

RESEARCH COMMITTEE

Chair: Cynthia Ortinau MD

Co-Vice Chairs: Caitlin Rollins MD and Jennifer Butcher PhD

Responsible for:

- Overseeing and promoting the collaborative research agenda of CNOC
- Taking a multicenter, multidisciplinary approach to better understanding the neurodevelopmental, behavioral, and mental health outcomes of individuals with congenital heart disease
- Supporting investigator-initiated, patient/family supported, and cross-consortia/network projects that include development of data collection and sharing methodology
- Review and oversight of all CNOC research proposals including:
 - Creating, implementing, and maintaining a submission process for research proposals
 - Facilitating quick review of research proposals, including those part of grant submissions

Short-term goals:

- Publish a manuscript describing the development of CNOC's Clinical Registry
- Complete data analysis in collaboration with the DCC, DAC, and NDC for the first two aims of the collaborative research agenda
- Finalize the development of ancillary proposal submission guidelines
- Develop approaches for incorporating telehealth assessments into design and implementation of the collaborative research agenda

Long-term goals:

- Protocol development committees
- Writing committees
- Contribute to presentations and publications committee

Member expectations:

- Participate in scheduled monthly conference calls (approximately 12 calls per year)
- Participate in review of research proposals
- Contribute to the scientific program design
- Review abstract submissions to scientific sessions
- Help secure financial support through grants, industry and exhibitors

Role of patient/family committee members:

- Review ancillary study proposals
- Provide input about CNOC-driven projects
- Liaise with Communications and Community Outreach committees to make parents and parent organizations aware of the research initiatives of CNOC and to ensure our research agenda is relevant to all stakeholders

PROGRAM AND MEETINGS COMMITTEE

Co-Chairs: Bradley S. Marino MD MPP MSCE MBA and Nadine A. Kasparian MAPS PhD

Responsible for:

Annual Scientific Sessions of the Cardiac Neurodevelopmental Outcome Collaborative, including oversight of:

- Site selection
- Needs assessment
- Scientific program
- Faculty invitations
- Abstract submission
- Marketing/advertising
- Exhibitor prospectus
- Fundraising
- Faculty and attendee support throughout the conference planning process and the actual meeting
- Presentation awards (e.g., Best of the Best Abstract Award)
- Analysis of meeting evaluation survey results and development of responsive plan for future meetings

Long term goals:

- Developing a long-term goal of patient, family and community stakeholders in the Annual Scientific Sessions, 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 conference 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 conferences
- Contribute to the scientific program design
- Review abstract submissions
- Help secure financial support through grants, industry and exhibitors

Role of patient/family committee members:

- Provide representation of the views and perspectives of patients and family members during all aspects of CNOC program and meeting development and delivery, including CNOC’s Annual Scientific Sessions
- Provide input and leadership in the development of new initiatives specifically addressing the needs of patients and families (e.g., partnership in the creation of a joint session during CNOC’s Annual Scientific Sessions)

DATABASE AND IMPLEMENTATION COMMITTEE

Chair: Andrew Van Bergen MD

Vice Chair: Joanne Bonanno MA

Responsible for:

- Assuring the quality of the database
- Modifying the database variables as the data evolves
- Facilitating data collection and analyses

Membership consists of:

- CNOc Steering Committee Co-Chairs, Co-Vice Chairs, and Immediate Past Chairs
- DCC, NDC, and DAC representatives
- Current and immediate past leadership from the Research and Database committees

Long term goals:

- Oversight of the DCC and data sharing across CNOc sites to ensure the overall quality of the data
- Reviews and possible new development of an RFA for the DCC/DAC/NDC every five years

Member expectations:

- Participate in scheduled conference calls
- Provide feedback about current database
- Provide input into changes to be made to database

EDUCATION AND TRAINING COMMITTEE

Chair: Laurel Bear MD

Vice Chair: Jennifer Fogel SLP

Responsible for:

- Serving as a resource for identifying and disseminating best practice approaches for the neurodevelopmental care for children with CHD and their families
- Providing education and training to CNOC members, patients and their families over a broad range of topics as they relate to the developmental care of children with complex congenital heart disease
- Providing ongoing resource support as it relates to using standard measures for neurodevelopmental evaluations
- Developing and disseminating education and training programs in collaboration with the Membership and/or Communications committees at the direction of the Steering Committee

Short- and long-term goals:

- Translate AHA guidelines into user-friendly materials for community providers and parents
- Review and collate/communicate important Neurodevelopmental Outcomes literature
- Develop and present webinars about Neurodevelopmental Tele-health Visits and How to Use the Bayley 4 Q-interactive
- Develop a CNOC Parent Education Handbook
- Develop a "Hearts in the Classroom" training module and materials for schools
- Continue to revisit the Education & Training survey to ensure that the needs of CNOC member are being met

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

Role of patient/family committee members:

- Provide feedback regarding what resources would be beneficial to patients/families including, but not limited to, feeding recommendations, addressing parental/patient anxiety, explanations of sensory processing difficulties, school intervention strategies (IEP, etc.)
- Help determine what areas of development parents would like to see professionals research or learn more about in regard to children with CHD

COMMUNITY OUTREACH COMMITTEE

Co-Chairs: Elizabeth Blumenfeld JD and Jessica Cowin MS

Responsible for:

- Serving 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, policy makers
- Identifying opportunities to engage diverse stakeholders in activities stemming from CNOOC
- Advocacy relating to issues impacting cardiac neurodevelopmental patients and their families

Short term goals:

Educational Resources

- Gather a baseline of existing resources for patients and families, providers
- Identify gaps in education for key stakeholders

Telehealth

- Work with Telehealth Taskforce to develop a summary of gaps and unknowns regarding the financial implications of telehealth models, and recommendations regarding the need for advocacy to improve insurance reimbursement and delivery of care across state lines

Long term goals:

- Update the website with resources aimed at community stakeholders
- Develop process for prioritizing, developing and disseminating educational materials in collaboration with the Education and Training Committee and the Communications Committee
 - This includes, but is not limited to, electronic materials, print materials, webinars, learning modules, lay summaries of conference materials
- In conjunction with other relevant committees and SIGS, increase patient/parent involvement with CNOOC
- In conjunction with other relevant committees and SIGS, increase access to CNOOC related materials to underserved communities and populations

Member expectations:

- Participate in scheduled monthly conference calls
- Assist in the planning, development and implementation of short- and long-term goals
- We encourage members to take the lead on specific projects within the committee

COMMUNICATIONS COMMITTEE

Chair: Sarah Kelly PsyD

Co-Vice Chairs: Susan Bowen PhD and Justin Elhoff MD

Responsible for:

- Optimizing communication to CNOC members
- 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

Short- and long-term goals:

- Draft email newsletters to all CNOC members with a goal of quarterly communications
- Review other CNOC email blasts, as well monitor the timing of various communications
- Manage social media presence and activity, including Twitter platform
- Develop website content and offer edits for optimizing consumer experience

Committee member expectations:

- Participate in 75% of committee conference calls/in-person meetings, occurring approximately six times per year.
- Take a leadership or co-leadership role of an aspect of communication duties, including active projects or serving as a communication liaison for other committees
- Interested parties may apply for two- or three-year terms; time commitment is expected to be four hours per month, with more responsibilities typically increasing in the three months leading up to the annual scientific sessions.

Role of patient/family committee members:

- Liaison with the Community Outreach Committee in order to support their dissemination of information
- Prepare the CNOC Star section of the Milestones Newsletter, which highlights a patient, parent, and/or family member.

PUBLICATIONS COMMITTEE

Co-Chairs: Bea Latal MD MPH and Karen Uzark PhD CPNP

Responsible for:

- review and approval of all abstracts, presentations and manuscripts for publication

Member expectations:

- Actively participate in the critical review of four to five abstracts/manuscripts per year
- Critical reviews performed and feedback delivered via email to the program chair within 14 days of receipt
- Committee meeting once per year during annual scientific session

Role of patient/family committee members:

- Assess the relevance to the larger stakeholder community of patients/caregivers
- Assess the inclusion of implications of the data presented to the patient/caregiver audience
- Assure the perspective/"voice" of the patient/caregiver is accurately represented

QUALITY IMPROVEMENT COMMITTEE

Co-Chairs: Samantha Butler PhD and Jennifer Cass PhD ABPP

Vice Chair: Kristi Glotzbach MD

Responsible for:

- Review, scope, and prioritization of quality improvement initiatives for CNOC
- Continue to implement CNOC QI project aimed toward improving outpatient cardiology identification and referral of high-risk status for children with CHD.
- Working with the Education and Training and Research Committees to support quality improvement initiatives

Member expectations:

- New members would be expected to participate on the current QI project (see description above), including data collection at their institution.

Role of patient/family committee members:

- Take part in discussion and review of our ongoing QI data collection at individual sites
- Help create interventions in the outpatient cardiac clinic geared toward patients, families and cardiology staff