

**Cardiac Neurodevelopmental Outcome Collaborative (CNOC)**  
**Amended and Restated Bylaws**  
**Date of Approval: 10/5/2023**

**I. Name**

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

**II. Purpose**

CNOC is a nonprofit organization established to determine and implement best practices of neurodevelopmental and psychosocial services for every individual with pediatric or 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 sustenance of the 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 CNOC 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 four types of membership: Affiliated, Special Interest Group (SIG)/Committee-Only; International, and Patient/Family Member
2. Only Affiliated Members may serve as: 1) Steering Committee Co-Chairs, Vice Chairs, Immediate Past Chairs, Secretary, Treasurer, or Members-at-Large; or 2) Voting member of the Data Coordinating Center, Data Analytic Core, or Neurodevelopmental Core Lab;
3. Affiliated Members, International Members, and Patient/Family Members may serve as Standing Committee Chairs, Standing Committee Vice Chairs, and Standing Committee Immediate Past Chairs.
4. Access to the CNOC Clinical 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 Members from a participating institution will not pay an additional individual annual membership fee to join the CNOC. Affiliated Members will be allowed a discounted registration fee for CNOC's Annual Scientific Sessions.
- d. SIG/Committee-Only Members will pay an annual membership fee to join the CNOC. SIG/Committee-Only Memberships will have a two-tiered fee structure, wherein Masters- or Bachelors-level professionals pay a lower membership fee than do Doctoral-level professionals.
- e. International Members are based in countries outside of the United States of America and Canada. Fee structure is on a sliding scale based on the World Bank of Economies Tiers. There are International Institutional and Individual Membership options.
- f. Patient/Family Members will not pay an annual membership fee.

## V. Organization

### a. The 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 (Co-Chairs are the same Patient/Family Representatives as listed in V.a.11)
  - c) Database and Implementation
  - d) Finance (Chair is Treasurer as listed in V.a.4)
  - e) Nominations (Co-Chairs are the same Immediate Past-Chairs as listed in V.a.6)
  - f) Learning and Resource
  - g) Program and Meetings
  - h) Publications
  - i) Quality Improvement
  - j) Research
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 the USA and Canada)
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 by the Nominations Committee from the Members and submitted electronically.
- b) Members will be sent electronic ballots. Members will vote for two 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 60 days from the start of the new term.

## 2. **Nominations and Terms**

- a) For CNOc 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 four-year terms, two years as Vice Chair of the Community Outreach Committee and then two years as Chair. Nominations for the Patient/Family Representative 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 Representatives by vote.
- e) International Representatives will be appointed to serve two-year terms. International Members outside of the USA and Canada 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 Members 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) The Steering Committee Chairs automatically stand down to Immediate Past Chairs after two years and are succeeded by the Vice Chairs.
- g) Standing Committee Chairs will be appointed to serve two-year terms.
- h) Candidates may be self-nominated or nominated by Affiliated 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 (i.e., total time served in that office can be four

years) and will be eligible for re-election for that specific office four years after completion of their most recent term. Officers and Members-at-Large may run for other offices at the completion of an initial term, as they desire.

**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 Standing Committee Chairs, in consultation with the Immediate Past Chairs on each Standing Committee**, will create a list of Vice Chair nominees. Nominations of Standing Committee Vice Chair candidates will be reviewed by the Nominations Committee. The Nominations Committee will then present the slate to the Steering Committee for approval.
3. **Vice Chairs** will ascend to Committee Chair positions after the completion of the Chairs' two (2)-year appointment. 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. Approval of Standing Committee 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.

**d. Standing Committee Member Appointments:**

1. Each Standing Committee will determine its total membership, which will include at least one Chair, Vice Chair and Immediate Past Chair.
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 the CNOC.
3. In order for there to be two (2) members from the same Participating Institution on a single committee they must be from different disciplines or contribute different subject matter expertise.
4. Members can join up to two (2) Standing Committees concurrently.
5. It is recommended that at least one-quarter of each Standing Committee turn over each two-year cycle.
6. Members (which collectively include Affiliated, SIG/Committee-Only, International, and Patient/Family Members) are eligible to join Standing Committees. The Nominations Committee will solicit Committee Membership opportunities annually from the Standing Committee Chairs. At least once every two (2) years, the following Standing Committees must provide opportunity for new members to join their Standing Committee: Research, Quality Improvement, Learning and Resource, and Communications). The Nominations Committee will make an annual call for applications at the beginning of each calendar year with information on available Standing Committee opportunities, review applicants and make recommendations to the CNOC Steering Committee for new appointments.

7. The Publications Committee will be populated by invitation rather than by a call for applications. Individuals will be nominated by the Publications Committee Chair and Vice Chair, and approved by the Steering Committee.
8. The Community Outreach Committee will be populated by invitation and/or call for applications at the discretion of the committee leadership. This committee will consist of both patient/family members and healthcare professionals.
9. The Nominations Committee will be chaired by the CNOC Immediate Past Co-Chairs and will include as members: Nominations Committee Immediate Past Chairs (2), CNOC Co-Chairs, CNOC Co-Vice Chairs, Secretary, a past Newburger-Bellinger Award winner, two (2) rotating Standing Committee Chairs, International Representative, and a Patient/Family Representative.
10. The Finance Committee will be chaired by the CNOC Treasurer and will include as members: CNOC Co-Chairs, CNOC Co-Vice Chairs, Secretary, CNOC Immediate Past Co-Chairs, Immediate Past Treasurer, at least one Co-Chair of the Program and Meetings Committee, representation from current management company, and relevant standing committee leadership as appropriate.
11. The Database and Implementation Committee 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 Committee and Database and Implementation Committee.
12. The Program and Meetings Committee will be populated by invitation rather than by a call for applications. Individuals will be nominated by the current Programs and Meetings Committee Co-Chairs, and approved by the Steering Committee. Program and Meetings Committee members will include CNOC Co-Chairs, CNOC Co-Vice Chairs, representation from the two most recent and the next two host institutions (when known) of the Annual Scientific Sessions, representation from the Communications Committee, and representation from the current management company.

## 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 Secretary** will be responsible for the following: Recording and distributing summaries of Steering Committee meetings (and other CNOC meetings upon request) that include a list of action items (if the Secretary is absent, the Secretary will designate another note-taker for that meeting), updating and administering membership activities in consonance with the management company including, but not limited to, assisting the Nominations Committee with overseeing the Steering Committee elections process, the nomination and voting processes for CNOC Awards, populating Standing Committees with clinician, researcher, and Patient/Family representatives, participating in the Communications Committee as a Steering Committee Liaison, and working

with the management firm to maintain a membership registry which should include key personnel at each participating site.

3. **The Treasurer** will serve as the Chair of the Finance Committee. In this role, 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 NDC, 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, oversee CNOC investments, and assist with organizational fundraising efforts including, but not limited to, membership and retention.
  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.
  6. **In case of death, sickness, or resignation, or succession to Chair of the Vice Chair, Secretary or Treasurer, the Nominations Committee** will present a list of candidates to the membership for election.
- b. Responsibilities of the Steering Committee include:**
1. Oversight of activities of the CNOC to ensure that the work being performed by the CNOC Officers, Steering Committee Standing Committees, CNOC Cores, Special Interest Groups, and Task Forces is consistent with the vision and mission of the CNOC.
  2. Executive oversight of CNOC's financial income and expenditures, with advisement by the Finance Committee.
  3. Solicitation, management and allocation of funds for research and educational support.
    - a) Unrestricted funds are allocated by the Steering Committee in conjunction with the Finance 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.

4. Advocacy for increased awareness of neurodevelopmental issues among the pediatric cardiac and congenital heart disease populations.
5. Approval of Standing Committee leadership and membership.
6. Steering Committee voting quorum: A quorum will consist of representation from three-quarters of the Steering Committee members including at least one (1) CNOc Chair and one (1) CNOc Vice Chair.

**c. Responsibilities of the Standing Committees:**

1. **Communications Committee:** The Communications Committee is responsible for optimizing communication to CNOc members as well as creating and overseeing content to communicate to the larger heart community distributed through various modalities including, but not limited to, email, website, social media, and/or listserv. The Communications Committee will work closely with the Community Outreach and the Learning and Resource Committees.
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 congenital heart disease 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 will work closely with the Communications and the Learning and Resource Committees.
3. **Database and Implementation Committee:** The Database and Implementation Committee assures the quality of the data within the CNOc Clinical Registry 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 Request For Applications for the management of the Data Coordinating Center every five (5) years. The Database and Implementation Committee will coordinate closely with the Research Committee.
4. **Finance Committee:** The Finance Committee is responsible for reviewing the proposed annual budget and making recommendations to the Steering Committee regarding approval/revision of the proposed annual budget. The Finance Committee is responsible for reviewing proposed changes to the budget quarterly and making recommendations to the Steering Committee regarding approval/revision. The Finance Committee is responsible for reviewing budget variances semi-annually and making recommendations to the Steering Committee regarding changes in budget or approaches for minimizing variance. The Finance Committee is responsible for developing and making recommendations to the Steering Committee regarding strategic investment and funding collaborative initiatives (e.g., research grants).
5. **Learning and Resource Committee:** The Learning and Resource Committee is responsible for serving as a resource for identifying and disseminating best practice approaches for the neurodevelopmental care for individuals with congenital heart disease and their families. The content and work will be guided by the input and collaboration of the inclusive CNOc community. The committee is responsible for providing educational opportunities through a

variety of platforms (e.g., webinars, informal chats, podcasts and social media). CNOC members and patients/families will be engaged over a broad range of topics as they relate to the developmental care of children with congenital heart disease. The committee will disseminate information and act as a resource repository. The committee will work in close collaboration with the Community Outreach and Communications Committees.

6. **Nominations Committee:** The Nominations Committee is responsible for soliciting and reviewing Steering Committee nominations with the Secretary to ensure all candidates are eligible and the planned ballot will have enough applicants to fulfill the professional diversity and other requirements needed to populate the Steering Committee. The Committee is responsible for reviewing Newburger-Bellinger Award nominations and presenting the slate to the CNOC Steering Committee for vote. The Committee is responsible for reviewing Standing Committee Vice Chair and member selections submitted by current Standing Committee Chairs, making recommendations, and presenting the slate to the CNOC Steering Committee.
7. **Program and Meetings Committee:** The Program and Meetings Committee supports the development of the agenda/schedule/fundraising for the CNOC meetings including CNOC's Annual Scientific Sessions. 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.
8. **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.
9. **Quality Improvement Committee:** The Quality Improvement (QI) Committee is responsible for the QI agenda of the CNOC. The QI 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, and reviewed and how investigators will receive feedback. The QI committee reviews all QI-related proposals to the CNOC and works closely with the Learning and Resource Committee to lead initiatives for improving clinical care and outcomes.
10. **Research Committee:** The Research Committee is responsible for shepherding the collaborative research agenda of the CNOC. Initially this will include the development of data collection and sharing methodologies. The Research Committee will review all research proposals to the 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. At least quarterly conference call meetings of the Steering Committee members.
- b. In-person meetings of the Steering Committee and Standing Committees shall occur once a year at the Annual Scientific Sessions. Additional meetings can occur at the discretion of the Steering Committee.
- c. 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. Removal of a Participating Institution or Steering Committee Member**

Should concerns arise about the performance of a Participating Institution or Steering Committee member, a three-quarters 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).

## **IX. CNOC Operations**

- a. **CNOC Clinical Registry:** The CNOC Clinical Registry is owned by the organization known as CNOC. It is managed and overseen by the Data Coordinating Center.
- b. **Changes to Bylaws:** Any changes to the bylaws must be approved by a three-quarters majority of the Steering Committee members, including at least one (1) CNOC Chair and one (1) CNOC Vice Chair.

## **X. Nonprofit 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 three-quarters 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.