



Policies and Procedures for Special Interest Groups (SIGs)

Purpose

The purpose of Special Interest Groups (SIGs) within the Cardiac Neurodevelopmental Outcome Collaborative (CNOCC) is to facilitate multicenter, multinational, and multidisciplinary (including patients and caregivers) collaboration to further the vision and mission of CNOCC. SIGs are formed by CNOCC members and are focused on a specific topic or interest area related to cardiac neurodevelopment.

Procedure for Forming a SIG

Any CNOCC member affiliated with a CNOCC Institutional Member site may apply to form and chair a SIG. In the case of Co-Chairs, at least one Co-Chair must be affiliated with a CNOCC member site, whereas the other Co-Chair can be a non-affiliated CNOCC member (Patient/Caregiver member or SIG/Committee-Only member). See the Membership section of the CNOCC website (www.cardiacneuro.org) for information about membership types and associated annual dues.

The Application for SIG Formation (max. 2 pages) should include the following information and should be emailed to the CNOCC Members at Large for review and approval by the CNOCC Steering Committee:

- the name and chair(s) of the proposed SIG,
- short-term goals (years 1-2),
- long-term goals (years 3-5), and
- the knowledge, clinical, education, policy and/or advocacy gap(s) the SIG will address.

Applications will be reviewed by the Steering Committee and voted on for approval. Once a SIG is approved, any individual with an active CNOCC membership (Affiliated Membership, SIG/Committee-Only Membership, Patient/Caregiver Membership) will have the option of joining the SIG.

SIG Leadership

Every SIG should have a Chair (or Co-Chairs) that is/are elected by the SIG membership for a two-year term. Each Chair (or Co-Chairs) can serve a maximum of two consecutive terms (with no limit on non-consecutive terms). For newly formed SIGs, founders/co-founders will serve as Chair (or Co-Chairs) for the first two-year term and elections will be held thereafter. In the case of a sole SIG Chair, this individual must be affiliated with a CNOCC member site. In the case of SIG Co-Chairs, at least one Co-Chair must be affiliated with a CNOCC member site, whereas the other Co-Chair can be a non-affiliated CNOCC member (Patient/Caregiver member or SIG/Committee-Only member). Co-Chairs from different institutions, disciplines, and/or roles are encouraged.

Each SIG should have a succession plan in place, which includes a method for electing a new chair (either due to term expiring or the chair(s) opting to step down). As such, SIGs are encouraged to consider positions of SIG chair-elect and SIG past-chair to facilitate smooth transition of leadership responsibilities. Other officers (e.g., SIG Secretary, SIG Student/Trainee Representative, SIG Patient/Caregiver Lead) may be elected or appointed at the discretion of each SIG. If this is the case, responsibilities for each office should be clearly detailed in a position description document outlining defined roles and responsibilities. Each of the individual officer terms can commence/terminate in a staggered fashion so as to maximize board experience and facilitate smooth transition of leadership responsibilities. Each SIG is responsible for holding its own elections and (self- or other-) nominations.

SIG Responsibilities

SIGs have a responsibility to further the mission and uphold the image of CNOc through the advancement of cardiac neurodevelopmental research, quality improvement, clinical care, education, outreach, and advocacy. SIGs should serve as a forum for collaboration within the interest area and be a resource in the dissemination of knowledge and information related to this area of cardiac neurodevelopment.

1) No SIG shall communicate an opinion or position in the name of CNOc without formal (in writing) approval from the CNOc Steering Committee. SIGs are encouraged to include their name (____ *Special Interest Group of the Cardiac Neurodevelopmental Outcome Collaborative*) and CNOc logo on scientific and community publications and educational/outreach materials, but these materials must first be reviewed and approved by the appropriate CNOc Standing Committee (e.g., Publications, Education & Training, or Community Outreach Committees) and/or Steering Committee. Requests for review and approval should be directed to the CNOc Members at Large.

2) Any individual with an active CNOc membership (Affiliated Membership, SIG/Committee-Only Membership, Patient/Caregiver Membership) will have the option of the joining one or more SIGs. Individuals from institutions that are not members of CNOc must submit an application for SIG/Committee membership and pay the associated fee prior to joining one or more SIGs. Membership will be verified annually by CNOc and individuals who do not meet the stated requirements will be removed from SIGs after a 6-month grace period.

3) Fundraising by a SIG to support SIG activities is discouraged as there is no existing structure to assist with these activities. However, reasonable requests for funding with specific objectives will be considered by the CNOc Steering Committee. To make a funding request, please refer to the SIG Funding Policies section in this document.

To maintain SIG status within CNOc, SIGs must:

1) Maintain a minimum of 10 members.

2) Maintain appropriate leadership, as outlined below.

3) Hold a SIG Annual Meeting. SIGs are strongly encouraged to hold their annual meeting in conjunction with the CNOc Annual Scientific Sessions (see SIG Participation in Annual Scientific

Sessions section). If this is not possible, SIGs can hold their annual meeting at another time and location (including a virtual meeting), at the discretion of the SIG.

4) Submit bi-annual reports. Twice per year, the chair(s) of each SIG will be required to submit a brief report of their activities over the past six months, demonstrating progress towards the goals stated in their original application. These reports will be requested and compiled by the CNOG Members-at-Large and reviewed by the CNOG Steering Committee.

5) Provide updates to the CNOG Communications Committee regarding their activities for inclusion in CNOG e-newsletters, e-blasts, and social media at least twice per year.

6) Maintain the accuracy of SIG information made available on the CNOG website.

SIG Resources Provided by CNOG

SIGs will have the following support from CNOG:

1) Once a SIG has formed, CNOG will disseminate information about the new SIG to CNOG members, including instructions on how to join. CNOG will maintain lists of current SIG members with contact information and will provide this information to SIG chair(s) for the purposes of SIG communications.

2) CNOG will host SIG information on the CNOG public facing website, including instructions on how to join the SIG, and will periodically feature SIGs in CNOG e-newsletters, e-blasts, and social media. SIGs may be invited to highlight their work at the Annual Scientific Sessions through invited talks (not guaranteed every year).

3) SIG meeting time and space will be provided at the CNOG Annual Scientific Sessions at no cost to the SIG (see related section of this document).

4) SIGs can access consultation and review of materials from CNOG Standing Committees to support high-quality, impactful work.

5) SIGs can use the CNOG name (_____, *Special Interest Group of the Cardiac Neurodevelopmental Outcome Collaborative*) and CNOG logo on scientific and community publications and educational/outreach materials following review and approval by the appropriate CNOG Standing Committee (e.g., Publications, Education & Training, or Community Outreach Committees) and/or Steering Committee. Requests for review should be directed to the CNOG Members-at-Large.

6) CNOG will house SIG documents and materials on the CNOG members-only webpage. Individuals from institutions that are not members of CNOG but who have applied and paid for SIG/Committee membership will receive a log-in to the CNOG members-only webpage.

7) CNOG will provide SIG Chair(s) with a conference call number that can be used by SIGs for conference calls (up to 12x per calendar year). A schedule of upcoming SIG conference calls and events will be displayed on the CNOG members-only webpage.

8) CNOG will send out member surveys designed by SIGs only after approval by the CNOG Steering Committee to ensure that the survey does not overlap in content with other surveys and that the

knowledge gained from the survey is likely to further the vision and mission of CNOC. Questions about surveys and requests for survey review should be directed to the CNOC Members-at-Large.

9) Guidelines regarding access to CNOC multi-site registry data for research and quality improvement are detailed in the CNOC Manual of Operations.

10) Other requests from SIGs for support from CNOC should be forwarded to the Members-at-Large who can present these requests to the CNOC Steering Committee for consideration.

SIG Participation in Annual Scientific Sessions

SIGs are encouraged to hold annual in-person meetings in conjunction with CNOC's Annual Scientific Sessions. As available, CNOC will provide space and time for SIGs to hold these meetings at no cost to the SIG. Space specifications and meeting length will be dependent upon what is available at CNOC's Annual Scientific Sessions host site and is likely to differ year to year. Audio/visual technology may be requested but is not guaranteed. SIGs are encouraged to plan activities in conjunction with their meetings. Ideas include: hosting a research blitz or case presentations, SIG poster awards, and other SIG-related social activities. SIGs should develop their own processes for selecting presentations and other programming content. Once each SIG determines its needs for the meeting, these should be shared six (6) months or more in advance of the meeting with the Program and Meetings Committee Chairs. The Members-at-Large can facilitate this conversation. Any new SIG created within six (6) months of the upcoming CNOC Annual Scientific Sessions will not be guaranteed meeting space at that year's Scientific Sessions.

SIG Listserv Policy

SIGs are permitted to utilize SIG-specific email listservs to facilitate communication among members. Requirements for the use of a SIG-specific listserv are as follows:

- 1) Only individuals from CNOC member institutions, patient/caregiver members, and individuals with active SIG/Committee membership are permitted to participate in a SIG-specific listserv. Those individuals who do not meet these requirements should be removed from the listserv by the SIG Chair(s) after a six-month grace period.
- 2) It is the responsibility of the SIG Chair (or Co-Chairs) to monitor the content and activity of listserv posts.
- 3) If a SIG chooses to utilize a separate listserv for communication purposes, this must be reported to the CNOC Steering Committee through the Bi-Annual Report.

SIG Funding Policies

Reasonable requests for funding of SIG activities with specific objectives will be considered by the CNOC Steering Committee. Catering for Annual SIG Meetings is not an allowable cost and is the responsibility of the SIG. Funding requests should be emailed by the SIG Chair(s) to the CNOC Members-at-Large who will present the request to the CNOC Steering Committee. Approval or denial of the funding request will be communicated to the SIG Chair(s) within 45 days. Once funding has been spent, an email requesting reimbursement including the name and address of the individual to be reimbursed along with a copy of the itemized receipt(s) should be sent to the Members-at-Large for reimbursement. Annual Scientific Sessions A/V spending is covered with

funds outside of this allocation; however, A/V may not be available for all SIG meetings.

Procedure for Dissolving a SIG, Divesting SIG Chair(s) of their Position, or Removing a SIG Member

If a SIG has been unable to fulfill, or is considered to be noncompliant with, any of the SIG Responsibilities, the SIG will be put on probation and must demonstrate compliance within six months. If a SIG does not address deficiencies within six months following notice of probation, the SIG will be considered to not have sufficient interest among the CNOC membership to warrant further support from CNOC and, as such, will be dissolved. A SIG may appeal the decision of the CNOC Steering Committee within 30 days of notification by submitting written documentation to justify why dissolution should be rescinded. If the SIG does not exercise its appeal option, the CNOC Steering Committee's decision to dissolve is final and cannot be appealed. If the SIG does submit an appeal, the CNOC Steering Committee will review the SIG's appeal and make a decision consistent with the process for establishing a SIG. A proposal to re-establish a new SIG may be submitted after one calendar year.

The CNOC Steering Committee has the power to divest any SIG leader of his/her/their position should that individual consistently fail to fulfill his/her chair responsibilities. Failure to fulfill chair responsibilities may include: failure to respond in a timely fashion to emails and/or requests for information, failure to provide bi-annual reports to the Steering Committee, failure to meet CNOC membership requirements, and/or any concerns regarding misconduct or failure to serve the SIG membership in the spirit in which the office is intended. Concerns regarding SIG Chair responsibilities or behavior will be discussed directly via email and/or phone and an attempt at successful resolution of concerns will be made prior to divesting the individual from their leadership role. The SIG leader may appeal the decision of the CNOC Steering Committee within 30 days of notification by submitting written documentation to justify why removal should be rescinded. If the SIG leader does not exercise his/her appeal option, the CNOC Steering Committee's decision to remove them from the leadership role is final and cannot be appealed. If the SIG leader appeals the decision, the CNOC Steering Committee will review the SIG leader's appeal and make a decision after careful reflection and discussion.

The CNOC Steering Committee also has the power to remove an individual member from a CNOC SIG should that individual fail to meet CNOC membership requirements or due to misconduct. The individual may appeal the decision of the CNOC Steering Committee within 30 days of notification by submitting written documentation to justify why removal should be rescinded. If the individual does not exercise his/her appeal option, the CNOC Steering Committee's decision to remove them from the SIG is final and cannot be appealed. If the individual appeals the decision, the CNOC Steering Committee will review the appeal and make a decision after careful reflection and discussion.