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Cite this article: Sood E, Jacobs JP, and Marino BS (2020) The Cardiac Neurodevelopmental Outcome Collaborative: a new community improving outcomes for individuals with congenital heart disease. *Cardiology in the Young* **30**: 1595–1596. doi: 10.1017/S1047951120003509

Received: 17 September 2020
Accepted: 22 September 2020

Keywords:
Paediatric cardiology; neurodevelopmental outcomes; congenital heart disease

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*The online version of this article has been updated since original publication. A notice detailing the changes has also been published.

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The Cardiac Neurodevelopmental Outcome Collaborative: a new community improving outcomes for individuals with congenital heart disease

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Abstract

Improved survival of patients with paediatric and congenital cardiac disease has led to a heightened awareness of the cognitive, neurodevelopmental, psychosocial, and physical functioning deficits that limit health, academic functioning, adaptive functioning, behavioural and emotional outcomes, health-related quality of life, and well-being for children and adults with congenital heart disease. The Cardiac Neurodevelopmental Outcome Collaborative was founded in 2016; its mission is to determine and implement best practices of neurodevelopmental and psychosocial services for individuals with paediatric and congenital heart disease and their families through clinical, quality improvement, and research initiatives.

Cardiology in the Young is devoted to cardiovascular issues affecting the young, and older patients with congenital heart disease, or with other cardiac diseases acquired during childhood. The journal serves the interests of all professionals concerned with these topics. By design, the journal is international and multidisciplinary in its approach, and members of the editorial board take an active role in its mission, helping to make it an indispensable reference for paediatric and congenital cardiac care. All aspects of paediatric and congenital cardiac care are covered in the journal. The content includes original articles, brief reports, editorials, reviews, and papers devoted to continuing professional development. High-quality colour figures are published on a regular basis, and without charge to the authors. Regular supplements are published containing the abstracts of the annual meetings of the Association for European Paediatric and Congenital Cardiology, along with other occasional supplements. These supplements are supplied free to subscribers.

The vision of *Cardiology in the Young* is to use print and electronic media to improve paediatric and congenital cardiac care. The mission of *Cardiology in the Young* is to be a premier global journal for paediatric and congenital cardiac care – an essential journal that spans the domains of patient care, research, education, and advocacy, and also spans geographical, temporal, and subspecialty boundaries.

Cardiology in the Young and the Cardiac Neurodevelopmental Outcome Collaborative* are pleased to announce that *Cardiology in the Young* will serve as the official journal of the Cardiac Neurodevelopmental Outcome Collaborative.* This new partnership between the Cardiac Neurodevelopmental Outcome Collaborative and *Cardiology in the Young* will facilitate the dissemination of knowledge and recommendations to the scientific, clinical, and patient advocacy communities, ultimately improving paediatric and congenital cardiac care and outcomes for individuals with paediatric and congenital heart disease and their families.

The population of survivors with congenital heart disease has increased dramatically over the last several decades due to diagnostic, surgical, and perioperative advances.[1–3] However, improved survival has led to a heightened awareness of the cognitive, neurodevelopmental, psychosocial, and physical functioning deficits that limit health, academic functioning, adaptive functioning, behavioural and emotional outcomes, health-related quality of life, and well-being for children and adults with congenital heart disease.[4–9] To meet the pressing needs of this growing population, the focus has now shifted from reducing mortality to improving long-term health and well-being.

The Cardiac Neurodevelopmental Outcome Collaborative was founded in 2016; its mission is to determine and implement best practices of neurodevelopmental and psychosocial services for individuals with paediatric and congenital heart disease and their families through clinical,

quality improvement, and research initiatives.[10] To achieve this mission, the Cardiac Neurodevelopmental Outcome Collaborative has established several key partnerships:

- The Cardiac Neurodevelopmental Outcome Collaborative has partnered with more than 40 member institutions across the United States of America, Canada, and Europe to establish this transformational collaborative.
- The Cardiac Neurodevelopmental Outcome Collaborative has also partnered with the healthcare technology company ArborMetrix to develop a registry of neurodevelopmental and psychosocial data.
- The Cardiac Neurodevelopmental Outcome Collaborative has also partnered with Cardiac Networks United (CNU),[11] a collaboration of registries focused on paediatric and congenital cardiac quality improvement and outcomes research. Cardiac Networks United includes the following registries and collaboratives:[10,11] Pediatric Cardiac Critical Care Consortium (PC4), Pediatric Acute Care Cardiology Collaborative (PAC3), National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), Advanced Cardiac Therapies Improving Outcomes Network (ACTION), and Cardiac Neurodevelopmental Outcome Collaborative (CNOC).
- Recently, a partnership with *Cardiology in the Young* and the Cardiac Neurodevelopmental Outcome Collaborative was established. We are pleased to announce that *Cardiology in the Young* will now serve as the official journal of the Cardiac Neurodevelopmental Outcome Collaborative.

This issue of *Cardiology in the Young* contains the inaugural four manuscripts from the Cardiac Neurodevelopmental Outcome Collaborative[10,12–14] and marks the beginning of the partnership between the Cardiac Neurodevelopmental Outcome Collaborative and *Cardiology in the Young*:

- First, Marino and colleagues describe the development and organisation of the Cardiac Neurodevelopmental Outcome Collaborative and the infrastructure that facilitates collaboration across sites and with patients and caregivers, meaningful and innovative science, and the establishment and dissemination of best-practice guidelines.[10]
- Second, Miller and colleagues characterise the variation in structure and personnel across cardiac neurodevelopmental follow-up programmes within member institutions of the Cardiac Neurodevelopmental Outcome Collaborative and highlight the need for more resources dedicated to school-age, adolescent, and young adult patients.[12]
- Finally, Ware and colleagues and Ilardi and colleagues describe strategies and considerations for conducting the neurodevelopmental evaluation of infants and children with congenital heart disease and provide specific recommendations for brief core assessment batteries and extended comprehensive assessment batteries, as defined by expert working groups comprised of multidisciplinary members of the Cardiac Neurodevelopmental Outcome Collaborative.[13,14]

A second set of manuscripts defining the cardiac neurodevelopmental research agenda will be published in an upcoming issue of *Cardiology in the Young* in 2021. These papers represent the work of a large, multidisciplinary, multinational group of medical experts and patient and caregiver stakeholders who convened for a 2-day meeting in 2018, funded by an R13 grant from the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) of the United States of America awarded to the Cardiac Neurodevelopmental Outcome Collaborative in partnership with Ann & Robert H. Lurie Children's Hospital of Chicago. This group has been working collaboratively over the past 2 years to identify significant gaps in knowledge in cardiac neurodevelopmental care and outcomes, critical questions that must be answered, and investigations needed to address these critical questions. Results and recommendations based on this work will guide the investigational aims of the Cardiac Neurodevelopmental Outcome Collaborative over the next decade. We are confident that this new partnership between the Cardiac Neurodevelopmental Outcome Collaborative and *Cardiology in the Young* will facilitate the dissemination of knowledge and recommendations to the scientific, clinical, and patient advocacy communities, ultimately improving paediatric and congenital cardiac care and outcomes for individuals with congenital heart disease and their families.

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https://doi.org/10.1017/S1047951120003509 Published online by Cambridge University Press