

CNOC Committee Descriptions

Patient/Parent Committee Member Time Commitment: 2-4 hours per month

Membership and Communications Committee

Chair: Jennifer Butcher PhD, Vice-Chair: Gretchen Carroll MA

Responsible for:

- Maintaining membership directory and growing membership
- Communicating with members and the community
 - Developing website content including education for patients and families
 - Creating and editing membership newsletter
 - Bi-annual reports to institutional leadership
- Overseeing the yearly Newburger-Bellinger Award

Long term goals:

- Expanding website content
- Expanding to social media or listserv communications
- Providing community education events in collaboration with the Education and Training Committee

Member Expectations:

- Participate in Committee conference calls approximately 6 times per year
- Take a leadership role on an aspect of membership or communication duties. This leadership role may include:
 - Serving as editor of the membership newsletter
 - Overseeing the development of twice yearly reports to CNOC institutional leadership
 - Managing and updating the content of the patient/family section of the website
 - Ensuring that membership databases are up-to-date
 - Participating in the development of community education events

Research Committee

Chair: Tom Miller DO, Vice-Chairs: Michael Seed MD and Dawn Ilardi PhD

Responsible for:

- Overseeing and promoting the collaborative research agenda of the CNOC
- Taking a multicenter, multidisciplinary approach to better understanding the neurodevelopmental, behavioral, and mental health outcomes of individuals with congenital heart disease
- Supporting both investigator-initiated, patient/family supported, and cross-consortia/network projects that include:
 - Development of data collection and sharing methodology
 - Creating a process for submission and review of research proposals

Long term goals:

- Review and oversight of all CNOC research proposals
 - Protocol development committees
 - Writing committees
 - Contribute to presentations and publications committee

Member Expectations:

- Participate in scheduled conference calls (approximately 6 calls per year)

- Actively participate in the review and implementation of proposals
- Provide strategic input to the CNOC research agenda

Database Committee

Chair: Bill Gaynor MD, Vice-Chairs: David Wypij PhD and Anjali Sadhwani PhD

Responsible for:

- Assuring the quality of the CNOC database
- Facilitating data collection and analyses
- Modifying the database as the data evolve
- Partnering with the CNOC Data Coordinating Center (DCC) including:
 - Developing an RFA for the DCC for multicenter neurodevelopmental outcomes following infant cardiac surgery
 - Participation in the selection of the DCC
 - Finalizing the clinical and neurodevelopmental variables and patient selection that will constitute the initial CNOC database
 - Developing data sharing methodology for CNOC sites

Long term goals:

- Oversight of the DCC and data sharing across CNOC sites to ensure the overall quality of the data
- DCC review and possible new development of an RFA for the DCC every five years

Member expectations:

- Participate in scheduled conference calls
- Actively participate in the review and selection of the DCC
- Actively participate in the development of the initial CNOC database

Program and Meeting Committee

Chair: Gill Wernovsky MD, Vice-Chair: Cheryl Brosig Soto PhD

Responsible for:

- Annual Scientific Sessions of the Cardiac Neurodevelopmental Outcome Collaborative, including
 - Site selection
 - Needs assessment
 - Scientific program
 - Abstract submission
 - Marketing/advertising
 - Exhibitor prospectus
 - Fundraising

Long term goals:

- Developing a long-term goal of patient, family and community stakeholders in the Annual Scientific meeting, as well as regional and national ad hoc meetings; enduring materials (education, lectures, etc.) and social media educational presence
- Strategy for long-term sustainability of the meeting through 2025

Member expectations:

- Participate in scheduled conference calls (2-4 calls per month)
- Review evaluations of “needs assessments” (prior symposia evaluations, provider, patient and family surveys, known knowledge gaps) to shape future meetings

- Contribute to the scientific program design
- Review abstract submissions
- Help secure financial support through grants, industry and exhibitors

Education and Training Committee

Chair: Janice Ware PhD, Vice-Chair: Renee Sananes PhD

Responsible for:

- Serving as a resource for developing and disseminating best practice approaches for the neurodevelopmental care of children with CHD and their families
- Providing education and training to new members and ongoing resource support involved in using standard procedures for assessment
- Quality assurance of data collection
- Partnering with the CNOC Neurodevelopmental (ND) Core to revise data collection protocols
- Developing metrics to evaluate the training process
- Finalizing plan to fold former Birth to Five and School-Age Working Groups into committee as sub-committees

Long term goals:

- Providing community education and training programs in collaboration with the Membership and Communications Committee
- Development of Young Adult-Transition and International Cross-Age Working Group sub-committees
- Creating education and training materials for CNOC members and the community. This may include:
 - Developing a training module/manual for new CNOC sites that will be reviewed at annual symposia
 - Translation of AHA guidelines into user-friendly materials for community providers and parents
 - Developing a CNOC Parent Education Handbook
 - Developing a “Hearts in the Classroom” training module and materials for schools

Member expectations:

- Participate in scheduled conference calls
- Assist in the development and initiation of multidisciplinary training experiences and discipline specific training for selected measures or initiatives.
- Participate in the development of community education events and materials

Quality Improvement Committee

Chair: George Verghese MD MBA, Vice-Chairs: Samantha Butler PhD and Jennifer Cass PhD ABPP

Responsible for:

- Review, scope, and prioritization of quality improvement initiatives for the CNOC
- Develop aim, measures, and change strategies/interventions for specific QI projects
- Developing data collection and measurement strategies for specific QI projects to test the effectiveness of various interventions
- Working closely with the Education and Training and Research Committees to design and execute quality improvement initiatives
- Educating broader CNOC community on formal quality improvement principles

Long term goals:

- To harness the power of multicenter and multidisciplinary collaboration to implement formal quality improvement strategies focused on improving neurodevelopmental clinical care processes and ultimately outcomes, including quality of life for both the child with high risk heart disease and their family.
- To focus our initial efforts on improving the identification and referral of high-risk, school age children for neurodevelopmental evaluation per national guidelines

Member expectations:

- Participate in scheduled conference calls
- Assist in the development of project aims, measure development, and change strategies/interventions.
- Develop local approaches for robust data collection to facilitate understanding of whether the proposed changes have resulted in measurable improvement.
- Execute local “tests of change” and report successes and failures back to the broader QI committee in order to foster continuous improvement