REQUEST FOR APPLICATIONS:

CNOC INVESTIGATOR AWARD 2025

Program Description

The Cardiac Neurodevelopmental Outcome Collaborative (CNOC) is pleased to announce a Request for Applications (RFA) for the **CNOC Investigator Award**.

CNOC was founded in 2016 with the mission to determine and implement best practices of neurodevelopmental services for *every* individual with pediatric and congenital heart disease and their families through clinical, quality improvement, and research initiatives.

Since then, CNOC has grown to include 52 institutional member sites and more than 1400 individual members across North America and Europe.

Purpose of Award

The purpose of the CNOC Investigator Award is to provide funding support for CNOC members to leverage the CNOC Clinical Registry and infrastructure to conduct research and/or quality improvement science aimed at improving neurodevelopmental, psychosocial, and/or quality of life outcomes for children and families affected by pediatric or congenital heart disease (CHD).

Background

Cardiac neurodevelopment includes all aspects of motor, language, cognitive, social-emotional, and psychological development throughout life for individuals with pediatric and congenital heart disease. Children with heart disease can have challenges in one or more of these areas. While some of these challenges are detected during infancy or early childhood, others may not develop until later childhood, adolescence, or even adulthood. CNOC is a collaborative of clinicians, researchers, patients, and families from across the world working together to address these challenges and improve neurodevelopment, mental health, and quality of life for people of all ages and stages with pediatric and congenital heart disease.

CNOC Clinical Registry

In 2019, CNOC launched its Clinical Registry, which serves as a repository for high-quality, longitudinal neurodevelopmental, psychosocial, and quality of life outcomes data for individuals with CHD. As a founding member of Cardiac Networks United (CNU; <u>https://cardiacnetworksunited.org/</u>), CNOC neurodevelopmental and psychosocial outcomes data can be linked with additional cardiac medical and surgical data through collaborating networks, including the Pediatric Cardiac Critical Care Consortium (PC4), the Pediatric Acute Care Cardiology Collaborative (PAC3), and other networks.

CNOC's Clinical Registry is a centralized clinical data registry for standardization of data collection across our member institutions. The goal of the registry is to foster collaboration for multicenter research studies and quality improvement initiatives that will benefit people affected by CHD and improve their quality of life. Using CNOC's registry, we hope to gain greater insight into the factors that influence patient and family outcomes, and to ultimately improve the quality of care and health outcomes for all.

Details regarding specific content in the registry are contained in the manual of operations, and in the Registry section of the CNOC member website (See "<u>Data Dictionary December 2024</u>" for most recent updates to Data Dictionary). For an overview of how to leverage the registry for research questions, please see the July 2024 Webinar, available in the Education section of the CNOC website entitled, "**CNOC Research 101: A how-to guide for conducting research within CNOC.**"

(https://www2.cardiacneuro.org/members/webinars/CNOC_Research_101_A_How_to_Guide.mp4)

Questions regarding the CNOC Clinical Registry and associated CNU registries may be directed to the CNOC Research Committee Chair and Vice-Chairs: Dr. Justin Elhoff, Dr. Adam Cassidy, and Dr. Sarah Morton (email addresses below).

Award Priorities

Proposed study aims must address neurodevelopmental and/or psychosocial outcomes within the context of CHD <u>and</u> utilize data from the CNOC Clinical Registry. All applications that have the potential to advance knowledge and/or improve neurodevelopmental, psychosocial, and/or quality of life outcomes in CHD will be considered. Collaboration across multiple sites and disciplines is strongly encouraged. **Proposals that utilize registry data throughout their application/project will be prioritized over proposals that use registry for a small portion of the project**.

Areas of priority include:

- 1. Interventions to improve neurodevelopmental, psychosocial, and/or quality of life outcomes
- 2. Implementation science for improving access to and engagement with cardiac neurodevelopmental follow-up
- 3. Characterizing, predicting, and/or supporting optimal neurodevelopmental and/or psychosocial outcomes during later childhood/adolescence
- 4. Social determinants of health and disparities in care
- 5. Child and family mental health
- 6. Innovative models for predicting neurodevelopmental, psychosocial, and/or quality of life outcomes, including neuroimaging/monitoring or genetic relationships
- 7. Underlying mechanisms of neurodevelopmental, psychosocial, and/or quality of life outcomes
- 8. Collaborative neuroimaging studies leveraging the CNOC consortium and registry

Award Information

Funding Instrument	Grant	
Application Types Allowed	Pilot study	
	Clinical research study Quality improvement study	
	Collaborative studies involving multiple centers	
	Ancillary studies to other projects	
Funds Available and Resources	Study proposals may request funding of up to \$75,000 in total costs	
Available	over two years. The award amount will be determined by proposal	
	strength, level of priority, and budgetary requirements. One or more	

	study may be funded (up to a combined total funding amount of		
	\$75,000). Sub-awards to collaborators must be included in the		
	overall budget. Applicants may propose data analysis time to be		
	conducted by the CNOC Data Analysis Center (DAC), which will need		
	to be included in the proposed budget. Consultation with the		
	Research Committee and Data Analytic Core is strongly encouraged		
	prior to submission for estimation of needs and cost.		
Award Budget	Application budgets should reflect actual needs of the proposed		
	project. Items that applicants should consider including are		
	personnel costs, CNOC Data Coordinating Center and Data Analytic		
	Core costs, and any other costs associated with application.		
Budget Limitations	Indirect costs are not allowed		
Award Project Period	The period of support will be for 2 years.		

Key Dates

Posted Date	March 3, 2025
Letter of Intent Due	May 1, 2025
Invitation for Full Proposals	July 1, 2025
Full Application Due	September 1, 2025
Notice of Awards	November 1, 2025
Earliest Start Date	January 1, 2026

Eligibility

The PI must be from a CNOC Institutional Member site.

Review Criteria

Letters of intent will be reviewed by a committee comprised of individuals from CNOC leadership and the Research Committee along with other required content experts based on relevance, impact, and feasibility. Invitations for full proposal will be based on review. Full proposals will be reviewed and scored based on modified NIH criteria of Significance, Investigator(s), Innovation, Approach, and Environment.

Application Components

<u>Letter of Intent</u>: All applicants are required to submit a Letter of Intent (LOI) to CNOC Secretary, Sarah Kelly, PsyD, at <u>sarah.kelly@childrenscolorado.org</u> by May 1, 2025.

A strong LOI will include a preliminary feasibility review. Current volume reports in the CNOC clinical registry (filtered by question of interest) can be accessed through the ArborMetrix platform as demonstrated in the "CNOC Research 101" guide referenced above, specifically at **minute mark 55**. Investigators with questions regarding feasibility are encouraged to contact Research Committee leadership (emails below) by <u>April 10, 2025</u>.

Please include in the LOI:

- Descriptive title of the proposed research, lay summary, brief background/significance, and specific aims (1 page)
- Specific use of clinical registry data with estimated volume report obtained through feasibility review, research strategy, and alignment with CNOC mission (1 page)
- Special reviewer expertise, if applicable
- Name, email address, institution, and discipline of the Principal Investigator (PI)
- Names, institutions, and disciplines of other key personnel

<u>Full Proposals</u>: Criteria used to judge full proposals will include feasibility, impact, utilization of CNOC registry data, multi-institutional and interdisciplinary collaboration, and alignment with the CNOC mission. Additionally, consideration will be given to the status of data entry and participation in data audits at the research team's institutions. All applications must be submitted as a single pdf document via email to sarah.kelly@childrenscolorado.org and should include the following:

- Title, background and significance, study team members (including institution and discipline), lay summary, specific aims, data analytic plan with mock tables/figures, innovation, impact, and target journal(s) for publication (Maximum 6 pages total, not including references)
- One page budget justification, including a summary table organized into the following categories (as applicable): salaries, student scholarships, research equipment, materials and supplies, contract services (including data analysis support through Data Analytic Core), payments to study participants, publications fees, and other costs.
- Biosketch (Current NIH format) of Principal Investigator (required) and relevant other key personnel (optional, up to 3 total)
- Up to 2 letters of support

Contact Us

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