/AAFC has a successful research agenda. It shall consist of not fewer than five members and not more than twelve members and shall be composed as follows:

a. **Chair and Support Chair:** The initial selection shall be done via survey. Thereafter, these roles shall be appointed by the SCDAC/AAFC Board of Directors and they shall be eligible to hold the position for a two terms of three years with yearly renewal. If the Chair resigns during the term, a successor will be appointed for the time remaining in that term. Chair and Support Chair shall ideally be individuals with strong research background in the field of hematology.

b. **Membership:** The initial members of the committee will be selected based on survey. Thereafter, the members of the committee will be appointed by the Chair and Support chair in consultation with the board and will consist of individuals with relevant research interests, skills or experience. In choosing members, consideration should be given to varied representation from different disciplines (medical, nursing, physiotherapy, psychosocial). One or more members representing the patient and family member perspective may also be on the committee. The term of appointment for members shall be two years and members shall be eligible for re-appointments. To ensure continuity, efforts must be made to ensure that the majority of the Peer Review Committee members do not rotate at one time.

c) **Ex-officio:** The SCDAC/AAFC President/Executive Director will be a non-voting member of the Peer Review Committee to provide support, documentation and linkage with the SCDAC /AAFC Management and Board of Directors.

5

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TIMING, NOTICE OF MEETINGS & QUORUM:

The Committee shall meet in person or by teleconference at such other times as the Chair may require a minimum of two tele-conferences and one face to face meeting/year to review applications and make recommendations on awards is preferred. Unless otherwise agreed, notice of each meeting confirming the venue or mode of meeting, time and date, together with an agenda of items to be discussed, shall be forwarded to each member of the committee no fewer than 14 days prior to the date of the meeting. At least half of the members of the Research Advisory Committee must be present at a meeting to constitute a quorum.

AUTHORITY:

The Research Advisory Committee is a standing committee of the SCDAC/AAFC. It reports through its Chairperson to the President/Executive Director who in turn reports to the Board of Directors; the Chairperson also keeps the Research Peer Review Committee informed of its activities.

6

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