

Cardiac Neurodevelopmental Outcome Collaborative (CNOC)
Bylaws, Amended and Restated
Date of Approval: 2/4/2021

I. Name

The organization shall be called the Cardiac Neurodevelopmental Outcome Collaborative (CNOC).

II. Purpose

CNOC is a not-for-profit organization established to determine and implement best practices of neurodevelopmental and psychosocial services for individuals with pediatric and congenital heart disease and their families through clinical, quality improvement, and research initiatives.

III. Participating Institutions and Membership

a. Participating Institutions:

1. A participating institution is defined as an institution that has made contributions to the creation and sustaining of CNOC through the payment of annual dues and involvement in CNOC activities.
2. Each participating institution must designate a corresponding member who will be the liaison and contact for communication between the organization and the participating institution.
3. Each participating institution can recognize an unlimited number of individuals affiliated with that institution as Affiliated Members.

b. Membership:

1. There shall be three types of membership: Affiliated, Special Interest Group (SIG) /Committee-Only; and Patient/Caregiver.
2. Only Affiliated Members may serve as: 1) Steering Committee Co-Chairs, Vice Chairs, Immediate Past Chairs, Secretary, Treasurer, or Members-At-Large; 2) Voting member of the Data Coordinating Center, Data Analytic Core, and Neurodevelopmental Core Lab; 3) International Representatives.
3. Affiliated Members and Patient/Caregiver Members may serve as Standing Committee Chairs, Standing Committee Vice Chairs, and Standing Committee Immediate Past Chairs.
4. Access to the CNOC Data Registry based on membership type is outlined in the CNOC Clinical Registry Manual of Operations.
5. SIG/Committee-Only Members may serve as members on CNOC Standing Committees and SIGs. They will receive access to the Members Only section of the CNOC website and will receive communications and access to educational materials from CNOC.

IV. Dues

- a. All dues and membership fees will be determined by the Steering Committee.
- b. Participating institutions will pay a fee based on a schedule determined by the Steering Committee.

- c. Affiliated Staff from a participating institution will not pay an additional individual annual membership fee to join CNOC. Affiliated Staff will be allowed a discounted registration fee for the Annual Scientific Sessions of CNOC.
- d. SIG/Committee-Only Members will pay an annual membership fee to join CNOC. SIG/Committee-Only memberships will have a two-tiered fee structure, wherein master's- or bachelor's-level professionals pay a lower membership fee than do doctoral level professionals.
- e. Patient/Caregiver Members will not pay an annual membership fee.
- f. Individuals who are not Affiliated Staff will pay a higher registration fee for the Annual Scientific Sessions of CNOC.

V. Organization

a. CNOC shall be administered by a Steering Committee consisting of:

1. **Co-Chairs (2)** – The two (2) Co-Chairs must be of different disciplines, thus reflecting the diverse membership of the CNOC.
2. **Co-Vice Chairs (2)** – The two (2) Co-Vice Chairs must be of different disciplines, thus reflecting the diverse membership of the CNOC.
3. **Secretary**
4. **Treasurer**
5. **Members-at-Large (2)**
6. **Immediate Past Chairs (2)**
7. **Standing Committee Chairs:**
 - a) Communications
 - b) Community Outreach Committee (same two Patient/Family Representatives as listed in V.a.11)
 - c) Database and Implementation
 - d) Education and Training
 - e) Program and Meeting
 - f) Publications
 - g) Research
 - h) Quality Improvement
8. **Voting representative designated by the Data Coordinating Center (DCC)**
9. **Voting representative designated by the Neurodevelopmental Core Lab (NDC)**
10. **Voting representative designated by the Data Analytic Core (DAC)**
11. **Patient/Family Representatives (2)**
12. **International Representatives (number determined by the number of interested regions outside of North America)**
13. **Standing Committee Vice Chairs will be invited to participate in Steering Committee meetings. If the Standing Committee Chair is absent, the Standing Committee Vice Chair may vote in place of the Standing Committee Chair.**

b. Election of Steering Committee Members:

1. **General Election Process**
 - a) Willingness to Serve Applications for CNOC Steering Committee Co-Vice Chairs, Secretary, Treasurer, and Members-at-Large will be solicited from the Members and submitted electronically.

- b) Members will be sent electronic ballots. Members will vote for two (2) candidates for Vice Chair and Member-at-Large, and one candidate for Treasurer and Secretary. The Secretary or their designee will be responsible for tallying the results and communicating the results to the Steering Committee. Results will be communicated to the candidates no fewer than 90 days prior to the Annual Scientific Sessions of the election year.

2. Nominations and Terms

- a) For Co-Vice Chairs, where different disciplines are required, the two (2) individuals with the highest vote totals will be elected from the following professional categories:
 - i. Physician (MD/DO)
 - ii. Nurse
 - iii. Psychologist (PhD/PsyD)
 - iv. Therapist (e.g. PT/OT, CCC-SLP)
 - v. Other allied health professional
- b) Officers (Co-Vice Chairs, Secretary and Treasurer) shall be elected to serve two-year terms.
- c) Members-at-Large will be elected to two-year terms.
- d) Patient/Family Representatives will be appointed to serve two-year terms. In the first term (beginning summer 2018), one patient/family representative will be elected to a three-year term. The existing steering committee will select the patient/family member to serve the three-year term. For subsequent terms, nominations for the Patient/Family Representative to serve for the next two-year term will be solicited from cardiac patient/family advocacy organizations, the Steering Committee, and CNOC membership. The Steering Committee will then review the nominations and appoint the new Patient/Family Representative by vote.
- e) International Representatives will be appointed to serve two-year terms. Institutional Members outside of North America may request an International Representative position on the Steering Committee to represent their region. In the first term for a region, the existing Steering Committee will select the International Representative to serve the two-year term. For subsequent terms, nominations for the International Representative will be solicited from CNOC Affiliated Staff from that region, relevant regional organizations, and the Steering Committee. The Steering Committee will then review the nominations and appoint the new International Representative for that region.
- f) Standing Committee Chairs will be appointed to serve two-year terms.
- g) The Chairs automatically stand down to Immediate Past Chairs after two years and are succeeded by the Vice Chairs.
- h) Candidates may be self-nominated or nominated by Affiliated Staff members.
- i) Candidates may only run for one (1) position.
- h) Secretary, Treasurer and Members-at-Large may only run for re-election for that specific office once (total time served in that office for four years) and will be eligible for re-election for that specific office four years after

completion of their most recent term. Officers and at-large members may run for other offices at the completion of an initial term, as they desire.

3. **Initial Election/Appointment of the Steering Committee** will be held after ratification of the CNOC Bylaws by the Founding Steering Committee and will follow the process below:
 - a) Election of initial Co-Chairs, Co-Vice Chairs, Secretary and Treasurer, and Members-at-Large will be supervised by the Founding Steering Committee.
 - b) Candidates shall submit a paragraph to the Founding Steering Committee stating their intention to run for office outlining their background, experience and goals.
 - c) The election will be held electronically within 90 days of the ratification of the CNOC bylaws.
 - d) The electorate for the first election will be members of the three (3) initial CNOC Working Groups [Cross-Site Collaboration Group, Infant Working Group (Birth to 5 years), and School-Age Working Group (6 to 18 years)]. Working Group Chairs will define the list of working group voting members.
 - e) CNOC Working Group members will be sent electronic ballots with return of ballots within three (3) weeks of the opening of the election period. Designees of the Founding Steering Committee will be responsible for tallying the results and communicating the results to the new Steering Committee members.
 - f) For the first elected Steering Committee, Jane Newburger, MD, MPH and David Bellinger, PhD, MSc, will serve as Immediate Past Chairs.
 - g) Standing Committee Chairs will be appointed by the Founding Steering Committee following the initial election of officers. Four of the seven appointed Standing Committee Chairs and one of the initial Patient/Family Representatives will serve three-year initial terms instead of two-year terms to make sure that there is appropriate continuity on the Steering Committee. The Founding Steering Committee will determine the two vs. three-year distribution among the appointed Standing Committee Chairs and Patient/Family Representatives.

c. Standing Committee Leadership Appointments:

1. **Standing Committee Chairs** will become the Immediate Past Chairs for two (2) years following the completion of their term as Standing Committee Chair.
2. **The Secretary** will solicit nominations from CNOC Standing Committees in July by electronic mail for Vice Chair candidates for each Standing Committee.
3. **The Standing Committee Chair, in consultation with the Immediate Past Chair on each Standing Committee**, will create a list of Vice Chair nominees to be considered by the Steering Committee.
4. **Vice Chairs** will ascend to Committee Chair positions after a two (2) year appointment.
5. **To be considered for ascension to Committee Chair from the Vice Chair position, the Committee Chair** must present the Vice Chair to the Steering Committee for approval. Standing Committee Chairs who present Chair candidates will abstain from voting.

6. **Approval of Chair candidates** requires at least a majority of the entire Steering Committee; the absolute number of voters may vary depending on the number of Steering Committee members present within the voting quorum. A voting quorum is defined as the presence of at least one (1) Chair and one (1) Vice Chair, the Secretary and Treasurer and three-quarters of the Steering Committee membership.

d. Standing Committee Member Appointments:

1. **Members** (which collectively include Affiliated, SIG/Committee-Only, and Patient/Caregiver Members) are eligible to join Standing Committees. At least once every two (2) years, Standing Committee Chair, Vice Chair, and Immediate Past Chair will call for applications for new members of their Standing Committee (with the exception of the Publications Committee and the Community Outreach Committee, whose membership appointment processes are detailed below [9] and [10]). They will review applicants and make recommendations to the CNOC Steering Committee for new appointments.
2. **Each Standing Committee** should attempt to have at least one (1) early-career member (< 5 years faculty or post-graduate experience), should attempt to have at least one (1) patient/family member, and should attempt to have a membership that has broad representation consistent with the membership of CNOC.
3. Each Standing Committee will determine its total membership, which will include a Chair, Vice Chair and Immediate Past Chair.
4. It is recommended that at least one-quarter of each Standing Committee turn over each two-year cycle.
5. Members can join up to two (2) Standing Committees concurrently.
6. There is no maximum duration of committee membership.
7. In order for there to be two (2) members from the same participating institution on a single committee they must be from different disciplines.
8. Members must recuse themselves from voting on proposals from their institution.
9. The Publications Committee will be populated by invitation rather than a call for applications. Individuals will be nominated by the Publications Committee Chair and Vice Chair, and approved by the Steering Committee.
10. The Community Outreach Committee will be populated by invitation and/or call for applications at the discretion of the Committee Co-Chairs. This committee will consist of both patient/family members and healthcare professionals.

VI. Responsibilities

a. Responsibilities of Officers:

1. **The Co-Chairs** shall preside at all the meetings, have general supervisory powers over the organization, see that officers perform their duties and enforce the bylaws. The Co-Chairs will supervise the nominations process and appointment of steering committee and standing committee members.
2. **The Treasurer** shall perform monthly reviews of budgets/expense reports provided by the CNOC Steering Committee-approved management firm, collaborate with the firm to ensure accurate and timely reporting of financial

matters to the Steering Committee, assist with building and reporting of subcommittee budgets and grant-supported activities of the DCC, DAC, and ND Core, serve as the authorizing CNOC Steering Committee member for payment remission, collaborate with CNOC Steering Committee-approved accountant to submit all required CNOC financial reporting documentation including, but not limited to, tax-related forms, serve as a resource or financial liaison with ability to translate financial concepts and information to CNOC Steering Committee members and/or CNOC organizational members serving on subcommittees who do not have backgrounds or experience in finance, ensure or provide accurate, concise reporting of financial concerns of subcommittee members to Steering Committee and Steering Committee-approved management firm, and assist with organizational fundraising efforts including, but not limited to, membership and retention.

3. **The Secretary** will be responsible for the following: Recording and distributing summaries of Steering Committee meetings that include a list of action items (if the Secretary is absent, the Secretary designates another note-taker for that meeting), updating and administering membership activities in consonance with the management company including, but not limited to, overseeing the Steering Committee elections process, assisting Standing Committee leadership with populating their committees with providers and Patient/Family member Representatives, collating and distributing membership applications/inquires overseeing and updating the rules involving requirements and opportunities for membership, reviewing the status of specific CNOC non-Steering Committee members and providing recommendations to the Steering Committee regarding their continued participation in CNOC; creating and maintaining a membership registry in consonance with the management firm, which should include key personnel at each participating site; identifying and communicating with new/potential members; soliciting nominations for the Newburger-Bellinger Award annually.
4. **Members-at-Large** will be responsible for leading specific CNOC initiatives/special projects to be decided based on the expertise of the individual and the needs of the organization.
5. **The Co-Vice Chairs (first in line), Secretary (second in line) and Treasurer (third in line)** shall preside in the absence of the Co-Chairs and in case of death, sickness, resignation, disqualification, refusal or neglect of the Co-Chairs, will discharge the duties of his/her office. The succeeding officer shall then perform all duties incumbent upon the Chair for the remainder of the term of office. They shall keep a record of the proceedings of the organization and prepare a roll of members. They shall support scheduling and leading the meeting program each year with the Program and Meeting Committee Chair and shall inform the membership regarding CNOC activities on a quarterly basis through the Program and Meeting Committee.
6. **In case of death, sickness, or resignation, or succession to Chair of the Vice-Chair, Secretary or Treasurer, the Steering Committee** will present a list of candidates to the membership for election.

b. Responsibilities of the Steering Committee include:

1. Oversight over activities of CNOC to ensure that the work being performed by the CNOC Officers, Steering Committee and Standing Committees is consistent with the vision and mission of the CNOC.
2. At least quarterly conference call meetings of the Steering Committee members.
3. Financial oversight regarding educational and research grants.
4. Solicitation, management and allocation of funds for research and educational support.
 - a) Unrestricted funds are allocated by Steering Committee.
 - b) Grant funds for a specific project submitted by a Principal Investigator in collaboration with the CNOC are administered by that project's Principal Investigator.
5. Advocacy for increased awareness of neurodevelopmental issues among the pediatric cardiac and congenital heart disease populations.
6. Approval of Standing Committee leadership and membership.
7. Steering Committee voting quorum: A quorum will consist of representation from 3/4 of the Steering Committee members including at least one (1) Chair and one (1) Vice Chair.

c. Responsibilities of the Standing Committees:

1. **Communications Committee:** The Communications Committee is responsible for communicating information to committee members and potential committee members, in consonance with the management company, about upcoming meetings, symposia, and educational opportunities as well as routine updates to members about CNOC initiatives. They will also create and oversee content to communicate to the larger community including member leadership, non-member providers, and individuals diagnosed with congenital heart disease and their family members, in collaboration with the Community Outreach Committee. Information may be distributed through several modalities including, but not limited to, email, listserv, website, and/or social media.
2. **Community Outreach Committee:** The Community Outreach Committee serves as a resource for developing and disseminating educational materials regarding the neurodevelopmental care of children with CHD and their families to external stakeholder groups, including but not limited to, patients, families, primary physicians, and policy makers, and for identifying opportunities to engage diverse stakeholders in activities stemming from CNOC. The Community Outreach Committee is co-chaired by the two Patient/Family Representatives and will work closely with the Communications and the Education and Training Committees.
3. **Database and Implementation Committee:** The Database and Implementation Committee assures the quality of the data and facilitates data collection and analyses, modifying the database as the data evolves. The Database and Implementation Committee will collaborate closely on the work of the Data Coordinating Center and lead the RFAs for the management of the Data Coordinating Center every five (5) years. The Database and Implementation Committee will coordinate closely with the Research

Committee, and will include CNOC Steering Committee Co-Chairs, Co-Vice Chairs, and Immediate Past Chairs; DCC, NDC, and DAC representatives, and current and immediate past leadership from the Research and Database committees.

4. **Education and Training Committee:** The Education and Training Committee is responsible for providing education and training to Members interested in developing a neurodevelopmental follow-up program, developing specific metrics and methodologies for evaluation of the training process. The Education and Training Committee works closely with the Research Committee to assure that the advocated batteries are consistent across sites and over time as much as possible. This committee may explore a possible review process for clinicians who have received training and have passed some evaluation on the recommended battery. The Education and Training Committee collaborates closely with the work of the Neurodevelopmental Core Lab and leads the RFAs for the management of the Neurodevelopmental Core Lab every five (5) years. The Education and Training Committee will also work closely with the Community Outreach Committee.
5. **Program and Meeting Committee:** The Program and Meeting Committee supports the development of the agenda/schedule/fundraising for CNOC meetings including the Annual Scientific Sessions of CNOC. This committee will determine the bidding process and decide upon future sites for the Annual Scientific Sessions. The committee will develop and maintain a manual of operations, and serve as a resource to the host institution for the Annual Scientific Sessions. This committee will include at least one member from the two most recent and the next two host institutions of the annual symposium.
6. **Publications Committee:** The Publications Committee is responsible for review and approval of all abstracts, presentations and manuscripts for publication. All reviews of abstracts and presentations will be performed and feedback delivered within 14 days of submission to the Publications Committee. All manuscript reviews will be completed within 30 days of submission to the Publications Committee.
7. **Quality Improvement Committee:** The Quality Improvement Committee is responsible for the quality improvement agenda of CNOC. The Quality Improvement Committee collaborates closely with the Database and Implementation Committee to oversee QI projects. In collaboration with the Research Committee, the QI Committee determines how proposed QI and research studies will be submitted, processed, reviewed and how investigators will receive feedback. The QI committee reviews all QI-related proposals to CNOC and works closely with the Education and Training Committee to lead initiatives for improving clinical care and outcomes.
8. **Research Committee:** The Research Committee is responsible for shepherding the collaborative research agenda of CNOC. Initially this will include the development of data collection and sharing methodology. The Research Committee will review all research proposals to CNOC and oversee protocol development committees as well as all writing committees. The Research Committee is expected to closely collaborate with the Database and

Implementation Committee. The Research Committee will determine how proposed studies will be submitted, processed, reviewed and how investigators will receive feedback.

VII. Meetings

- a. In-person meetings of the Steering Committee and Standing Committees shall occur once a year at the Annual Scientific Sessions. Additional in-person meetings can occur at the discretion of the Steering Committee.
- b. **Standing Committee Meetings:** The scheduling of additional Standing Committee meetings is at the discretion of the Committee Chairs but committees are encouraged to meet virtually at least quarterly.

VIII. CNOC Database

- a. The CNOC Database is owned by the organization known as CNOC. It is managed and overseen by the Data Coordinating Center.

IX. Changes to Bylaws

Any changes to the bylaws must be approved by a 3/4 majority of the Steering Committee members, including at least one (1) Chair and one (1) Vice-Chair.

X. Non-Profit Status and Dissolution

- a. This organization is developed exclusively for educational and scientific purposes, including distributions to organizations that qualify as exempt organizations described under Section 501(c)3 of the Internal Revenue Code or corresponding section of any future federal tax code.
- b. Where appropriate, the Steering Committee may determine to compensate reasonably any member of the organization in accordance with and commensurate with, the labor, services, or other endeavors performed by such persons. In this case, the individual to be compensated will not be part of the Steering Committee vote on the topic.
- c. The organization may be dissolved by a 3/4 majority vote by the appointed corresponding members of the Participating Institutions.
- d. In the event of the dissolution of this organization, or in the event it shall cease to exist for the stated purposes, all the property and assets shall be distributed to an organization or agency of similar nature and charitable and nonprofit status. This allocation shall be decided by the Steering Committee at the time of dissolution. Under no circumstances shall any of the property or assets of this organization during the existence and/or upon the dissolution thereof go and be distributed to any officer or member of the organization.

XI. Removal of Steering Committee Members

Should concerns arise about the performance of a Participating Institution or Steering Committee member, a 3/4 vote of the Participating Institutions is required to remove the Participating Institution or Steering Committee member (voting members to be defined by each Participating Institution – see section III.a.2).

XII. CNOC Operations

Details regarding CNOC operations not described in these bylaws or the Manual of Operations can be found in the CNOC Policies and Procedures Manual.