Brossard-Racine, M., James, R., Gallagher, A., and the CNOC Program and Meeting Committees.

The Cardiac Neurodevelopmental Outcome Collaborative (CNOC) is a collaborative of clinicians, researchers, patients, and families from across the world working together to improve neurodevelopment, mental health, and quality of life for people of all ages and stages with pediatric and congenital heart disease (CHD).

In September 2024, St-Louis Children's Hospital/Washington University hosted the 12th Annual Scientific Sessions over 4-days. This year's pre-conference was organized in collaboration with the Adult Congenital Heart Association which was composed of a half-day workshop highlighting the current knowledge regarding neurodevelopmental and psychosocial needs and care for adults living with CHD.

During the main conference, recent discoveries and promising findings from novel interventions targeting children's physical and mental health and their family's well-being were presented during a series of scientific oral sessions and panel discussions. The increased participation of youth and adults with lived experience throughout the conference, as well as parents/caregivers, was also an important highlight of this year's meeting.

This supplementary issue showcases a collection of abstracts presented at the poster sessions. Important themes presented during this session included the role of early neurodevelopmental intervention, the critical value of structured developmental frameworks to optimize access to care and outcomes, and the prevalence of barriers such as service variability, access disparities, and navigation challenges. Education and school-based research highlighted the value of interventions such as educational advocates in neurodevelopmental clinics and other tailored support systems addressing academic and psychosocial difficulties.

Overall, the work presented highlighted the importance of addressing health disparities and advocated for the adoption of an integrated model of cares that combines medical, psychological, and educational support set up in partnership with the families.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

Cardiac Neurodevelopmental Outcome Collaborative

Volume 35 • Supplement S1 • Pages S1–S45
doi:10.1017/S1047951125000708

Cardiology in the Young



# *12th Annual Scientific Sessions of the Cardiac Neurodevelopmental Outcome Collaborative*

## 1. Impact of Facility Dog Intervention on Young Children's Anxiety During Outpatient Echo and EKG

*Leslie Grissim MA, CCLS[1], Spencer Shreeve RN[1], Briana Keller MEd, Jessika C. Boles PhD, CCLS[2] and Monroe Carell Jr.*
*[1]Children's Hospital Vanderbilt, Nashville, TN; [2]Vanderbilt University, Nashville, TN*

*Introduction:* Over a million children are hospitalized for cardiac conditions in the United States each year, often requiring years of ongoing monitoring and care. Chronic illnesses, repeat healthcare encounters, and painful or invasive procedures place children at high risk of healthcare-related anxiety and pediatric medical traumatic stress. These psychosocial sequelae in turn predict poorer healthcare use patterns in adulthood, making young children's distress during care a public health issue. Many techniques are emerging to prevent pediatric medical traumatic stress by providing information and support to children during procedures. Facility dogs are a quickly growing facet of intra-procedural care; however, little has been done to study the impact of these interventions in pediatric cardiology patients. Therefore, the purpose of this cross-sectional study was to examine the impact of facility dog intervention on young children's anxiety during outpatient echocardiogram or EKG.
*Methods:* This study was conducted at an academic children's medical center in the United States that houses a robust pediatric cardiology program (including transplant, quaternary intensive care, and ambulatory services). Seventy-five children ages 18-months to 8 years undergoing outpatient echo or EKG procedures who spoke English as their primary language participated. Parent/caregivers provided consent and demographic information as the child was introduced to the facility dog and handler. A nurse observer used the modified-Yale Preoperative Anxiety Scale (m-YPAS) to score the child's pre- and post- procedural anxiety, and videos of the procedural interaction were coded to identify specific stress point intervals. Parent/caregiver and technologists also completed a perceptions survey about their experiences.
*Results:* Descriptive statistics were used to characterize participant demographics, and nonparametric tests were used to assess pre- and post- procedural m-YPAS scores due to non-normal distributions. Results indicate facility dog procedural intervention was associated with statistically significant ($p<.0001$) decreases in young children's observed anxiety between the pre- and post-procedural time points that may be approaching statistical significance. More specifically, this intervention was seen to be feasible, acceptable, and beneficial by parents/caregivers and technologists who participated in the study.
*Discussion:* The results of this study demonstrate that facility dog interaction during echo or EKG for young children is a well-received and favorably perceived intervention from the perspectives of families and staff. Additionally, facility dog intervention during outpatient echo/EKG is associated with a significant decrease in children's pre- and post- procedural anxiety levels, though more work is needed to better quantify any causality in this relationship. Given the lifelong health effects associated with pediatric medical traumatic stress and adverse childhood experiences, facility dog intervention may be a low- tech, low-cost, and widely acceptable strategy for preventing these effects in young children with cardiac conditions.

## 2. Parents' experiences of a decentralised neurodevelopmental follow-up care pathway for children with congenital heart disease: a qualitative evaluation

*B Abell[1], K Eagleson[2], T Donovan[1], D Rodwell[1], B Auld[2], R Justo[2], B McAlinden[2], S Riley[2,3], S Pagel[3] and S McPhail[1]*
*[1]Queensland University of Technology, Brisbane, Queensland, Australia; [2]Queensland Children's Hospital, Brisbane, Queensland, Australia; [3]Child Development Program, Children's Health Queensland, Brisbane, Australia*

*Introduction:* Optimal follow-up for children with congenital heart disease (CHD) and their families should include accessible models of neurodevelopmental care. The Congenital Heart Disease Long-term Improvements in Functional hEalth (CHD LIFE) decentralised care pathway was developed and implemented for children across the state who undergo open-heart surgery <12 months of age at the Queensland Paediatric Cardiac Service, Australia. This pathway seeks to empower families and facilitate access to the right surveillance, evaluation, and treatment in the right location at the right time. This study aimed to qualitatively explore families' experiences, perceptions and outcomes of the CHD LIFE pathway.
*Methods:* 35 mothers and 2 fathers with children registered on the pathway (n=36; aged 19 months to 10 years; 51% male)

participated in qualitative, semi- structured phone interviews. Transcripts were analysed inductively by two researchers adopting an iterative thematic analysis approach. Analysis also explored barriers, enablers and key implementation outcomes of the pathway.
*Results:* Interviews highlighted strong themes of parental satisfaction with the CHD LIFE pathway and positive outcomes for families. Parents reported increased awareness and knowledge of appropriate development for their children, which often resulted in proactively seeking professional follow-up for concerns. Eleven parents specifically reported improvements in their child's development after accessing allied health or disability services. The availability of ongoing access to health professionals for reassurance and expert knowledge to support concerns were seen as key benefits. However, many parents reported challenges with timely access to appropriate local services. The lack of a centralised touchpoint to coordinate ongoing follow-up placed an onus on families to drive and advocate for care. System navigation was a key challenge, which limited some families with poor health literacy or socioeconomic disadvantage. Most parents recalled receiving pathway education before hospital discharge and were aware of the need for recommended follow- up, but an unclear understanding of the pathway's structure, including how it differed to usual childhood developmental follow-up was also noted. Perceived success of the pathway varied across regions and services. Suggested opportunities for improvement included: care coordination; brief annual check-ins via phone or email; parental mental health support; and take-home resources inclusive of practical advice and additional information about the pathway's structure.
*Discussion:* The CHD LIFE pathway provides an exemplar of a successful decentralised neurodevelopmental care pathway for children with CHD. Embedding follow-up care into local community services was acceptable for families, yet constraints related to service capacity and perceived variability in local provider expertise were identified. Addressing identified opportunities for improvement is a priority for supporting the sustainment of CHD LIFE. This may include increased care coordination, pathway education, and an understanding of access barriers to scaffold equitable follow-up care for all families regardless of location or circumstances.

### 3. A PROMIS to Screen for Anxiety and Depression in Pediatric Heart Failure

*Matthew Wisniewski DNP, APRN, CPNP-AC[1], Katherine Cutitta PhD[2], Eleanor Howell RN, PhD[3] and Kriti Puri MBBS[1]*
*[1]Division of Critical Care Medicine, Department of Pediatrics, Baylor College of Medicine and Texas Children's Hospital, Houston, TX, USA; [2]Division of Psychology, Department of Pediatrics, Baylor College of Medicine and Texas Children's Hospital, Houston, TX, USA; [3]Auburn University College of Nursing, Auburn, Alabama, USA*

*Introduction:* Children with heart failure (HF) remain at an increased risk for developing anxiety and depression. Approximately 60% of children awaiting transplant demonstrate impaired psychosocial functioning, with 35% of these patients' meeting criteria for an emotional disorder diagnosis. In 2022, the American Heart Association (AHA), American College of Cardiology (ACC), and the Heart Failure Society of America (HFSA) released updated guidelines which recommend utilizing patient reported outcomes (PROs) for routine screening to evaluate the patient's functional status. The global aim of this quality improvement (QI) initiative was to improve the screening process for identifying anxiety and depression in children who are hospitalized for HF, with a VAD, or heart transplant, hence making identification and treatment timelier. The specific aim for this project was to increase the number of referrals to pediatric psychology or psychiatry from among hospitalized patients ages 5-21 years who are diagnosed with HF through the implementation of a screening process for depression and anxiety (as compared to usual care) utilizing the Patient-Reported Outcomes Measurement Information System (PROMIS).
*Methods:* Patients were identified by accessing electronic health records (EHRs) and those aged 5-21 years were added to an EPIC list during the screening period from October 2023 – March 2024. A rounding script was developed to obtain consent for screening utilizing PROMIS anxiety/depression tools. Process measures include: percent eligible patients rounded on, and percent of eligible patients receiving PROMIS. Outcome measures include number of new pediatric psychology consults. Balancing measures include surveyed families for satisfaction.
*Results:* 13 patients met criteria during the screening period. The mean range for age was 10.5 years (5-17). 62% were male, with 76% being of racial or the ethnic minority. 53% (7) had congenital heart defects as their underlying etiology of heart failure, with 47% (6) being primary cardiomyopathy. 54% (7) were primary HF, with 23% (3) being post heart transplant, and 23% (3) having mechanical circulatory support (MCS). 46% (6) met criteria for psychology consults. 100% (6) of patients who met consultation criteria, had psychology consults placed and were evaluated within 24 hours. Of the 6 patients with psychology consults; Five of the patients were diagnosed with adjustment disorder with mixed anxiety and depressive symptoms, and the remaining patient was diagnosed with non-specified depression disorder.
*Discussion:* Children with HF benefited from a standardized screening for mental health. The use of the PROMIS tool was well-accepted by patients/families and feasible for inpatient use. 46% of the screened patients met criteria for psychological evaluation given a t-score of $\geq 60$ on either the anxiety or depression screens. This is consistent with prior retrospective reports showing 20-40% of children on VAD or awaiting a heart transplant have psychological diagnoses or met criteria for psychological intervention. Limitations include a small sample size, and patients admitted outside of the Heart Center given staffing.

### 4. Educational Experiences of Teachers and Families of Children with Congenital Heart Disease

*Dr Sharon Millen[1], Prof Martin Dempster[1] and Prof Frank Casey[1,2]*
*[1]Queen's University, Belfast, Northern Ireland; [2]Royal Belfast Hospital for Sick Children, Belfast, Northern Ireland*

*Introduction:* The educational experience of children with CHD is often adversely impacted by factors such as medical burden, social and school functioning challenges. It is therefore vitally important that adequate support is provided at an early stage in order to facilitate better educational outcomes for this cohort. This study aimed to identify the challenges facing teachers and families of children with CHD in getting the best educational outcomes and explored how these challenges might be overcome to improve the school experience for these children.
*Methods:* A scoping review which focused on the educational challenges faced by children living with CHD was completed. Following this, a qualitative study was conducted which included three groups: (i) parents of children with CHD (ii) school teachers who have taught children with CHD and (iii) children and young people aged 11-17 with CHD. Focus groups/ one-to-one

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

interviews were conducted with each group to explore the lived experience and to establish the current level of need.
*Results:* It was evident from the scoping review that children with CHD face educational challenges in cognitive, psychomotor, behavioural and affective domains and also with school attendance. The findings from the qualitative study indicate that the main challenges for teachers include absenteeism as well as a lack of information around CHD and how it affects the individual child. Parents reported having concerns about how their child would cope academically as well as in a social, emotional, and physical sense. Building a strong relationship and having frequent communication between the teacher/ parent/ child was considered key in alleviating anxiety and promoting a supportive environment.
*Discussion:* Teachers of children with CHD would benefit from tailored written information pertaining to the individual child, updated on a regular basis. Parents require frequent communication with teachers as to how their child is coping.This information will be utilized in the next phase of the research to develop interventions to improve the overall educational experience for children and young people with CHD.

### 5. Higher Burden of Neurodevelopmental Delays in Children Undergoing Heart Transplantation in Early Childhood

*Sammie James MD, Chetna Pande MD, Sonia Monteiro MD, Faridis Serrano Forty PhD, Hari Tunuguntla MD and Kriti Puri MBBS*

*Introduction:* Children undergoing surgery for congenital heart disease (CHD) during early childhood have a greater risk of neurodevelopmental (ND) delays. However, data is scarce regarding the outcomes of children with heart failure needing ventricular assist device (VAD) support before heart transplantation (HTx). Our aim is to describe the ND outcomes of children undergoing HTx in the first 2 years of life. We hypothesized that children bridged to HTx on VAD support would have better ND outcomes.
*Methods:* We performed a single center retrospective cohort study from 01/2017 to 12/2022. Demographic and clinical data were collected by chart review including prematurity, socioeconomic status, birth weight, heart failure etiology, use of extra-corporeal membrane oxygenation, cardiopulmonary resuscitation, VAD support, hospitalization days, intubation days, heart failure etiology, and cardiopulmonary bypass time. All patients receiving VAD support or undergoing HTx at our center are referred to the Cardiac Developmental Outcomes Program (CDOP) where they undergo serial assessments, including the cognitive adaptive test (CAT), the clinical linguistic and auditory milestone scale (CLAMS), and Gessel's motor assessment. Available scores for the study cohort from testing at 6, 12, 24, 36, and 48 months were collected and classified as normal (100-85), at risk for delays (84-70), or delayed (<70). Our primary outcome was ND delay as diagnosed by physician or at least one test in delayed range in CDOP clinic.
*Results:* Forty patients met inclusion criteria (25 with CHD, 15 with cardiomyopathy), of whom 22 were followed in CDOP clinic (17 with CHD, 5 with cardiomyopathy). The study cohort is described in Table 1. Overall, 93% had ND delay and 28% were diagnosed with autism spectrum disorder (ASD) by a physician. Of those tested in CDOP, 96% showed delays on one of the three tests. The median scores for the entire cohort on CLAMS, CAT, and motor assessment respectively were 83, 66.6, and 62 at 6 months and 63.5, 73, and 48 at 12 months. The trend of CLAMS scores over the first 5 years of life is shown in Figure 1. There was no significant difference between those bridged on VAD support vs not at 6 and 12 months based on CLAMS (p=0.14,0.18 respectively), CAT (p=0.62,0.89), or motor assessment (p=0.62,0.89).
*Discussion:* We found that over 90% of children undergoing HTx in the first 2 years of life have ND delay, which is much higher than previously described in the CHD population. We also found a much higher rate of ASD compared to the general pediatric population. We found a disparity in access to CDOP clinic, with only a minority of those with cardiomyopathy being seen. Our study highlights the immense burden of ND delays and the need for continued close developmental follow up for children undergoing HTx.

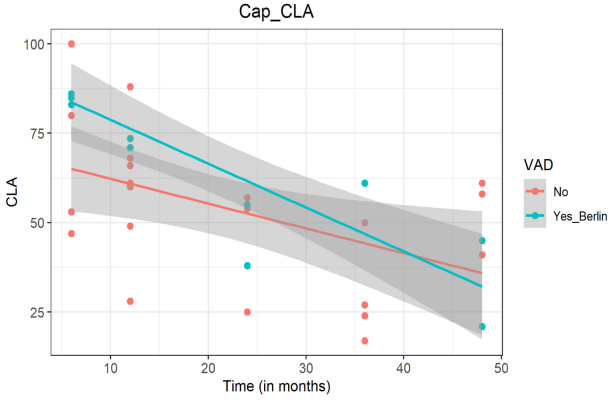



Figure 1. CLAMS Scores Show Decreasing Trend Over Time for Entire Cohort

This graph shows the CLAMS scores of our patient cohort over the 48 month time period. The y-axis shows scores categorized as normal (100-85), at risk for delays (84-70), or delayed (<70). The x-axis shows time in months going up to 48 months of age.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**Cohort Demographic and Clinical Characteristics Data**

| Sample Characteristic | | N=40 | % | Median | IQR |
|---|---|---|---|---|---|
| **Sex** | | | | | |
| | Male | 20 | 50 | | |
| | Female | 20 | 50 | | |
| **Age at Transplant** | | | | 0.70 | 0.44 - 1.13 |
| **Referrals** | | | | | |
| | PT | 34 | 85 | | |
| | OT | 32 | 80 | | |
| | ST | 29 | 72.5 | | |
| **Ethnicity** | | | | | |
| | White (non-Hispanic) | 11 | 27.5 | | |
| | Asian | 1 | 2.5 | | |
| | Hispanic | 22 | 55 | | |
| | Black | 6 | 15 | | |
| **HF Etiology** | | | | | |
| | Cardiomyopathy | 15 | 37.5 | | |
| | CHD | 25 | 62.5 | | |
| **Prematurity (<37 weeks)** | | 8 | 20 | | |
| **ECMO at any point** | | 9 | 22.5 | | |
| **Birthweight (<2.5kgs)** | | 6 (n=37) | 16.21 | | |
| **CPR at any point** | | 7 | 17.5 | | |
| **Hospitalization Days** | | | | 212 | 140.8 - 296.8 |
| **Intubation Days** | | | | 14.5 | 4 - 39.5 |
| **Area Deprivation Index** | | | | 70 | 51 - 82 |
| **Minutes of CPB Time in the first two years of life** | | | | 326 | 191 - 450 |
| **Required Gastric Tube** | | 24 | 60 | | |
| **Autism Spectrum Disorder Diagnosis** | | 11 | 28 | | |

Table 1. Cohort Demographic and Clinical Characteristics Data: For referrals, this includes referrals placed to physical therapy (PT), occupational therapy (OT), and speech therapy (ST) at any point during their lifetime. The following variables were analyzed for being present at any point in the patient's life at the time of data collection: use of ECMO, CPR, and presence of a g tube. The following variables were only analyzed for the first two years of life: hospitalization days, intubation days, and minutes of cardiopulmonary bypass. For socioeconomic status, we input patient addresses into the area deprivation index and reported scores compared to the rest of the country. For autism spectrum disorder diagnosis, we counted any diagnosis by a patient's primary care provider or by developmental pediatrics specialty provider.

### 6. Post-operative Brain Activity Measured with Quantitative EEG in Critical Congenital Heart Disease

*Kathleen Campbell[1], Nicholas S. Abend[1], Jillian L. McKee[1], Maryam Y. Naim[1], Nancy B. Burnham[1], Erin E. Zullo[1], Daniel J. Licht[2], Eric D. Marsh[1] and J William Gaynor[1]*
*[1]The Children's Hospital of Philadelphia, Philadelphia, PA, United States; [2]Children's National, Washington, DC*

*Introduction:* Abnormally low electroencephalography (EEG) amplitude and lack of recovery to continuous brain activity are associated with worse early neurodevelopmental outcome in children with critical congenital heart disease (CHD).[1] Existing studies used human rating of EEG which is time consuming and limits interpretation of trends over time. Quantitative EEG uses computer-based analysis to measure EEG features. This study investigated the trajectory of quantitatively assessed EEG amplitude during post-operative recovery and the impact of Clinical Factors.

*Methods:* In this prospective cohort study, we analyzed EEG recorded for 48 hours post-operatively on 14 neonates with CHD and surgery in the first week of life and a group of 7 neonatal controls with suspected seizure but normal EEG (Table 1). EEG

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

Table 1: Sample characteristics

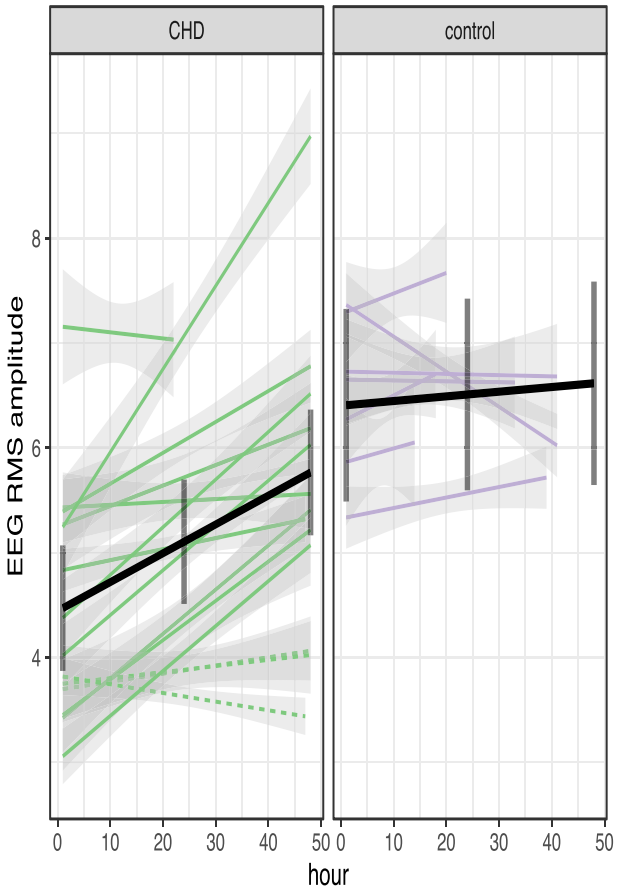
| | CHD (n=14) | Control (n=7) |
|---|---|---|
| Age at EEG in days, mean (SD) | 3.2 (1.9) | 8 (3.8) |
| Gestational Age, mean (SD) | 38.8 (0.8) | 37.9 (1.6) |
| Males | 10 (79%) | 7 (100%) |
| Stroke: Intraventricular Hemorrhage, Parenchymal Hemorrhage on MRI | 3 (21%) | 0 (0%) |
| Type of CHD | | NA |
| Single Ventricle with Arch Obstruction | 6 (43%) | |
| Two Ventricle with Arch Obstruction | 2 (14%) | |
| Two Ventricle without Arch Obstruction | 6 (43%) | |
| Deep Hypothermic Cardiac Arrest Used | 8 (57%) | NA |
| Duration of Bypass in minutes, mean (SD) | 66 (26.4) | NA |
| Medication Exposure during EEG | | |
| Ketamine | 13 (93%) | 0 (0%) |
| Dexmedetomidine | 13 (93%) | 0 (0%) |

was processed in MATLAB with filtering and artifact rejection.[2] EEG root mean square (RMS) amplitude was averaged to an hourly value for the whole head. Linear mixed effects models were used in R to compare group differences, measure change in amplitude over time, and find within-group effects of clinical factors including sex, stroke, type of CHD, deep hypothermic cardiac arrest, and duration of bypass.

*Results:* Neonates with CHD had lower EEG RMS amplitude than controls (estimate -1.6, p=.001) and amplitude increased to the control range by 48 hours after surgery (Figure 1). Within the CHD group, neonates with stroke had lower EEG amplitude (-1.5, p=.02, Figure 1) and did not recover to the control range. Females with CHD had higher amplitude than males (1.6, p=.002; Figure 2). Other clinical factors did not independently impact EEG amplitude.

*Discussion:* Quantitative assessment of EEG in neonates with CHD revealed that clinical factors and timing of measurement impact interpretation of post- operative EEG amplitude. Lower amplitude brain activity that does not recover may be a clinically useful

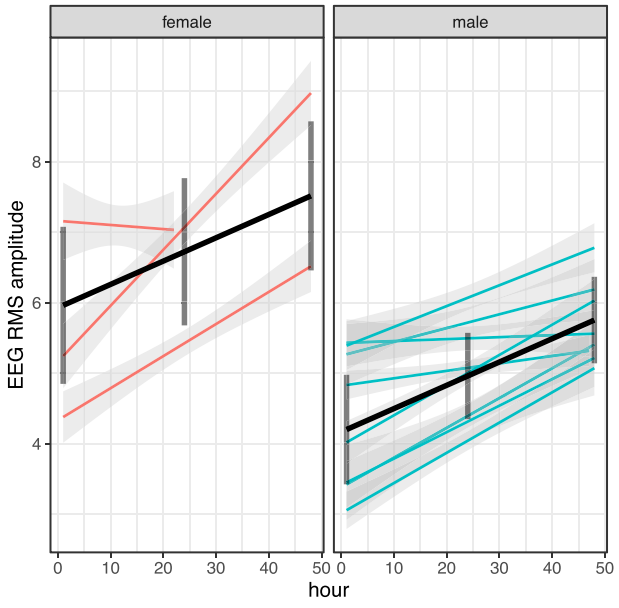
Figure 1: Individual trajectories of EEG root mean square (RMS) amplitude in CHD neonates (green lines) and controls (purple lines). Shaded margins show standard error. Solid black lines show group estimated marginal means and vertical bars show group standard error at 1, 24, and 48 hours. Dashed lines show lower amplitude and lack of recovery in 3 neonates with stroke




https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

marker of stroke. Higher amplitude brain activity in females may be related to the better developmental outcomes in females with CHD. Quantitative EEG measures could be used with larger samples to investigate the relationship between EEG measures, clinical factors, and developmental outcomes.

Figure 2: Individual trajectories of EEG root mean square (RMS) amplitude in females (red lines) and males (blue lines) within the CHD group (shaded margins show standard error). Solid black lines show group estimated marginal means and vertical bars show standard error at 1, 24, and 48 hours.




**7. Breastfeeding infants with critical congenital heart disease: A science advisory and call to action from the Cardiac Newborn Neuroprotective Network**

*Elgersma Kristin M.[1], Davis Jessica A.[2], ONeill Shripriya M.[3], Overpeck Shannon R.[4], Desai Hema[5], Gauntt Jennifer[6], Godsil Jairrah L.[7], Gray Julie K.[8], Harris Dixon Brittney D.[8], Hodgson Sarah W.[9], Marks Cat J.[10], Mekler Elizabeth R.[11], Momin Nashifa H.[12], Morris Kimberly M.[13], Muller Kacee M.[14], Negrin Karli A.[15], Scheiderer Virginia L.[10], Slater Nancy L.[16], Butler Samantha C.[17] and Peterson Jennifer K.[18]*

*[1]University of Minnesota, Minneapolis, MN, USA; [2]University of Pittsburgh, School of Medicine, Pittsburgh, PA, USA; [3]University of Virgina, Charlottesville, VA, USA; [4]Children's Hospital Orange County, Orange, CA, USA; [5]Children's Hospital of Orange County, Orange, CA, USA; [6]Nationwide Children's Hospital, Columbus, OH, USA; [7]Children's Mercy Hospital, Kansas City, MO, USA; [8]Children's Medical Center of Dallas, Dallas, TX, USA; [9]Shenandoah University, Winchester, VA, USA; [10]University of California San Francisco, San Francisco, CA, USA; [11]CS Mott Children's Hospital, Ann Arbor, MI, USA; [12]Children's Healthcare of Atlanta, Atlanta, GA, USA; [13]Rady Children's Hospital San Diego, San Diego, CA, USA; [14]Primary Children's Hospital, Salt Lake City, UT, USA; [15]Nemours Children's Health, Wilmington, DE, USA; [16]Children's Minnesota, Minneapolis, MN, USA; [17]Harvard Medical School, Boston, MA, USA; [18]Johns Hopkins University, Baltimore, MD*

*Introduction:* Infants with critical congenital heart disease (CCHD) in the United States have low direct chest/breastfeeding (BF) rates. Human milk is globally acknowledged as essential for hospitalized infants, with documented benefits for immune, gut, cardiac, and brain health. Direct BF increases human milk duration and is a critical intervention to improve the health of vulnerable infants; however, there are no formal guidelines to drive CCHD BF practice. The purpose of this presentation is to review evidence on BF for infants with CCHD, identify key barriers to and facilitators of BF in this population, and recommend future directions for research and care.

*Results:* For infants with CCHD, evidence-based benefits of BF include reduced incidence of inflammatory disorders and infection, improved cardiorespiratory stability while feeding, shorter length of stay, longer human milk feeding duration, better neurodevelopmental function, and improved parent mental health. Primary barriers include (1) dysphagia/aspiration, (2) growth concerns, (3) clinical instability, (4) finite developmental windows for BF acquisition, (5) institutional policies/ implementation, and (6) common BF challenges (eg, volume, latch). Evidence related to these barriers is limited. For example, while infants with CCHD may be at risk for aspiration, improved respiratory regulation while BF suggests that aspiration research in bottle-fed infants may not extrapolate. Infants with CCHD may also experience malnutrition or energy deficit. Research does not support a link between BF and poor growth, yet there is little data on incorporating BF into high-energy nutrition plans. Physiologic stability may vary, and there is no consensus on contraindications for BF. Moreover, BF establishment occurs during an 8–12 week window of opportunity for oromotor development, which is compressed by neonatal surgery. Implementation barriers include limited clinician lactation education, infant/parent separation, and staff time constraints. Structural health inequities can exacerbate these challenges. Evidence on BF facilitators is also limited, and most strategies known to increase BF have not been tested for effectiveness/acceptability in the medically-unique CCHD population. Strategies for other hospitalized infants include skin-to-skin holding, early pumping, non-nutritive BF, infant-driven feeding, parent/staff BF education, peer coaching, and financial compensation for pumping/ BF. As preoperative BF predicts later BF success for infants with CCHD, a focus on lactation support and opportunities for infant- driven BF during the prenatal/preoperative times may be particularly effective.

*Discussion:* Improving BF care has potential to improve health outcomes for infants with CCHD and their families. There are barriers to BF for these infants, however, with limited evidence to guide practice. Thus, there is a critical need for further research and quality improvement to identify interventions that equitably and effectively support BF for infants with CCHD.

**8. Ready or Referral? Increasing School age Readiness Referrals at Riley**

*Julie Gardner MSN, RN, CPN and Chelsea Kaai*
*BSW Riley Hospital for Children at IU Health, Indianapolis, IN*

*Introduction:* Our institution wanted to increase referrals for patients recommended to be seen by the Cardiac Neurodevelopmental

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

Outcome Collaborative (CNOC) and American Heart Association (AHA) guidelines. Would partnering with Cardiology and targeting an age specific recommended CNOC visit increase the number of referrals placed to Neuropsychology?
*Methods:* The Data Coordinator (DC) presented the School Age Readiness Referral Program (SARRP) at a Cardiology faculty meeting for approval. After approval, an SBAR was emailed to all Cardiologists. Next, our Data Analyst created a PowerBI patient list that connected the outpatient Cardiology schedule with our Cardioaccess database with an applied filter of 4.5-5.5 years old. The DC reviewed each patient for inclusion into the CNOC registry based on the AHA guidelines for screening. The DC sent an Electronic Medical Record (EMR) message to Cardiology Providers the week before the appointments of patients that met inclusion criteria. The EMR message included specific cognitive skills that can be assessed by Neuropsychology, common cognitive concerns to add to the referral if applicable, and how to place a referral to Neuropsychology. After the visit, charts were reviewed to see if referrals were placed. Referred patients were then tracked to see if a Neuropsychology appointment was scheduled and attended.
*Results:* From August 2023 to March 2024, 128 patients had a scheduled outpatient visit with Cardiology while between 4.5-5.5 years old. Of the 128 patients reviewed, 53 patients met inclusion for high-risk criteria. Therefore, 53 EMR messages were sent to Cardiology providers. This resulted in a referral rate of nearly 30% with 15 referrals being placed to Neuropsychology. So far, 5 patients have attended appointments and been entered into the registry. Six patients have an upcoming appointment now scheduled, one patient deferred, and one missed their appointment. Three patients have referrals but were unable to be reached for scheduling. Our institution's volume for CNOC qualifying Neuropsychology visits was 19 patients for 2023. With the SARRP, we are on track to increase our volume by more than 50% for 2024.
*Discussion:* Partnering with Cardiology to target a specific age group was an effective method of increasing referrals to Neuropsychology. Over 8 months, 15 referrals were generated for patients that otherwise may have been missed. At our institution, nearly every cardiac patient leaves their Neuropsychology visit with either a new diagnosis, referral, or IEP recommendations, showing these visits are essential for patients with Congenital Heart Disease. Targeting specific age groups or cardiac diagnoses may be effective methods for increasing patient volume that can be replicated at other institutions. Of note, an increase in referrals was seen for other age groups following the presentation of the SARRP to the Cardiology Faculty meeting. Building relationships may also help increase referrals for other programs.

### 9. Understanding Sleep Habits in Families with CHD to Better Support Life at Home

*Christy Gaus RN[1], Mary Jane Broge MSN,CPNP[1], Stumpf Julie MSN,RN[1], Caroline K. Lee MD[2], Mason Basler BS[2] and Sarah Bauer Huang MD[3]*
*[1]St. Louis Children's Hospital, St. Louis, MO, USA; [2]Department of Pediatrics, Washington University School of Medicine, St. Louis, MO, USA; [3]Department of Neurology, Washington University School of Medicine, St. Louis, MO, USA*

*Introduction:* Sleep is a crucial component of physical, mental, and emotional well-being throughout the lifespan. In childhood, sleep is essential for brain development, growth, physical and mental health, and immune function. Children with congenital heart disease (CHD) are at risk for developmental delay which includes difficulty with self-regulation, which can manifest as sleep disturbances. They are also often medically complex and are frequently discharged home after a prolonged hospitalization during infancy with multiple medications and medical equipment. There is little literature describing how these factors may contribute to sleep problems and disruptions at home for both children with CHD and their families. **Study Aim**: To describe the sleep habits of children with CHD and their families, the incidence and reasons for bed-sharing among caregivers and children with CHD, and to understand factors that contribute to child and caregiver sleep disruption.
*Methods:* The Cardiac Neurodevelopmental Program (CNDP) at St. Louis Children's Hospital conducted a 16-question caregiver survey from March 2023 to March 2024 about sleep patterns of children with CHD, 6 months to 4 years of age, who had received neonatal or cardiac intervention. Questions included child's place of sleep, reasons for bed-sharing (if applicable), caregivers' quality of sleep and factors that impact it, and guidance on sleep practices families received prior to hospital discharge.
*Results:* Of 80 participants, 19% (n=15) had single ventricle anatomy and 81% (n=65) had two ventricle anatomy. The average length of stay for single ventricle patients was 123 days, and 34 days for two ventricle patients. Bed-sharing was prevalent among 23% (n=18) of patients, with 13% (n= 2) of single ventricle patients and 25% (n=16) of two ventricle patients. Among those, the majority (78%, n=14) did not wish to change the bed-sharing situation. Over half of caregivers (56%, n=45) reported their sleep has been impacted by their child's heart condition. Of the 45 families, 60% (n=27) attributed their sleep disruption to worry and stress about their child, while 42% (n=19) reported quality of sleep was negatively affected by use of nighttime feeding pumps, and 37% (n=17) to nighttime medication administration. When asked what they wanted the cardiology team to discuss about their child's sleep practices, the most common responses were how long is it acceptable to let the baby cry; risk of death while sleeping; and use of home monitors during sleep.
*Discussion:* The prevalence of bed-sharing among CHD infants and toddlers with their caregivers is similar to what is reported in the general US infant population (23% and 22%, respectively). Despite more complex CHD and longer length of stay, patients with single ventricle anatomy were not more likely to bed-share than two ventricle patients, and the majority of caregivers did not perceive bed-sharing as a problem. This study unveiled factors that negatively impact caregivers' sleep including stress/worry about the child's heart function as well as sleep disruption due to feeding regimen and timing of medications. It indicates the need for counseling and intervention to optimize the sleep needs of our families with CHD.

### 10. Implementation of the Cardiac iRainbow©: A Developmental Care Pathway Based on Clinical Severity

*NP Kelly Kirby[2], MD Ramirez Alice[1], NP Hannah Noori[2], Allison Freccero OTD[2], PT Amanda Hollander[2], PT Eilish Byrne[3], RN Sheila Gamuciello[2], RN Giulia Maffei[2], Melissa Scala MD[1] and Kathleen R. Ryan MD[1]*
*[1]Stanford University; [2]Stanford Medicine Children's Health; [3]University of St Augustine for Health Sciences*

*Introduction:* The Cardiac iRainbow© is a developmental care pathway based on clinical criteria for infants 0-6 months of age with

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

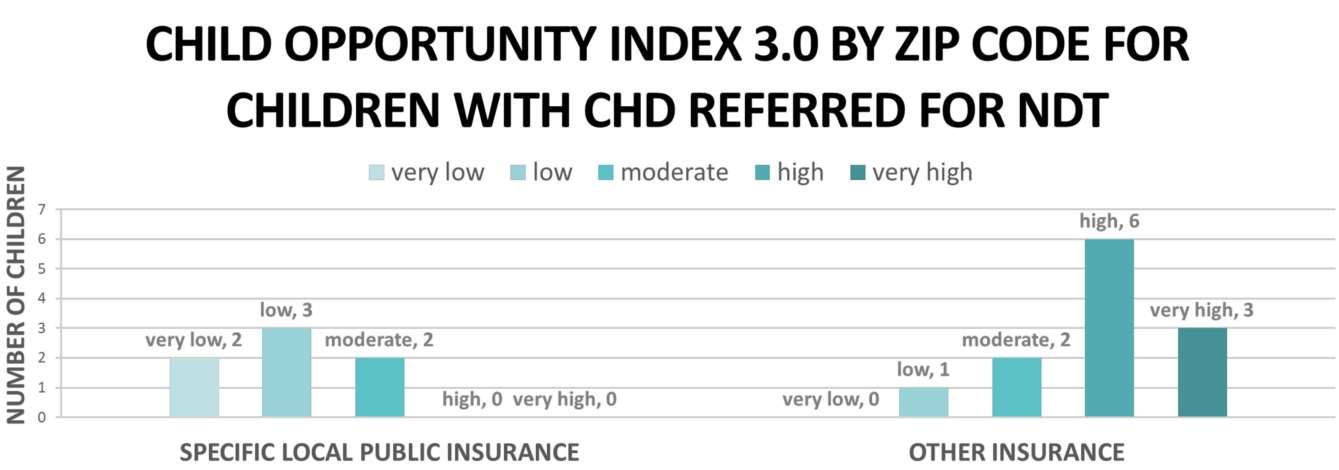
congenital heart disease in the cardiovascular intensive care unit (CVICU) and acute care cardiology unit (ACCU). This pathway is an adaptation of our neonatal intensive care unit iRainbow© pathway and is evidence-based practice. Cardiac iRainbow© is multi-disciplinary, guided by our Rehabilitation Team, and co-designed by Nursing, Heart Center Family Advisory Council, Office of Patient Education and Health Literacy, and Cardiac Neurodevelopmental Program (CNP). There are 5 stages based on objective medical criteria- Stage 1 Red (most unstable) to Stage 5 Blue (most stable). Each shift the nurse selects the appropriate stage for the patient, provides suggested developmental interventions, and documents in the electronic medical record (EMR). Together with the Holding Algorithm (HA), the pathway is intended to standardize safe holding practices and empowers bedside providers and caregivers to engage in developmental care.
*Methods:* Implementation of the Cardiac iRainbow© involved nursing and staff education in varied formats: in-person didactic and virtual lectures, simulation laboratory hands-on sessions, PowerPoint lecture videos, staff meeting updates, and targeted education for nursing orientation and the neonatal CVICU nurse champions. Nurse surveys were conducted pre- and 6 months post-implementation and 20 months post- implementation to evaluate need, understanding, comfort level using the pathway, and sustainability.
*Results:* The Cardiac iRainbow© launched in December 2021. Current caregiver documents include Cardiac iRainbow©, Developmental Activities, Infant Stress Signs. All documents are approved by our institution's Health Literacy department and are available in Spanish. Current provider documents include Cardiac iRainbow© and HA. Nurses use bedside tools (printed copies and QR codes linking videos of stages and developmental interventions) for caregiver education and to encourage caregiver involvement. CNP rounds twice monthly to evaluate pathway usage, understanding and EMR documentation. Nurses responded to a Likert survey question "I have sufficient training to select developmental activities" on a scale from 1 (Strongly Disagree) to 5 (Strongly Agree). Improvement pre- to post-implementation was seen with mean scores increased 3.3 to 3.8 ($p = 0.047$); however, at our sustainability check, mean scores returned to 3.3. While 83% of nurses were aware of the pathway, usage was less than 50%. The most cited barriers were low priority, not remembering, or patient instability.
*Discussion:* Given recent results of inconsistent use, our CNP team is conducting a formal A3 process to understand barriers to pathway adherence. We are considering EMR prompts to encourage documentation. Our current pathway only applies to a small subset of patients and can be easily forgotten. Current development of a comparable version for infants and children not currently included is in process. We aim to enhance referral rates for continuity to our outpatient CNP clinic and have ongoing collaboration with the Office of Child Health Equity to address health disparities and barriers to accessing CNP care.

## 11. Improving Access to Neurodevelopmental Testing for Children with Congenital Heart Disease: A Collaborative Approach Centering Equity

*NP Kirby Kelly[1], PH Bruce Janine Dr MPH[2], Joan Baran PhD[1], Meera Sukumaran MD[1], Casey Krueger PhD[3] and Kathleen R. Ryan MD[1]*
*[1]Stanford University, Stanford Medicine Children's Health Cardiac Neurodevelopmental Program; [2]Office of Child Health Equity; [3]Developmental Behavioral Pediatrics*

*Introduction:* Children with congenital heart disease (CHD) are at risk of developmental delay, behavioral challenges, and academic under performance. The American Heart Association and American Academy of Pediatrics recommend that children at high risk receive neurodevelopmental testing (NDT), while those at low risk undergo routine surveillance/screening. However, accessibility of services varies by insurance type leaving some children unable to access these recommended services. Subsequently, health disparities may widen for children already marginalized due to income and other social determinants of health. We identified barriers to NDT access at our center to develop strategies to improve access and reduce disparities.
*Methods:* Retrospective chart review was conducted for children referred to the Cardiac Neurodevelopmental Program (CNP) from June 2023 – March 2024 (IRB-66963). Demographic characteristics, insurance type, primary language, zip code, Childhood Opportunity Index (COI) 3.0 by zip code, NDT testing approval, NDT status, and receipt of new supports and therapies were extracted and analyzed using descriptive statistics. For individuals not approved for NDT, families were contacted to inquire about receipt of in-network NDT and offer instructions for contacting insurance provider. The project was guided by a community Family Resource Center (FRC) and Senior Policy Analyst.
*Results:* Nineteen patients were referred to CNP clinic, and 21% spoke Spanish as their primary language (n=4). Twelve patients received ND testing in CNP with age distribution: 5 (3.9 to 4.2 years); 5 (6.7 to 9.9 years); 2 (>age 14). Diagnoses at end of visit included: Global Developmental Delay/Intellectual Disability (25%), Autism (16%), Specific Learning Disability or Learning Challenges (25%), Anxiety/nervousness (33%), Weakness in working memory impacting quality of life (16%), and no cognitive/learning/mental health concerns or diagnosis (8%). Specific Local Public Insurance (SLPI) considered our institution out-of-network and denied insurance coverage for seven patients referred to us for NDT. SLPI offers in-network NDT; however, it was not obtained for any of these 7 patients due to limited ND provider availability and families expressing limited understanding/difficulty navigating the process.
*Discussion:* Children with CHD are at increased risk of developmental challenges. Pernational recommendations, our CNP provides NDT to children who are at high risk. Our analysis identified a high- risk cohort not able to access NDT and not receiving

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press




therapeutic interventions. We adapted processes to identify in-network NDT providers for patients with SLPI who are denied. Staff will now proactively provide 1:1 family support to navigate the process, provide a list of available in-network providers, facilitate PMD referral and activate FRC resources. We aim to further understand family perspectives from diverse backgrounds to ensure equitable access to care.

**12. Regional Brain Growth Differences in Fetuses with Congenital Heart Disease and Low Socioeconomic Status**

*Olivia Brumfield[1], Kaysi H. Pujols[2], Nicholas Hart[2], Kyla Waring, Valerie Rofeberg ScM[2,4], David Wypij PhD[4,5,8], Cynthia M. Ortinau[9], Ali Gholipour PhD[6] and Caitlin K Rollins MD, SM[2,3]*
*[1]Harvard Medical School, Boston, MA, USA; [2]Department of Neurology, Boston Children's Hospital, Boston, MA, USA; [3]Department of Neurology, Harvard Medical School, Boston, MA, USA; [4]Department of Cardiology, Boston Children's Hospital, Boston, MA, USA; [5]Department of Pediatrics, Harvard Medical School, Boston, MA, USA; [6]Department of Radiology, Boston Children's Hospital, Boston, MA, USA; [8]Department of Biostatistics, Harvard T.H. Chan School of Public Health, Boston, MA, USA; [9]Department of Pediatrics, Washington University School of Medicine, St. Louis, MO, USA*

*Introduction:* Children diagnosed with congenital heart disease (CHD) have small regional and total brain volumes *in utero*. Socioeconomic status (SES) is associated with fetal brain development. Using fetal brain magnetic resonance imaging (MRI), we sought to determine whether markers of SES, including income and parental educational attainment, are associated with fetal brain volumes in fetuses with CHD compared to controls. We also explored whether the relationship between SES and brain volume differed by group.
*Methods:* We included pregnant persons aged 18-45 years with fetuses at 24-36 weeks gestation, with and without CHD, and with no known congenital/genetic abnormalities. The cohort was divided into two groups: healthy fetuses, "Controls" and fetuses with CHD. SES was measured using the following dichotomized predictors: income-to-needs ratio (INR) with low income defined as INR<1 and maternal education with low defined as less than a college degree. The primary outcome was total brain volume; secondary outcomes included regional brain volumes. Linear regression using generalized estimating equations adjusting for gestational age (linear and quadratic terms), sex, and group (Control *vs* CHD) including interaction terms for group by volume were used to evaluate relationships between brain regions and both INR and maternal education. Exploratory analysis evaluated the effect of SES by CHD subtype: transposition of the great arteries or hypoplastic left heart syndrome, "TGA/HLHS" - diagnoses expected to have a more severe impact on fetal cerebral substrate delivery, and fetuses with other CHD types, "Other CHD."
*Results:* Control fetuses had larger brain volumes than those with CHD (10.1 [5.2, 15]; p<0.001). Low income was not associated with total brain volume (-2 [-8.1, 4.1]; p=0.517) but was associated with smaller cerebellar volume (-0.5 [-0.8, -0.1]; p=0.012). Lower maternal education was associated with smaller subcortical gray matter (-0.3 [-0.4, -0.1]; p<0.001) and cerebellar volume (-0.4 [-0.8, -0.1]; p=0.016). The effect of income and education on total and regional brain volumes did not differ between groups (Control *vs* HLHS/TGA *vs* Other CHD).
*Discussion:* Low SES was not associated with global measures of the fetal brain, but both income and education were associated with smaller regional volumes. The volumetric changes associated with low INR and low maternal education level did not differ between groups. It is possible that the sample size was inadequate to detect an effect. However, findings may support hemodynamics as the predominating driver of altered brain growth in this population. These findings suggest that distinct mechanisms may underlie associations between unique elements of SES and regional fetal brain development in congenital heart disease.

**13. Who Do Cardiac Neurodevelopmental Programs Care For? A Study of Visual Representation Online**

*Gabrielle Chinman[1], Diego Cisneros[2], Krisjon Olson[3], Peter Ferrazano[3] and Jesse Boyett Anderson[3]*
*[1]Department of Neuropsychology, UW Health Hospitals and Clinics, Madison, WI; [2]David Geffen School of Medicine at UCLA, Los Angeles, CA; [3]Department of Pediatrics, University of Wisconsin School of Medicine and Public Health, Madison, WI*

*Introduction:* Patients with congenital heart defects and their caregivers search online and consult with healthcare providers to learn about their future medical and developmental needs. This is true for patients of all racial and ethnic backgrounds. Patients report enhanced communication and experience improved outcomes when they are cared for by a physician of the same race, however

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

neither the racial and ethnic composition of the pediatric cardiology workforce, nor that of the patient pictures shared online by hospitals mirror the racial and ethnic composition of their patient populations. Lack of racial congruence between providers and patients and the lack of racial and ethnic representation in hospital communication have been posited to intensify the disconnect between healthcare institutions and their patients. The objective of this study was to assess the visual representation of different racial and ethnic groups, as well as visible markers of cardiac disease on heart center websites in the United States discussing neurodevelopment.
*Methods:* The websites of all 129 congenital cardiac surgical programs listed in the Congenital Cardiology Today 2021-2022 directory were reviewed in 2022. Web pages containing information about cardiac neurodevelopment were coded for the number of images of patients, family members, and medical providers from different racial and ethnic groups, with different ability levels, as well as with any notable physical differences (e.g. scars, use of medical technology for daily living, syndromes, etc.). These proportions were compared to national and state-level demographics.
*Results:* Fifty-one websites included information about cardiac neurodevelopment. Of these, only 14% (7 programs) had at least one image of a patient or medical provider who was biracial or a person of color. Of the nineteen programs located in a state or district where more than 40% of the population is comprised of individuals who are biracial or people of color, only three included pictures of patients and/or providers who were biracial or people of color. Eight websites included a photo of a patient with a visible acute illness; two included a patient with a visible scar. Six showed visible disabilities; four showed children with visible syndromes, one showed a patient using medical technology, and one showed a patient with multiple visible disabilities.
*Discussion:* The lack of visual representation of our diverse patient population on congenital cardiac program web pages dedicated to the neurodevelopmental sequelae of congenital heart disease may contribute to a disconnect between patients, caregivers and their providers for neurodevelopmental follow-up services. Many of the analyzed websites did not present non-white, syndromic or disabled patients. If patients and caregivers feel they will be seen and understood by their providers and can see, through diverse and representative websites, that there are others like them receiving services, they may be more likely to connect with the care their children need to succeed.

### 14. Empowering Education: The Transformative Role of Embedded Advocates in Neurodevelopmental Clinics

*Michelle L Hughes MEd[1], Abigail Demianczyk PhD[2], Katherine Myers DO, MPH[2], Jenna Kolschetzky BSN, RN[3], Kelly Campbell DPT[4], Meghan Siegfried MSW LSW[1], Mayme Marshall MD[5], Bradley S. Marino MD MPP, MSCE, MBA[5] and Rashmi P Rao MD[5]*
*[1]Pediatric Social Work, Cleveland Clinic Children's Hospital, Cleveland, OH; [2]Pediatric Behavioral Health and Neurosciences, Cleveland Clinic Children's Hospital, Cleveland, OH; [3]Nursing, Cleveland Clinic Children's, Cleveland, OH; [4]Pediatric Therapy Services, Cleveland Clinic Children's, Cleveland, OH; [5]Department of Heart, Vascular & Thoracic, Cleveland Clinic Children's, Cleveland, OH*

*Introduction:* Children with congenital heart disease (CHD) often face neurodevelopmental (ND) challenges that can impact school performance (1-2). Many require special education services, but coordination gaps hinder implementation of recommended interventions (3). Integration of an educational advocate (EA) in cardiac ND follow-up clinics may significantly impact educational supports and/or services in high-risk CHD patients. We aim to (1) quantify the number of patients receiving EA services; (2) document the number of modifications in 504 Plans or Individualized Education Programs (IEPs); (3) describe the EA's role during prolonged inpatient admissions through a case report.
*Methods:* We conducted a retrospective review of all patients seen in our cardiac ND follow-up clinic from July 2023 to July 2024 who received EA services.
*Results:* A total of 123 school-age patients were seen for ND follow-up, of which 76 (62%) had preexisting IEPs/504 plans. Initial IEPs were developed with EA support in 9 patients (5.7%). In those with preexisting plans, the EA facilitated modification of 94% of IEPs and 57% of 504 Plans. This was accomplished through EA participation in a total of 66 parent follow-up meetings, 39 school meetings, and writing 41 letters of support. We highlight a case study demonstrating the EA's role across the continuum of care. Patient JL is a 5-year-old male with complex CHD, who was evaluated in the ND follow-up clinic for pre- kindergarten assessment. Testing revealed concerns related to cognition, inattention, and executive and adaptive functioning. EA assisted with implementation of IEP services in kindergarten. He was later admitted due to failing Fontan physiology and is awaiting heart transplant. Through collaboration with the school and hospital administration, EA ensured JL received services outlined in his IEP during this prolonged hospitalization. This resulted in virtual speech-language therapy, additional tutoring, and inclusion of IEP physical and occupational therapy goals in hospital provider treatment plans
*Discussion:* We demonstrate the significant impact that integrating an EA in ND follow-up can have on our patients' educational experience through tailoring of educational plans and implementation of appropriate, legally available supports and services. An EA can support patient education in both the outpatient and inpatient settings, which may be particularly impactful for patients facing prolonged hospitalization. These findings highlight the crucial role of the EA in achieving positive outcomes and safeguarding equitable access to education and supports for pediatric patients with CHD.

### 15. Developmental, Academic and Health Impacts in School Age Children Born with Heart Disease

*Sarah Hodgson MS, OT,R/L[1] and Jennifer K. Peterson PhD, APRN-CNS, CCNS, CNE, FAHA[2]*
*[1]Division of Occupational Therapy, Shenandoah University, Winchester, VA; [2]Johns Hopkins University School of Nursing, Baltimore, MD*

*Introduction:* Children born with heart disease (HD) differ from peers in numerous neurodevelopmental and health domains throughout childhood. There is limited research on how these differences translate into need for special school services or affect school outcomes in children born with heart disease; previous studies have examined children with asthma or children born prematurely. Therefore, this study compared school needs and outcomes between children ages 6-17 years born with HD, children with asthma, and children born prematurely.
*Methods:* This study involved secondary data analysis from the 2022 National Survey of Children's Health (NSCH). Data were analyzed using procedures for complex survey data. Respondents were divided into mutually exclusive categories: 1. Born with HD (n = 535), 2. Asthma (n = 3706), and 3. Born > 3 weeks prematurely (n = 2907). Children with more than one of these conditions were excluded. Chi-square tests were used to compare health status, school services, and school outcomes between these 3 groups.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*Results:* Of the 54,065 NSCH responses, 26,814 were specific to a child ages 6 to 17 years. Children born with HD were more likely to be White (84.95% vs 63.1% and 69% respectively, p <0.001) and reside in a two-parent family (75.4% vs 65.3% and 70.4%, respectively, p = 0.006) than children with asthma or those born prematurely. Children born with HD and those with asthma were more likely to fit criteria of Special Health Care Needs designation than those born prematurely (45.8% and 48% vs 27% respectively, p <0.001). Children born with HD had a greater negative impact of their health conditions on daily activities than comparators (consistent and often greatly affects = 16.3% vs 4.6% and 3.7%, p >0.001). Children born with HD were more likely than either comparator group to be diagnosed with behavior problems (21% vs 12.6% and 10.6%, p = 0.007), intellectual disability (13.4% vs 1.4% and 2.2%, p <0.001), speech disorder (26.6% vs 10.9% and 12.4%, p >0.001), learning disability (25.1% vs 13.3% and 12.7%, p = 0.002). Children born with HD were more likely than either comparator group to have a Special Education Plan (32.6% vs 18.4% and 23.3%, p = 0.001) or receive special developmental services (36.9% vs 19.4% and 28.5%, p = 0.001). Children born with HD also missed more school days due to illness or injury than either comparator group (11 or more days = 13.7%, vs 11.8% and 6.7%, p <0.001). There were no significant differences in school engagement, usual grades, need to repeat a grade, or bullying between the 3 groups.
*Discussion:* Children born with HD present a unique phenotype of school needs, and their health has a greater negative impact on daily activities and school attendance than children with asthma or those born prematurely. Care coordination within primary and specialty care with school professionals may be helpful to maximize school success in this vulnerable population of children born with HD.

Table 1. Demographics and Health Status of Children 0-5 years of age

| Variable | Not Born with Heart Condition % (95% CI) | Born with Heart Condition % (95% CI) | P value |
|---|---|---|---|
| Male sex | 51.09 (49.63-52.55) | 59.82 (51.64-67.49) | 0.0385 |
| Race | | | 0.9457 |
| White | 70.53 (69.15-71.86) | 71.89 (63.1-79.27) | |
| Black | 12.65 (11.55-13.84) | 12.23 (6.92-20.72) | |
| Other | 16.82 (15.85-17.83) | 15.88 (10.69-22.94) | |
| Hispanic ethnicity | 27.53 (26.05-29.07) | 14.88 (9.25-23.05) | 0.0042 |
| Primary household language | | | 0.1293 |
| English | 84.59 (83.26-85.83) | 91.63 (84.84-95.54) | |
| Spanish | 9.66 (8.52-10.94) | 4.82 (2.18-10.32) | |
| Other | 5.75 (5.16-6.39) | 3.55 (1.23-9.78) | |
| Insurance Type | | | <0.001 |
| Public | 31.32 (29.85-32.83) | 32.01 (24.34-40.78) | |
| Private | 57.8 (56.27-59.32) | 52.75 (44.01-61.33) | |
| Private and public | 4.83 (4.23-5.52) | 13.22 (8.03-21.01) | |
| Not insured | 6.04 (5.23-6.96) | 2.02 (0.89-4.57) | |

**16. Early Childhood Skill Acquisition in Children Ages 0 to 5 Years Born with Heart Disease**

*Sarah Hodgson MS, OT, R/L[1] and Jennifer K. Peterson PhD, APRN-CNS, CCNS, CNE, FAHA[2]*
*[1]Division of Occupational Therapy, Shenandoah University, Winchester, VA; [2]Johns Hopkins University School of Nursing, Baltimore, MD*

*Introduction:* Children with heart disease are at risk of developmental delays; however, there is limited research into how children with heart disease compare with healthy peers on specific skill acquisition that indicates school readiness. The purpose of this study was to compare health status as well as developmental skill acquisition in children ages 0 to 5 years born with heart disease and those born without heart disease, and to identify predictors of the need for Special Education or Early Intervention Plan (EIP) services.
*Methods:* This study involved secondary analysis of data from the 2022 US National Survey of Children's Health (NSCH). Data were analyzed using procedures for complex survey data. Chi-square tests were used to compare demographics and health status of children ages 0 to 5 years born with heart disease and those born without heart disease. Developmental skill acquisition was analyzed using Chi-square tests between the two groups using items that reflected Ages and Stages Questionnaire categories of communication, fine motor, personal-social and problem-solving skills. A multivariate logistic regression model was developed to identify demographic and health status predictors of receipt of Special Education services.
*Results:* Of 54,065 NSCH responses, 19,703 were in the 0-to-5-year age group including 2.36% born with heart disease. There were no demographic differences between the groups, except that

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**Table 1. (continue)**

| | | | |
|---|---|---|---|
| How Often Hard to Cover Basics (food or housing) | | | 0.2439 |
| Never or Rarely | 86.04 (94.96-97.14) | 82.53 (75.31-87.98) | |
| Somewhat or Very Often | 13.96 (12.86-15.14) | 17.47 (12.02-24.69) | |
| Caregiver Education | | | 0.4324 |
| Less than HS | 9.76 (8.57-11.10) | 8.01 (3.49-17.32) | |
| HS or GED | 15.65 (14.51-16.87) | 13.13 (8.31-20.14) | |
| Some College or VoTech | 16.3 (15.3-17.36) | 14.31 (9.96-20.14) | |
| Associate/Bachelor degree | 34.85 (33.54-36.18) | 33.55 (26.57-41.34) | |
| Graduate degree | 23.43 (22.34-24.56) | 31.00 (22.94-40.41) | |
| Family Structure | | | 0.440 |
| Two parent | 76.96 (75.58-78.28) | 77.66 (67.89-85.1) | |
| One parent | 19.06 (17.82-20.37) | 15.90 (9.70-24.96) | |
| Other | 3.98 (3.40-4.67) | 6.45 (2.64-14.93) | |
| Income % of FPL | | | 0.1914 |
| 0-99 | 18.63 (17.37-19.95) | 24.76 (17.37-33.99) | |
| 100-199 | 19.15 (17.95-20.41) | 17.02 (11.36-24.69) | |
| 200-399 | 27.41 (26.12-28.73_ | 21.03 (15.41-28.01) | |
| 400+ | 34.81 (33.53-36.11) | 37.2 (29.33-45.82) | |

**Table 1. (continue)**

| | | | |
|---|---|---|---|
| Reside in Metropolitan Statistical Area | 87.28 (86.37-88.14) | 86.18 (80.06-90.64) | 0.6762 |
| Health Status | | | |
| Special Health Care Needs | 10.62 (9.79-11.52) | 43.72 (35.31-52.52) | <0.001 |
| General Health | | | <0.001 |
| Excellent, Very Good, or Good | 99.26 (99-99.46) | 94.73 (90.75-97.05) | |
| Fair or Poor | 0.74 (0.54-1.00) | 5.27 (2.95-9.25) | |
| Born > 3 weeks premature | 11.57 (10.53-12.68) | 26.97 (19.93-35.41) | <0.001 |
| Ever diagnosed anxiety or depression | 1.65 (1.3-2.09) | 6.86 (2.92-16.27) | 0.0015 |
| Ever diagnosed developmental disorder | 11.63 (10.69-12.65) | 36.42 (28.32-45.26) | <0.001 |
| | Not Born with Heart Condition % (95% CI) | Born with Heart Condition | P |
| C Say One Word | 96.61 (95.78-97.29) | 90.57 (83.78-94.69) | 0.0007 |
| C Two Words Together | 86.89 (85.66-88.03) | 73.09 (64.47-80.26) | <0.001 |
| C Three Words Together | 78.22 (76.7-79.66) | 64.18 (55.05-72.38) | 0.0004 |
| C Follow Verbal Directions | 92.36 (91.32-93.28) | 81.93 (72.96-88.39) | 0.0002 |
| C Point to Things | 90.06 (88.89-91.12) | 81.51 (73.72-87.39) | 0.0021 |

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**Table 1. (continue)**

| | | | |
|---|---|---|---|
| C Follow two step directions | 88.71 (87.52-89.81) | 76.24 (67.26-83.36) | 0.0001 |
| C Understand "in" "on" "under" | 87.44 (86.29-88.5) | 72.46 (63.42-79.97) | <0.001 |
| F Draw a circle | | | 0.3325 |
| Cannot or not well | 12.44 (11.03-14.01) | 16.08 (9.59-25.72) | |
| Somewhat or very well | 88.97) | 83.92 (74.28-90.41) | |
| F Draw a face | | | 0.0020 |
| Cannot or not well | 25.32 (23.55-27.17) | 42.38 (31.01-54.63) | |
| Somewhat or very well | 74.68 (72.83-76.45) | 57.62 (45.37-68.99) | |
| F Draw a person | | | 0.0096 |
| Cannot or not well | 37.68 (35.74-39.66) | 53.13 (41.33-64.59) | |
| Somewhat or very well | 62.32 (60.34-64.26) | 46.87 (35.41-58.37) | |
| F Write First name | | | 0.0054 |
| Never/Sometimes | 46.41 (44.43-48.39) | 62.45 (51.21-72.49) | |
| Most of the time/Always | 53.59 (51.61-55.57) | 37.55 (27.51-48.79) | |
| P Smiles and Laughs | | | 0.6043 |
| Never/Sometimes | 1.69 (1.26-2.26) | 2.19 (0.85-5.54) | |
| Usually/Always | 98.31 (97.73-98.74) | 97.81 (94.46-99.15) | |
| P Waits for Turn | | | 0.0946 |
| Never/sometimes/ half the time | 88.73 (87.31-90.0) | 81.49 (69.09-89.83) | |
| Usually/always | 11.27 (9.99-12.69) | 18.51 (10.34-30.91) | |

**Table 1. (continue)**

| | | | |
|---|---|---|---|
| P Plays well with others | | | 0.0028 |
| Never/sometimes/ half the time | 13.1 (11.72-14.62) | 26.94 (16.95-40.0) | |
| Usually/always | 86.9 (85.38-88.28) | 73.06 (60.83-83.05) | |
| P Share toys | | | 0.0422 |
| Never/sometimes/ half the time | 32.67 (30.73-34.68) | 44.51 (33.14-56.48) | |
| Usually/always | 67.33 (65.32-69.27) | 55.49 (43.52-66.86) | |
| PS Recognize Alphabet Letters | | | 0.0145 |
| Some/Half | 35.85 (33.86-37.88) | 50.31 (38.63-61.95) | |
| All/Most | 64.15 (62.12-66.14) | 49.69 (38.05-61.37) | |
| PS Can Count to | | | 0.1508 |
| 0 to 5 | 11.95 (10.31-13.8) | 17.06 (10.11-27.32) | |
| 10-20 | 55.6 (53.61-57.57) | 59.89 (48.18-70.57) | |
| 30 plus | 32.46 (30.76-34.2) | 23.06 (15.09-33.57) | |
| PS Read One digit numbers | | | 0.0005 |
| Never/sometimes/ half the time | 26.75 (24.82-28.76) | 46.45 (34.66-58.65) | |
| Usually/always | 73.25 (71.24-75.18) | 53.55 (41.35-65.34) | |
| PS Can tell which group of objects has more | | | 0.0035 |
| Never/sometimes/ half the time | 28.31 (26.41-30.3) | 45.01 (33.38-57.21) | |
| Usually/always | 71.69 (69.7-73.59) | 54.99 (42.79-66.62) | |
| Ever received special services | 11.64 (10.66-12.68) | 36.31 (28.22-45.46) | <0.0001 |

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**Table 1. (continue)**

| | | | |
|---|---|---|---|
| If yes, special services currently | 66.22 (61.95-70.24) | 82.32 (72.76-89.03) | 0.0029 |
| Has child started school<br>Yes, preschool<br>Yes Kinder or 1st grade<br>No | 49.39 (47.43-51.36)<br>17.33 (15.9-18.85)<br>33.28 (31.36-35.28) | 49.71 (38.05-61.4)<br>10.99 (6.52-17.94)<br>39.3 (27.92-51.97) | 0.2611 |
| Ever received Special Ed or EIP | 6.28 (5.68-6.93) | 24.2 (17.48-32-48) | <0.0001 |

children born with heart disease were less likely to be Hispanic (14.9% vs 27.5%, p = 0.004), and had different types of insurance (p<0.001). Children born with heart disease were more likely than those born without heart disease to be identified as having Special Healthcare Needs (SHCN) (43.7% vs 10.6%, p<0.001), born more than 3 weeks prematurely (27% vs 11.6%, p<0.001), have parent-rated health as fair or poor (5.3% vs 0.7%, p <0.001), and be diagnosed with anxiety or depression (6.9% vs 1.7%, p = 0.001) or any type of developmental disorder (36.4% vs 11.6%, p<0.001). Children born with heart disease were less likely than children born without heart disease to achieve communication, fine motor, personal social, and problem-solving skills (all p<0.05), except for draw a circle, smile/laugh, and counting. Children born with heart disease were more likely than children born without heart disease to receive Special Education or EIP services (24.2% vs 6.3%, p<0.001). Multivariate predictors of receiving Special Education or EIP in children 0 to 5 years of age included public plus private insurance (aOR 2.64, 95% CI 1.58-4.42, p <0.001), classified as child with SHCN (aOR 3.22, 95% CI 2.34-4.42, p<0.001), and any developmental disorder (aOR 28.2, 95% CI 20.7-38.4, p<0.001). Being born with heart disease did not significantly predict receipt of Special Education or IEP services in the multivariate model.

*Discussion:* Pre-school age children born with heart disease demonstrate delayed acquisition of important developmental skills that are vital for school readiness and are more likely to receive Special Education or EIP services. Children who meet criteria for Special Healthcare Needs designation or are diagnosed with a developmental disorder are at highest risk. Screening at preschool healthcare visits may identify children at risk and allow timely referral for services.

### 17. "We are not alone": Building Community and Connection through Inpatient and Outpatient Cardiology Programming

*Erin Kelling (first author), Katherine Arora-Frank, Sherrill Caprarola, Elizabeth Christofferson, Kathleen Clark, Jeffrey Darst, Lain Jackson, Rachel Lindgren, Mattison Lord, Kristina Matkins, Chelsea Preuss, Andrea Rees, Laura Reinman, Sara Reynolds, Foster Rosemund, Kelly Wolfe, Kimberly Woodman and Sarah Kelly (last author)*

*Introduction:* At the Children's Hospital Colorado, the Heart Institute Wellness Program aims to create group programming in both inpatient and outpatient settings that decreases emotional distress and isolation, facilitates peer support and connection, and provides a supportive environment to discuss family adjustment and coping with their cardiac condition. Wellness team members, from disciplines including psychology, social work, child life, spiritual care, learning services, creative arts therapy, and medicine, collaborate to plan educational and community offerings to support patients and families psychosocially in pediatric cardiology.

*Methods:* Since 2016 with the creation of the Wellness Program, our team has worked to expand opportunities for patients with heart conditions and their families to connect both in the hospital and beyond. Cardiac inpatient services include weekly parent/caregiver coffee time, monthly holiday lunches, weekly story time, live therapeutic music, and school group. Outpatient, we offer a recurring transplant and a pulmonary vein stenosis parent/caregiver support group, as well as a formal peer-to-peer parent mentoring program for single ventricle, heart transplant, and other diagnoses. Community patient/family events include therapeutic gatherings at a pumpkin patch, zoo, arcade, and professional sport games. Staff are invited to events and we offer an annual Candlelight Remembrance Event to honor patients who have died. Historically, family educational events have also been hosted with partnership with the single ventricle and electrophysiology teams. Families provide feedback on services via a qualitative survey.

*Results:* With the expansion of the Wellness program, we have grown the number, type, frequency, and attendance of both inpatient and outpatient activities over time (e.g., one community event in 2016 to 4 events in 2023). We have advocated for increased institutional and donor financial support to broaden programming opportunities for our families and staff. Descriptive characteristics of our offerings will be shared with exemplar quotes from families. Lessons learned and limitations will be explored, and it is noted that events in 2020-21 were paused or transitioned to virtual formats due to COVID-19 pandemic.

*Discussion:* Feedback from families has been very positive, and since its initiation the Wellness Program events have increased to foster a sense of shared identity, social support, and community for our heart families. Next steps include continued implementation of these offerings to optimize feasibility and sustainability over time, as well as program evaluation. Future goals include restarting patient population-specific educational events that were put on hold due to social distancing guidelines in this medically complex group, as well as developing virtual outpatient support groups. Other educational opportunities we aim to initiate include monthly virtual health chats with teenagers to increase illness understanding and an educational school series for parents

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

regarding return to school, the impact on school attendance, and the neurocognitive effects of cardiac disease. Individual psychosocial and supportive services in pediatric cardiology benefit from additional inpatient and outpatient group programming as an adjunct to care for pediatric and congenital heart disease.

### 18. Striving for Head Shaping Success- A Quality Improvement Initiative in the Nemours Cardiac Center

*Bridy Hamilton OTR/L, Sarah Russell PT and Mary Ferrari DPT, PT*
*Nemours, Logan Township, NJ*

*Introduction:* Infants born with critical congenital heart disease often spend several weeks to months in the hospital where there are various barriers to promoting optimal positioning. These barriers include lack of mobility, inability to hold and position the infants out of bed, and the presence of critical lines and other medical equipment. Poor positioning can increase the risk of head-shaping deformities, such as flattening of the head (plagiocephaly), elongation on both sides of the head (dolichocephaly) and flattening on the back of the head (brachycephaly). Infants may also develop a neck preference, making it challenging for them to actively rotate their head to midline or the opposite side. Positional plagiocephaly is the most common head shaping deformity occurring in up to 30-50% of all infants. Poor head positioning may result in limitation in midline and visual skills and range of motion.
*Methods:* Population: Patients under the age of one in the Inpatient Nemours Cardiac Center. The collection of head measurements is carried out during the initial evaluation or at the discretion of the treating therapist. Patients not cleared for upright positioning, such as those with a critical line and/or airway, are excluded. Comprehensive observations of the head and face shape in all planes are documented. The following materials are required for measurements: a caliper (head measurement tool), educational resources, a spreadsheet for data collection, and a flowsheet in EPIC. The goal is to complete the head measurements monthly and document them in the electronic medical record and therapy database.
*Results:* The recommendations for inpatient care of infants are based on their individual scores and needs. Specific positioning devices and adaptations to the environment can be made to promote head rotation to the opposite side of preference with instructions placed at the bedside. Before discharge, infants are measured to establish a plan for follow-up which may include a home positioning program, outpatient therapy, and/or a referral for a helmet.
*Discussion:* After growing concern regarding poor head shaping in the cardiac unit, a quality improvement project was initiated. The project's objective was to develop a preventative model, in contrast to the current rehabilitative model. To achieve this, therapists were trained in the use of a caliper and the assessment and documentation of various head measurements. Scores and measurements are recorded monthly, as appropriate, to assess patient progress and determine the need for intervention. Future opportunities for improvement include further data collection and analysis, the development of protocols for patients with diagnoses that are at risk for poor head shaping outcomes, and collaboration with wound care and respiratory teams. With this protocol in place and team collaboration, we expect to see an improvement in the overall numbers within the next 12 months.

### 19. Postoperative cerebral blood flow and oxygen delivery are associated with 2-year neurodevelopmental outcome in infants with d- transposition of the great arteries

*Anurudhya Karthikeyan[1,2], Rasheda Chowdhury[1,2], Bohdana Marandyuk[1], Joaquim Miro[3], Nancy Poirier[3], Anne-Monique Nuyt[1,4], Anne Gallagher[1,5], Marie-Josée Raboisson[3] and Mathieu Dehaes[1,2,6] on behalf of the CINC multidisciplinary team[7]*
*[1]Research Center, Sainte-Justine University Hospital Centre, Montreal, Quebec, Canada; [2]Institute of Biomedical Engineering, University of Montreal, Montreal, Quebec, Canada; [3]Department of Cardiology, Sainte-Justine University Hospital Centre, Université de Montréal, Montreal, Quebec, Canada; [4]Department of Pediatrics, Sainte-Justine University Hospital Centr, Université de Montréal, Montreal, Quebec, Canada; [5]Department of Psychology, Sainte-Justine University Hospital Centre, Université de Montréal, Montreal, Quebec, Canada; [6]Department of Radiology, Radio-oncology and Nuclear Medicine, University of Montreal, Montreal, Quebec, Canada; [7]Clinique Intégrée de Neuro-cardiologie, Sainte-Justine University Hospital Centre, Montreal, Canada*

*Introduction:* D-transposition of the great arteries (TGA) is the 2nd most critical cyanotic congenital heart disease and requires surgery in the first few weeks of age. Even though corrective surgery has improved survival rates, infants with TGA are at risk of adverse neurodevelopmental outcomes. Identification of early biomarkers of brain health may help to improve risk stratification and neurodevelopmental outcome. The primary aim was to assess the associations of postoperative cerebral blood flow and oxygen delivery measured with bedside optical neuromonitoring with 2-year neurodevelopmental outcome in infants with TGA. These associations were also assessed when stratifying by the presence of a ventricular septal defect (VSD). The secondary aim was to examine the differences in postoperative neuromonitoring parameters between the TGA-VSD group, infants with an intact ventricular septum (TGA-IVS) and healthy controls.
*Methods:* This was a single-center prospective observational study. Exclusion criteria included prematurity, low birth weight, genetic syndrome, and previous cardiac surgeries. Healthy controls were recruited at the well-baby nursery and matched for postmenstrual age at the time of neuromonitoring in the TGA group. Diffuse correlation spectroscopy was used to measure an index of microvascular cerebral blood flow (CBFi) during the first 72h following the end of aortic cross-clamping. Peripheral arterial oxygen saturation and blood hemoglobin concentration (HGB) were retrieved from medical charts during this period and used to estimate an index of cerebral oxygen delivery ($CDO_{2i}$). Neuromonitoring sessions of 30 min were averaged over the 72h period. Neurodevelopmental outcome was assessed at 2 years of age with the Bayley scales of infant and toddler development Ed. III and IV. Pearson's correlation test was used to assess the associations between neuromonitoring parameters and long-term outcomes. Benjamini-Hochberg method was used to correct for multiplicity. Regression analyses were performed to evaluate the influence of other clinical parameters and demographic variables in explaining the variability of the statistical models.
*Results:* Thirty (30) infants with TGA were considered in this study. CBFi and $CDO_{2i}$ were positively associated with receptive communication ($r$=0.51, $p$=0.01; $r$=0.47, $p$=0.01, respectively) and gross motor (r=0.52, $p$<0.01; r=0.41, $p$=0.03, respectively) scores. When stratified based on TGA physiology, significant

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

associations were observed between CBFi and $CDO_{2i}$ with motor (composite, fine and gross scales) scores only in TGA-IVS group. Postoperatively, $CDO_{2i}$ and HGB were lower in TGA, TGA-IVS and TGA-VSD groups compared to controls. Regression analyses reported an increase in goodness of fit of CBFi and $CDO_{2i}$ to predict receptive communication from 26% to 37% and from 22% to 34% when sex was added as a confounder, respectively. The individual inclusion of duration of aortic cross clamping, balloon arterial septostomy, oxygen saturation measured from blood draw on 1st day of life and form of TGA physiology in the model improved the goodness of fit (from 16% to 21-31%) of $^{CBF}i$ to predict motor composite scores.
*Discussion:* Low early postoperative $CDO_{2i}$ in neonates with TGA may represent a potential biomarker of adverse neurodevelopment. Postoperative cerebral oxygen availability (CBFi and $CDO_{2i}$) increased with neurodevelopmental outcomes scores, which may reflect the level of brain maturity. Some of these associations were improved when considering sex and cardiac anatomy in the models. Higher postoperative $CDO_{2i}$ may also reflect better cerebral hemodynamic adaptation to normal circulation and recovery, which may improve further brain development. These findings show the potential of bedside optical neuromonitoring to provide early indicators of neurodevelopmental risk in infants with TGA and other forms of congenital heart disease and suggest the need for individualized care management.

### 20. Not just medical history: the role of social determinants of health in predicting school-age neuropsychological functioning

*Kirsty Coulter Ph.D[1], Samantha van Terheyden B.S.[1], Rachel Richie M.A.[1], Mary Donofrio M.D.[1] and Jacqueline Sanz Ph.D.*
*[1]Children's National, Rockville, MD; [2]Children's National, Washington, DC*

*Introduction:* Children with critical congenital heart disease (cCHD) are at risk for neurodevelopmental challenges due to changes in brain development related to multiple medical factors. However, individual outcomes vary. We examined the impact of medical factors (e.g., cCHD diagnosis, perioperative seizures, prenatal diagnosis, genetic condition) and social opportunity (neighborhood resources) in predicting school-age IQ and executive functioning (EF) in children with cCHD.
*Methods:* Children with cCHD attended a routine neuropsychological assessment in the Cardiac Neurodevelopmental Outcome (CANDO) program at Children's National. Children ages 5-18 living in the DC Metro Area were included. Childhood Opportunity Index (COI 3.0; metro normed) and medical factors were predictors of IQ and EF in multiple regression analyses. COI quantifies resources in a child's community. Medical factors included cCHD diagnosis type (single (n=65) vs. 2 (n=133) ventricle, aortic obstruction (n=57)), genetic condition (n=43), prenatal diagnosis (n=94), history of stroke (n=31) or seizure (n=23), and prematurity (n=42). The final sample included 198 children (124 boys, 73 girls, 1 gender-nonconforming child).
*Results:* Genetic condition (t=-3.54, p<.001), history of seizures (t=-2.52, p=.013), and COI (t=6.20, p<.001) independently predicted IQ. The model explained 32% of the variance in FSIQ. Genetic conditions and history of seizures predict 12- and 11-point decrements in IQ, respectively, and each 10- point decrease in Child Opportunity Score predicts a 2.6-point decrease in IQ. Of the 3 COI domains, Education was the only significant predictor of IQ (t=2.53, p=.012). Within this domain, Educational Resources (t=2.70, p=.008) was significant and Elementary Education (t=1.76, p=.080) neared significance. Aortic obstruction (t=2.37, p=.019) and history of seizure (t=2.19, p=.03) were predictors of parent-reported EF problems (BRIEF-2 GEC), but COI was not. This model explained only 11% of the variance. In contrast, *only* COI significantly predicted EF scores on performance-based measures (TOL, t=2.89, p=.005, $R^2$=.128; DKEFS Trails Switching, t=2.31, p=.024, $R^2$=.142, DKEFS Verbal Fluency, t=2.46, p=.016, $R^2$=.224).
*Discussion:* Aspects of a child's medical history *and their social environment* impact intellectual functioning at school age. 32% of the variance in school-age IQ is explained by medical factors (genetic condition, history of seizures) and social factors (COI), specifically, differences in community educational resources. Predictors of school-age EF are less clear, with different patterns for parent-reported vs. performance-based EF. As EF is very sensitive to neurodevelopmental insults, further examination is necessary. Results may be influenced by differences in reporting of EF deficits across diverse communities, or it is possible that the etiology of these deficits is more complex and multifactorial. Importantly, of the factors that most strongly predict IQ at school age, *access to educational resources* is a factor that may be highly amenable to risk prevention work. Allocating additional educational resources and opportunities to children with these risks may be a simple and elegant method for mediating neurocognitive risk.

### 21. Project RECESS: RE-imagining Continuum of Service for Equity, Effectiveness, Efficiency, Satisfaction & Sustainability

*Christie A Ruehl JD, MBA[1], Kyle K Landry MEd[2], Jody Barbeau BS[3], Karen C Stoiber PhD[1], Bridget M Clementi MBA[1] and Cheryl L Brosig PhD*
*[1]Department of Community Health & Education, Children's Wisconsin; [2]Department of Pediatrics, Medical College of Wisconsin; [3]Department of Educational Psychology, University of Wisconsin – Milwaukee*

*Introduction:* To bridge gaps in home-health-school care coordination, some medical centers offer school liaison services, which vary in intensity from consult (low) to comprehensive (high).[1] While some comprehensive services report effective outcomes (i.e., obtaining new or expanded education plans and improving school performance),[2] caseload maximums and families' ongoing support needs limit service availability.[1] Consult and tiered services often report process efficiency measures (i.e., caseload volumes and service time),[3] but few measure or report service effectiveness. Project RECESS aims to improve school liaison services for children with heart disease by creating a new care system with a continuum of service that increases equity and efficiency while maintaining effectiveness and satisfaction.
*Methods:* Inspired by the School-Friendly Health Systems framework,[4] the project team at a single center developed a new school liaison care system by shifting the liaison role from "central service provider" to "empowerment coach." The new service advances self-sufficiency by teaching families to become project managers of home-health-school care coordination. Individualized goal setting focuses services on aspects of school that matter most to families. Risk assessment matches goals with services, benchmarks, and timelines for measuring progress. Services include a 6- part webinar series and 1:1 consulting. 1:1 service steps are either family-led (with liaison guidance) or liaison-led (with family coaching),

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

depending on families' individual risk, support needs, and empowerment readiness. Phase 1 of this project piloted the "School Success Coaching" webinar series (see Table for topics). Live and recorded participation was offered at no charge. In January 2024 invitations were emailed to families and shared by medical providers, parent advocacy groups, and social media. Inclusion criteria were English language proficiency.

*Results:* 85 families registered and 43 participated in the webinar series, which ran biweekly from January to April 2024. Webinar-based services increased efficiency 467% compared to prior caseload to staff ratios. Feedback reflects 95% overall satisfaction and preliminary indicators of effectiveness (less than 19% requested additional 1:1 services). See Table for detailed results.

*Discussion:* The webinars were designed for families with low risk, low need, and high empowerment readiness. Most participants were expected to be from high socioeconomic backgrounds. 1:1 consult services were designed for families with greater risk and support needs. Phase 2 of this project will evaluate 1:1 consult service equity and effectiveness using goal attainment scaling.

**Table.**

*Webinar Series Demographics and Pilot Results*

| **Participant Demographics** (parent/caregiver) | **N** | **n** | **%** |
|---|---|---|---|
| **Gender**, female | 43 | 41 | 95.3% |
| **Race and ethnicity**, Caucasian or White | 43 | 36 | 83.7% |
| **Education**, bachelor degree or higher | 43 | 29 | 67.4% |
| **Employment**, full or part time | 40 | 28 | 70.0% |
| **Marital status**, married | 40 | 36 | 90.0% |
| **Annual household income**, >$75,000 | 31 | 23 | 74.2% |
| **Child Demographics** | **N** | **n** | **%** |
| **Age in years**: range (3-21), mean (11.4) | 43 | | |
| **Gender**, female | 43 | 16 | 37.2% |
| **Race and ethnicity**, Caucasian or White | 43 | 35 | 81.3% |
| **Preexisting education plan**, IEP, 504, other | 43 | 37 | 86.0% |
| **School type**, public | 43 | 34 | 79.1% |
| **School level**, (grades): | 43 | | |
| Preschool (K3-K5) | | 6 | 14.0% |
| Elementary (1st-5th) | | 13 | 30.2% |
| Middle (6th-8th) | | 10 | 23.3% |
| High (9th-12th) | | 13 | 30.2% |
| Other | | 1 | 2.3% |
| **Most common medical specialties**: | 43 | | |
| Cardiology | | 34 | 79.1% |
| Mental and behavioral health | | 22 | 51.2% |
| Neurology | | 15 | 34.9% |
| Gastroenterology | | 14 | 32.6% |
| Pulmonary | | 13 | 30.2% |

**Table (Continued)**

| **Reach** | **N** | **n** | **%** |
|---|---|---|---|
| **Counties**, unique | 43 | 18 | |
| **Community type**, suburban | 36 | 25 | 69.4% |
| **School districts**, unique | 38 | 31 | |
| **Webinar Topics** | **Total Views (N)** | | **Rankings[A] (n=16)** |
| **1.** The Parent as the "Project Manager" | 46[B] | | 2nd |
| **2.** Health-Body-Brain Connections | 40 | | 1st |
| **3.** Identifying & Communicating School Concerns | 26 | | 3rd |
| **4.** Understanding & Managing Education Plans | 27 | | 3rd |
| **5.** Managing Health at School | 27 | | 5th |
| **6.** Long-Game Planning | 23 | | 5th |

[A]Participants indicated the webinar topics most helpful for their needs.

[B]Webinar 1 had 3 unknown participants plus 43 known (registered) participants.

| **Particip tion Variables** | **N** | **n** | **%** |
|---|---|---|---|
| **Total webinar views**, live | 189 | 99 | 52.4% |
| **Views per webinar**, mean | 189/6 | 31.5 | |
| **Webinars per participant**, mean | 189/43 | 4.4 | |
| **Satisfaction Variables** (6 feedback surveys) | **N=73** | **n** | **%** |
| Webinars were "good" or "excellent" | | 72 | 98.6% |
| "Some" to "all" of the information was new to them | | 65 | 89.0% |
| Coaching strategies could be implemented "immediately" or within "1-2 months" | | 66 | 90.4% |
| Length and pace were "just right" | | 71 | 97.3% |
| "Very likely" to attend future webinars | | 72 | 98.6% |

## 22. The Impact of an Inpatient Reading Program on Home Environments in Children with Heart Disease

*Kia Quinlan MD[1], Lauren Ginn[2], Chetna Pande MD[3], Amanda Ruth MD[3] and Kriti Puri MBBS[3,4]*

*[1]Global Child Health Pediatrics Residency Program; [2]School of Medicine; [3]Division of Critical Care Medicine, Department of Pediatrics; [4]Division of Cardiology, Department of Pediatrics; [5]Baylor College of Medicine, Texas Children's Hospital, Houston, TX*

*Introduction:* Infants with heart disease are at increased risk of neurodevelopmental delays. A stimulating home environment has been associated with improved neurodevelopmental outcomes. However, the long-term impact of inpatient developmental care activities on the patient's home environment is unknown. We investigated whether an inpatient early childhood literacy program, Books@Heart, promoted a more cognitively stimulating home.

*Methods:* This single-center prospective cohort study assessed the long-term impact of Books@Heart. Through Books@Heart, all infants (age <12mo) admitted to the Texas Children's Hospital Heart Center receive books, reading guidance, and speech/

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

Table 1: Characteristics and CSPS Scores of Participants

| Characteristic (N = 22) | Median (IQR) | No Medal/Trophy n = 17 | Medal/Trophy n = 5 | P |
|---|---|---|---|---|
| Age at survey (months) | 12.4 (7.0-19.4) | 10.3 (5.5 - 16.4) | 19.6 (17.3 - 27.7) | **0.021** |
| Age at first book (months) | 0.2 (0.1-6.0) | 0.2 (0.1 - 5.9) | 0.23 (0.1 - 0.27) | 0.906 |
| Time from first book (months) | 9.6 (4.5-20.7) | 7.7 (3.9 - 10.9) | 19.6 (11.0 - 27.1) | *0.065* |
| No. of books received through Books@Heart | 1 (1-2) | 1 (1-2) | 2 (1.5 - 2.5) | **0.03** |
| **CSPS Survey items** | **N (%), Median (IQR)** | **No Medal/Trophy** | **Medal/Trophy** | **P** |
| **In your home does your child have access to:** | | | | |
| 1. Toys that teach colors and shapes | 22 (100%) | 17 (100%) | 5 (100%) | n/a |
| 2. Cassette/CD/DVD Player | 16 (73%) | 14 (83%) | 2 (40%) | 0.062 |
| 3. YouTube | 20 (91%) | 15 (88%) | 5 (100%) | 0.421 |
| 4. Computers/iPads/iPhone | 20 (91%) | 15 (88%) | 5 (100%) | 0.421 |
| 5. Learning Apps such as Peek-a-Boo, Peppa Pig, or Fish School | 14 (64%) | 11 (65%) | 3 (60%) | 0.848 |
| 6. Fine motor toys, such as LEGO, coloring books, or arts/crafts materials | 19 (86%) | 14 (83%) | 5 (100%) | 0.312 |
| 7. Gross motor toys such as trains, cars, or bikes that your child can sit on and push along | 20 (91%) | 15 (88%) | 5 (100%) | 0.421 |
| 8. A child-size table and chair | 16 (73%) | 12 (71%) | 4 (80%) | 0.678 |
| 9. Toys that teach about household task, such as sweeping, ironing, washing or other daily activities | 11 (50%) | 8 (47%) | 3 (60%) | 0.611 |
| 10. Toys that stimulate number knowledge | 21 (96%) | 16 (94%) | 5 (100%) | 0.579 |
| 11. A musical instrument that your child owns | 16 (73%) | 11 (65%) | 5 (100%) | 0.119 |
| 12. 10 or more children's books | 21 (96%) | 16 (94%) | 5 (100%) | 0.579 |
| **In your home, do you teach your child:** | | | | |
| 13. Animal Names | 19 (86%) | 14 (83%) | 5 (100%) | 0.312 |
| 14. Alphabet | 21 (96%) | 16 (94%) | 5 (100%) | 0.579 |
| 15. Colors | 21 (96%) | 16 (94%) | 5 (100%) | 0.579 |
| 16. Shapes | 20 (91%) | 15 (88%) | 5 (100%) | 0.421 |
| 17. Numbers | 20 (91%) | 15 (88%) | 5 (100%) | 0.421 |
| 18. How shapes fit together | 18 (82%) | 13 (76%) | 5 (100%) | 0.23 |
| 19. Words | 21 (96%) | 16 (94%) | 5 (100%) | 0.579 |
| 20. Do parents read in their free time (or e-book)? | 20 (91%) | 15 (88%) | 5 (100%) | 0.421 |
| 21. Do parents read daily newspaper (or online)? | 12 (55%) | 8 (47%) | 4 (80%) | 0.193 |
| 22. Do parents regularly read magazines (or online)? | 11 (50%) | 7 (41%) | 4 (80%) | 0.127 |
| 23. Do parents follow current affairs? | 15 (68%) | 10 (59%) | 5 (100%) | 0.082 |
| **Please rate the below statements to indicate how often the activity typically occurs: [Median (IQR)]** | | | | |
| 1. Reading to child or telling stories (0=never, 6=daily) | 5 (5-6) | 5 (5-6) | 6 (4-6) | 0.612 |
| 2. Number of books at home (0= <10 books, 4= 100+ books) | 4 (2-4) | 4 (2.5-4) | 4 (2-4) | 0.783 |
| 3. Frequency of family trips (i.e. zoo, swimming, biking) (0= <2/month, 5=daily) | 3 (1-3) | 3 (1-3) | 1 (0.5-3.5) | 0.565 |
| 4. Frequency of big trips or family holidays (0=never, 4= 6+/year) | 2 (1-3) | 2 (1.5-3) | 2 (0-3.5) | 0.629 |
| 5. Frequency of museum visits (0=never, 4= 6+/year) | 1 (0-2) | 1 (0-1.5) | 1 (0.5-3.5) | 0.408 |
| **Total CSPS Score** | 33 (29 - 36) | 33 (29 - 36) | 33 (30 - 41) | 0.649 |

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

language pathology consultation to support cognitive development while inpatient. Books@Heart participants receive reading awards for 14 or more days of reading to their baby while admitted. After informed consent, parents of children who had received benefits through Books@Heart at least 3 months prior and had discharged home since then were administered the Cognitively Stimulating Parenting Scale (CSPS; score range 0-46). In this survey, higher scores indicate a more stimulating home. Descriptive statistics were reported for each survey item. We compared the median CSPS scores of children who received reading awards while previously inpatient to those who did not in order to assess the impact of engagement with this program on their home habits.
*Results:* Nineteen families consented to the study and 3 filled out serial surveys. The median age of respondents at the time of the survey was 12.4mo (IQR 7–19.4mo) with a median time elapsed since the first encounter with Books@Heart of 9.6mo (IQR 4.7–20.7mo). Families received a median of 1 book through the program (IQR 1-2). Five families (22%) had received reading awards. Patients who received more books (2 books vs 1 book, p=0.03) were more likely to earn reading awards. The median CSPS score was 33 (IQR 29–36). There was no association between reading awards and CSPS score (p = 0.610).
*Discussion:* Most infants receiving resources from an inpatient early childhood literacy program continued to have numerous books and frequent reading exposure at home. Though the median CSPS score in this Books@Heart cohort is higher than previously reported in infants with CHD, reading awards, used as a surrogate for inpatient reading exposure, were not associated with CSPS score. Larger studies are needed to assess the correlation of inpatient reading frequency with long-term home environment and with neurodevelopmental outcomes, as well as the implications of socioeconomic determinants of health on these findings.

### 23. Parent Experiences of Receiving a Fetal Diagnosis of Congenital Heart Disease and Perspectives on Psychological Intervention: A Qualitative Study

*Catherine Quinn[1], Professor Martin Dempster[1], Professor Nicola Doherty[2,3] and Professor Frank Casey[1,2]*
*[1]Queen's University, Belfast, Belfast, Co. Antrim, Northern Ireland; [2]Queen's University Belfast/Royal Belfast Hospital for Sick Children, Belfast, Co. Antrim, Northern Ireland; [3]Ulster University/Regional Trauma Network, Coleraine/Derry, Co. Derry, Northern Ireland*

*Introduction:* Parents who receive a fetal diagnosis of CHD commonly report symptoms of elevated psychological distress, depression, and anxiety (Mangin-Heimos et al., 2023) with recent research highlighting the association between higher maternal psychological distress and impaired fetal brain development (Wu et al., 2020). Given that parental mental health is both at elevated risk and can predict child-outcome, this study explored parental mental wellbeing following a fetal diagnosis of CHD and intervention preferences to inform the development of a psychological intervention to improve parental wellbeing antenatally.
*Methods:* The study employed a qualitative design using semi-structured interviews with parents ($N = 14$; 13 mothers; 29-44 years) who had received an antenatal diagnosis of CHD. Interviews were conducted in-person or online, were audio recorded and transcribed verbatim. The resulting transcripts were analysed using reflexive thematic analysis (Braun & Clarke, 2019; 2021).
*Results:* Four main themes were identified: (1) Uncertainty and Decision-Making, (2) Cumulative Losses, (3) Coping and Adjustment and (4) Seeking Psychological Safety. Parents experienced uncertainty surrounding various aspects of the antenatal journey which impacted on attachment and antenatal decisions. Fetal diagnosis of CHD is associated with loss and grief and changed how parents made sense of their pregnancy. Despite this, parents reported various sources of strength and resilience. Finally, parents reported the need for a psychologically safe space during pregnancy that supported their emotional needs, offered individualized and reputable information, provided opportunities to learn from the lived experiences of others and empowered them to advocate for their child.
*Discussion:* Supportive interventions during pregnancy following a fetal CHD diagnosis are necessary to address diverse parental needs including uncertainty and loss, while fostering psychological safety and enhancing emotional wellbeing. Findings have implications for the design of interventions to improve parental wellbeing during the antenatal period, and in turn, have potentially positive outcomes for the developing fetus.

### 24. The Relationship Between Social Determinants of Health and Mental Health Among Parents of Children with Congenital Heart Disease

*Andrea D. Smith BSN, RN[1], Leandra Bitterfeld MSN, RN[2], Alexa Black LCSW[1], Kristi L. Glotzbach MD[1], Whitnee Hogan MD[3], Nelangi M. Pinto MD[1], Laura K. Wood PhD[4], Zhining Ou MS[1] and Sean Cunningham PhD*
*[1]University of Utah/Primary Children's Hospital, Salt Lake City, UT; [2]Primary Children's Hospital, Salt Lake City, UT; [3]Seattle Children's Hospital, Seattle, Washington; [4]University of Utah, Salt Lake City, UT*

*Introduction:* A congenital heart disease (CHD) diagnosis is life-changing for families. Parental mental health (PMH) is a stronger predictor of a child's psychosocial and developmental outcomes than CHD severity or surgical factors. Sociodemographic factors and stressors beyond having a child with a chronic illness can have direct effects on a parent's mental health. The purpose of this analysis was to understand the relationship between social determinants of health (SDOH) and PMH in children with CHD.
*Methods:* PMH screening was performed in two clinics at a single center, the Fetal Heart Program (FHP) and Heart Center Neurodevelopmental Program (HCNP). Pregnant persons carrying a fetus with CHD likely requiring neonatal surgery (FHP) and parents of a child, ages 6m - 13y, who meet AHA recommendations for neurodevelopmental follow-up (HCNP) were included. PMH was screened using the 21 item Depression, Anxiety and Stress Scale (DASS- 21) and Edinburg Postnatal Depression Scale (EPDS) in FHP and the DASS-21 in HCNP. All participants completed the PRAPARE survey to assess SDOH. Descriptive statistics and univariate logistic regression with Firth's bias correction were used to analyze the relationship between SDOH and a positive PMH screening result.
*Results:* 134 parents were enrolled (FHP N=59, HCNP N=75). Both FHP and HCNP parents were majority White, female and English-speaking. In both clinics, parents were majority privately insured. 19 parents (31.7%) in the FHP and 21 parents

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*Table 1 – Univariate logistic regression for individual outpatient cardiology clinics describing the relationship between a positive mental health screen and individual SDOH indicators.*

| | FHP (n=59) | | HCNP (n=75) | |
|---|---|---|---|---|
| **SDOH Indicator** | n (%) positive | OR (95% CI) | n (%) positive | OR (95% CI) |
| **Social support (social interactions ≥3 times/ week)** | 40 (66.7%) | 1.2 (0.27, 6.35) | 52 (69 %) | 0.39 (0.13-1.15) |
| **Employment status – unemployed** | 10 (18 %) | 1.53 (0.47-4.95) | 11 (15 %) | 1.05 (0.01-21.08) |
| **Insurance status – Public insurance** | 16 (26.7%) | 2.64 (0.79-9.23) | 41 (55 %) | 1.24 (0.41-3.68) |
| **Income level >$80,000** | 21 (36 %) | 0.61 (0.16-2.27) | 35 (47 %) | 0.22 (0.06-0.66)** |
| **Housing Instability** | 1 (1.8 %) | NA^ | 3 (4%) | 21.8 (1.97-2986.8)** |
| **Unmet social needs** | | | | |
| **Food** | 2 (3.4 %) | 0.37 (0-4.91) | 6 (8%) | 6.5 (1.16-50.12)* |
| **Clothing** | 1 (1.7 %) | 0.64 (0-12.61) | 4 (5.3 %) | 29.73 (2.94-4017.67)** |
| **Utilities** | 0 (0%) | NA | 6 (8%) | 6.5 (1.16-50.12)* |
| **Medicine or health care** | 2 (3.4 %) | 2.06 (0.08-54.01) | 8 (11 %) | 28.54 (4.54-558.76)** |
| **Phone** | 0 (0%) | NA | 2 (2.7 %) | 14.73 (1.13-2068.57)* |
| **Transportation to medical appointments** | 0 (0%) | NA | 4 (5.3 %) | 5.89 (0.53-131.25) |
| **Transportation to non-medical appointments** | 1 (1.7 %) | 1.74 (0.48-7.68) | 3 (4%) | 9.35 (1.12-196.1) |

* p<.05
**p<.01
^ Family did not complete mental health screener

(26.9%) in HCNP had a positive PMH screen. Rates of unmet social needs were 1.7-3.3% in FHP and 2.6-10% in HCNP. Among parents in FHP, none of the SDOH indicators were predictive of a positive PMH screen. Among HCNP clinic parents, income >$80,000 was associated with 78% lower odds of a positive PMH screen, while housing instability was associated with an almost 22 times greater chance of positive PMH screen. The inability to get food, clothing, utilities, medicine or healthcare, phone, or transportation to non-medication appointments were all associated with higher odds of a positive PMH screen (Table 1).

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*Discussion:* Impaired mental health is prevalent in parents of children with CHD. In both FHP and HCNP, approximately one-third of parents had a positive PMH screen. The relationship between SDOH and PMH varies between the two groups and appears to change over time as the needs of parents and children change. Future research should further delineate the relationship between SDOH drivers over time and associated resiliency factors that may have positive impacts on PMH.

### 25. Active ingredients in a trauma-informed child life intervention to support non-sedated echocardiogram

*Emily Jones[1] and Nadine A. Kasparian[1,2]*
*[1]Heart and Mind Wellbeing Center, Heart Institute and Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, OH, United States; [2]Department of Pediatrics, University of Cincinnati College of Medicine, OH, United States*

*Introduction:* Echocardiograms (ECGs) are considered a noninvasive, painless procedure. It is not uncommon, however, for some children to have difficulty completing non-sedate ECGs, especially those aged <4 years, with a history of traumatic medical experiences, or neurodevelopmental delays. This case report charts the journey of Juan*, a 3-year- old with left ventricular non-compaction (LVNC), after four failed attempts at ECG with standard interventions. A novel series of trauma-informed child life interventions helped Juan complete a non-sedate ECG, highlighting the importance of a phased, proactive approach to child life support and family involvement in care.
*Case Report:* Juan was diagnosed with LVNC at 31 weeks gestation in the setting of a family history of LVNC. After birth, he was admitted to the cardiac intensive care unit, started on oral heart failure therapy, and discharged home on Day 4. Juan's early course was unremarkable; he remained stable on oral therapies with mildly diminished function. While Juan was scheduled for 6-monthly ECGs, at the time of referral, he had not had an ECG in over 2 years. He had four unsuccessful attempts; three non-sedate with standard child life support, and one sedate with intranasal dexmedetomidine and versed. Anesthesiology recommended general anesthesia for the next ECG, but Juan's mother was concerned about this. Juan's primary cardiologist referred him to a new integrated child life specialist (CLS) service tailored to CHD, with a goal to complete a non-sedate ECG. A child life assessment was undertaken via chart review and interview with Juan's mother. A phased preparation plan was co-developed, beginning at home with developmentally appropriate desensitization and medical play techniques modeled via video, coupled with practice materials (ultrasound gel, echo probe). Next, two in-person therapeutic visits in the echo lab were provided, including gradual exposure to the environment, equipment, and ECG demands and creation of positive associations through play. Juan's mother was pleased with his progress in removing his shirt, reclining on the bed, and touching the ECG probe, as just entering the ECG room had previously triggered a meltdown. Juan's parents attended the ECG and Juan chose his father to sit with him. Once Juan was comfortable, the sonographer began. Initially, Juan displayed distress (verbal protests and mild resistance) but responded to his parents' support and quickly calmed, holding still independently for the procedure.
*Discussion:* This case highlights a need to reimagine our approach to supporting patients who struggle with non-sedate ECGs. First, a proactive approach to child life services is recommended over traditional reactive models, initiated when the patient is already distressed. Second, desensitization techniques were key in assisting Juan to complete his ECG. Third, empowering families to be involved is critical; much of the preparation was done at home and family provided support during the procedure. Finally, use of a trauma-informed framework, ensuring Juan's voice and choices were included, enabled him to move forward from his previous negative experiences and complete the procedure. *Pseudonym used to protect privacy

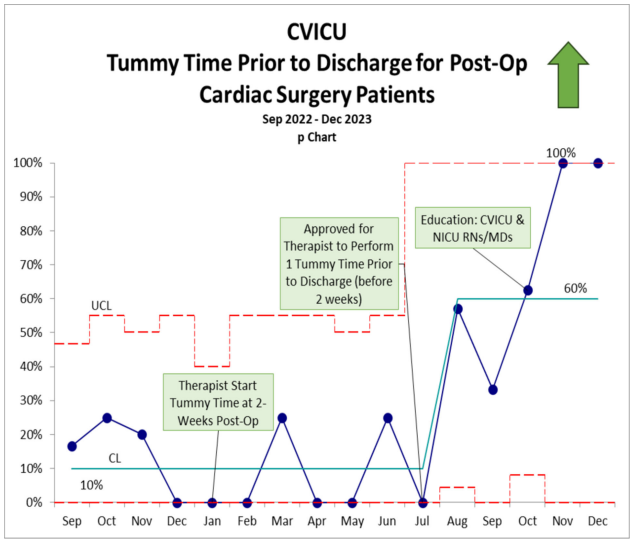
### 26. Utilizing QI Methodology to Increase Tummy Time in Post-Cardiac Surgery Infants

*Shannon Overpeck BSN, RN, CCRN, IBCLC, NTMNC, Leesha Augustine PT, DPT and Leigh Mohler MSN, RN, PCNS-BC, CCRN CHOC, Orange, CA*

*Introduction:* Tummy time plays a crucial role in the development of motor skills and chest wall structure during infancy. Infants with congenital heart disease who undergo sternotomy within the first six months of their life are at heightened risk for neurodevelopment impairments. A lack of tummy time can further delay motor development. In both hospital and home settings, the initiation of tummy time is often delayed due to concerns about prone positioning, pain, and wound complications. The primary goal of this project was to initiate tummy time in the hospital before discharge. Early tummy time exposure and parent education can potentially increase caregivers' comfort with initiating tummy time at home, ultimately leading to improved motor skill development after cardiac surgery. For patients under six months of age admitted to the cardiovascular intensive care unit (CVICU) post-sternotomy, we aimed to increase the initiation of tummy time before discharge from a baseline of 11% to 50% over a 12-month period.
*Methods:* An organizational model adapted from the Institute for Healthcare Improvement Model for Improvement was used to guide this work. A current state assessment was completed to evaluate the comfort and competency of staff performing tummy time in the CVICU. Additionally, baseline data was collected on the frequency of tummy time events before discharge. Key barriers identified included a lack of knowledge about the benefits of tummy time, low comfort levels among staff facilitating it, time constraints, and inconsistent guidelines regarding the initiation of tummy time in both the hospital and home settings. To address these issues, we engaged in Plan- Do-Study-Act (PDSA) cycles, which involved standardizing the timing for initiating tummy post- sternotomy, providing written and practical training for staff, and enhancing family education with a demonstration of tummy time led by a therapist before discharge.Results:
The Cardiothoracic Surgery team authorized the initiation of tummy time two weeks after surgery, provided that the sternotomy wound was healing well. In cases where patients were set to be discharged before the two-week mark, approval was also granted for physical therapists to demonstrate tummy time to families. Staff education on these protocols was completed successfully. By August 2023, there was a significant improvement, with the rate of at least one tummy time event prior to discharge increasing from 10% to 60%.
*Discussion:* Performing in-hospital tummy time for infant's post-sternotomy is possible. Future discussions and cycles of improvement will aim to refine the guidelines for initiating tummy time, ensuring that they cater to the varying healing trajectories of

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

sternotomy wounds. Developing clear, tailored guidelines will help to standardize care across different patient conditions and settings, reducing variability in care and potentially leading to better developmental outcomes.




## 27. Adherence to Recommended Outpatient Neurodevelopmental Follow-up by Congenital Heart Disease Patients: An Analysis Based on Risk Factors

*Samantha C. Butler[1], Stewart Lipsitz[2], Tal Ben Yishai[2], Ariane Michelson[2], Katrina Severtson[2], Annabelle Collins and Susan F. Saleeb[2]*

*[1]Boston Children's Hospital and Harvard Medical School, Boston, MA, USA; [2]Boston Children's Hospital, Boston, MA*

*Introduction:* Neurodevelopmental (ND) impairment is common in children with congenital heart disease (CHD). The American Heart Association (AHA) recommends a cadence of outpatient ND assessments for CHD patients undergoing cardiopulmonary bypass procedures in infancy. However, research notes poor adherence, particularly for those who are school-aged, less ill, or with insurance barriers. This study evaluates adherence with AHA recommended ND follow-up based on developmental and medical risk factors.

*Methods:* The current study was a derivative of the Cardiac Neurodevelopmental Outcome Collaborative quality improvement effort (2018-22), in which 20 cardiology notes were audited monthly of children 5- 18years of age for clinician recognition of ND risk and referral to ND care. The current study inclusion was broadened to children 0-18 years old and further included

Table 1: Bivariate Analyses between risk factors and outpatient neurodevelopmental (ND) follow-up

| **Primary Predictors (AHARisk Factors)** | **N** | **Percent (N) seen for Outpatient ND assessment; N=1041** | **P-Value** |
|---|---|---|---|
| Prematurity | | | 0.15 |
| < 32 weeks GA | 34 | 14.7 (5) | |
| 32 – 37 weeks GA | 153 | 26.8 (41) | |
| ≥ 37 weeks GA | 833 | 30.3 (252) | |
| Genetic Condition | | | < 0.001 |
| None | 799 | 30 (240) | |
| Common Condition* | 157 | 15.3 (24) | |
| Rare Condition** | 85 | 42.4 (36) | |
| Mechanical Use (ECMO or VAD) | | | <0.001 |
| No | 964 | 27.3 (263) | |
| Yes | 77 | 48.1 (37) | |
| Heart Transplant | | | 0.012 |
| No | 989 | 28 (277) | |
| Yes | 52 | 44.2 (23) | |
| Post-Operative Seizure within 7 Days | | | <0.001 |
| No | 1029 | 27.3 (296) | |
| Yes | 12 | 48.1 (4) | |
| LOS > 2 Weeks | | | <0.001 |
| No | 467 | 18.4 (86) | |
| Yes | 504 | 41.9 (211) | |
| Neuroimaging Abnormalities | | | 0.033 |
| No | 968 | 28 (271) | |
| Yes | 73 | 39.7 (29) | |

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**Table 1 (continued)**

| Secondary Predictors | N | Percent (N) Seen Outpatient by ND | P-Value |
|---|---|---|---|
| Number of Primary AHA Risk Factors | | | <0.001 |
| 0 | 333 | 18.3 (61) | |
| 1 | 390 | 32.1 (125) | |
| 2 | 219 | 32 (70) | |
| 3 | 73 | 42.5 (31) | |
| 4+ | 26 | 50.00 (13) | |
| Insurance Type | | | 0.014 |
| Private | 726 | 26.2 (190) | |
| Public | 288 | 35.4 (102) | |
| | 27 | 29.6 (8) | |
| Age at Audited Cardiac Clinic Visit | | | <0.001 |
| 0-4 years | 173 | 61.9 (107) | |
| | 868 | 22.2 (193) | |
| years | | | |
| Seen Inpatient by ND or Neurology | | | <0.001 |
| No | 533 | 19.9 (106) | |
| Yes | 422 | 46 (194) | |
| Executive Function (EF) Concerns § ^ | | | 0.026 |
| No | 867 | 30.2 (262) | |
| Yes | 174 | 21.8 (38) | |
| Behavioral Disorder § ^^ | | | 0.971 |
| No | 999 | 28.8 (288) | |
| Yes | 42 | 28.6 (12) | |
| Learning Disability or Developmental Delay § | | | 0.006 |
| No | 694 | 26.1 (181) | |
| Yes | 347 | 34.3 (119) | |
| Mood Disorder § # | | | 0.180 |
| No | 945 | 29.4 (278) | |
| Yes | 96 | 22.9 (22) | |

**Table 1 (continued)**

| | | | |
|---|---|---|---|
| Motor Disorder § ## | | | <0.001 |
| No | 976 | 26.5 (262) | |
| Yes | 65 | 58.5 (38) | |
| Feeding or Sleep Disorder § | | | <0.001 |
| No | 985 | 29 (286) | |
| Yes | 56 | 25 (14) | |
| Significant Intellectual Disability § | | | 0.536 |
| No | 1031 | 28.9 (298) | |
| Yes | 10 | 20 (2) | |
| Neurologic Concerns& | | | <0.001 |
| No | 803 | 23.9 (192) | |
| Yes | 238 | 45.4 (108) | |
| CHD – Category of Severity+ | | | <0.01 |
| Mild | 144 | 15.3 (22) | |
| Moderate | 487 | 24.9 (121) | |
| Severe | 410 | 38.3 (157) | |

American Heart Association (AHA); Congenital Heart Disease (CHD); Gestational Age (GA); Length of stay (LOS)

★Common genetic conditions included DiGeorge, Down, Noonan's, VACTERL, Charge, etc.

★★Less Common genetic conditions included conditions such as Klippel-Feil, Nager, Gitelman, Goldehar, Poland, Horners, Hot-Oram, Kabuki, Evans, etc.

§Previous ND concerns include documentation in the medical record (MR) for EF, behavior, learning, mood, motor feeding, sleep, or intellectual concerns.

^EF concerns include documentation in the medical record (MR) for ADHD, Autism, or disordered EF.

^^Behavior Disorders included documentation in the MR for Oppositional Defiant Disorder or Conduct Disorder.

#Mood Disorders included documentation in the MR for Anxiety Disorder, Depressive Disorder, or PTSD.

##Motor Disorders included documentation in the MR forDevelopmental Coordination Disorder, Tic Disorder, or a Movement Disorder.

& Neurologic Concerns included documentation in the MR for hemiplegia, hemiparesis, brain malformations,spinal cord disorders, auditory disorder, or visual disorder.

+CHD Category was divided into mild, moderate, and severe disease based on K. Stout et al, 2019.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

Table 2: Multivariate Analysis between risk factors and outpatient ND follow-up. N=1041

| Risk Factor | Odds Ratio of Outpatient ND assessment | Lower CL | Upper CL | P-Value |
|---|---|---|---|---|
| Genetic Condition | | | | |
| Common Condition vs. None | 0.27 | 0.15 | 0.48 | <.0001 |
| Rare Condition vs. None | 0.86 | 0.48 | 1.54 | 0.6035 |
| Number of Primary AHA Risk Factors | | | | |
| 4+ vs. 0 | 2.90 | 1.06 | 7.92 | 0.0380 |
| 3 vs. 0 | 3.27 | 1.59 | 6.72 | 0.0013 |
| 2 vs. 0 | 1.75 | 1.06 | 2.90 | 0.0286 |
| 1 vs. 0 | 2.15 | 1.42 | 3.26 | 0.0003 |
| Age at Audited Cardiology Clinic Visit | | | | |
| 0-4 yrs. vs. 5-18 yrs. | 4.69 | 3.08 | 7.13 | <.0001 |
| Seen Inpatient by ND or Neurology | | | | |
| Yes vs. No | 2.99 | 2.10 | 4.25 | <.0001 |
| Executive Function Concerns | | | | |
| Yes vs. No | 0.40 | 0.25 | 0.64 | 0.0001 |
| Neurologic Concerns | | | | |
| Yes vs. No | 1.55 | 1.08 | 2.24 | 0.0181 |
| CHD – Category of Severity | | | | |
| Severe vs. Mild | 3.03 | 1.69 | 5.44 | 0.0002 |
| Moderate vs. Mild | 2.31 | 1.32 | 4.05 | 0.0034 |

Variables defined similarly to Table 1.

demographics, cardiac disease severity, additional ND risk factors per the AHA (prematurity, developmental delay in infancy, genetic syndrome, perioperative seizure, stroke, microcephaly, heart transplantation, and length of stay after initial cardiac surgery), history of inpatient ND consultation, and previous documentation of ND concern. Bivariate associations between potential predictors and outpatient ND follow-up were tested using Pearson Chi-Square.Multivariate Analyses were performed Using Logistic Regression.

*Results:* The study population included 1041 patients who underwent infant cardiac surgery, for which 29% were seen in ND follow up. Primary and secondary predictors of ND follow up are noted in Table 1. Multivariate logistic regression is shown in Table 2. Individuals with a genetic condition, higher severity of CHD, multiple additional AHA risk factors, neuroimaging abnormalities, younger age, prior inpatient ND consultation, and those with previous ND concern (specifically executive functioning) were more likely to be seen for outpatient ND follow-up assessment ($p<0.001$).

*Discussion:* The study highlights challenges in adherence to AHA guidelines for ND follow-up in high-risk children with CHD, particularly for school age and older patients, and those who did not undergo ND evaluation during inpatient stays. Future research should focus on enhancing early engagement with ND teams, understanding and mitigating barriers to follow-up, and enhancing overall care and outcomes for this vulnerable population.

### 28. Heartstrings and Hardships: Navigating Parental Emotional Health during Infant Hospitalization for Complex Congenital Heart Disease (cCHD)

*Samantha C. Butler[1], Valerie Rofeberg[2], Laura Wood[3], Brittney Cangemi Dropkin[2], Ashley Robbins[2], Susan Herel[3], David Wypij[1], Annabelle Collins and Anjali Sadhwani[1]*

*[1]Boston Children's Hospital and Harvard Medical School, Boston, MA, United states; [2]Boston Children's Hospital, Boston, MA, United states; [3]University of Utah/Primary Children's Hospital, Salt Lake City, UT*

*Introduction:* Parents of children with complex Congenital Heart Disease (cCHD) frequently face psychological and emotional challenges alongside the difficult medical journey with their children. This study aims to explore the multifaceted impact of having a young infant with cCHD on the mental health of parents, employing a novel approach to provide a comprehensive understanding of potentially modifiable and non-modifiable factors during the inpatient hospital admission.

*Methods:* Subjects included parents of infants with cCHD under 12-months-old admitted to the cardiac intensive care unit for surgery and seen for neurodevelopmental assessment just prior to discharge. Predictors were divided into medical and demographic along with family and developmental factors. Primary outcome measures included a dichotomous score (either "not distressed" or "distressed") for the Depression, Anxiety, Stress Scale (DASS-21) and the Parental Stressor Scale: Infant Hospitalization (PSS:IH) (See Figure 1, Suggested model of predictors to parent mental health). Path analysis was used to determine interrelationships in temporal variables.

*Results:* Between 2016-2021, 142 of 267 (53%) parents were found to be in distress on the DASS-21 and 219 (83%) on the PSS:IH. Results of path analysis found that a later date of assessment, presence of an extracardiac congenital anomaly, longer length of stay (LOS) and having two or more parent reported developmental concerns for their child were significant predictors of parent distress on the DASS. Indirect effects analysis indicated that the impact of factors such as longer hospital LOS (>14 days), preterm birth, and non-oral feeding at discharge on parent distress was mediated through parent developmental concerns. Similarly, presence of an extracardiac congenital anomalies, and more than two parent reported external stressors were found to be predictive of parent distress as measured by the PSS:IH. Presence of a neurologic concern, genetic diagnosis, single ventricle anatomy, primary caregiver education less than college, and preterm birth had an indirect effect on parent distress on the PSS:IH through parent reported stressors. The impact of long hospital length of stay on distress on the PSS:IH was mediated through higher rate of parent reported stressors. (see Figure 2)

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*Discussion:* In conclusion, the medical journey of cCHD in an infant presents a profound psychological challenge for parents, necessitating a comprehensive support system to navigate the complexities of caregiving and to maintain emotional health. This study contributes to the growing body of evidence highlighting the need for holistic care approaches in pediatric CHD management, emphasizing the importance of addressing the psychological well-being of both the patients and their families. It also suggests potential modifiable factors, using interventions such as developmental care and increased resource support, to mitigate parent developmental concerns and external stressors with the goal of reducing overall parent distress during the inpatient hospital admission.

**Figure 1: Model of predictors of parent emotional health**

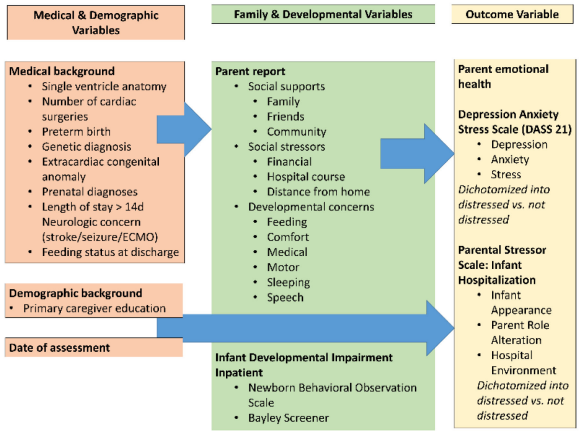
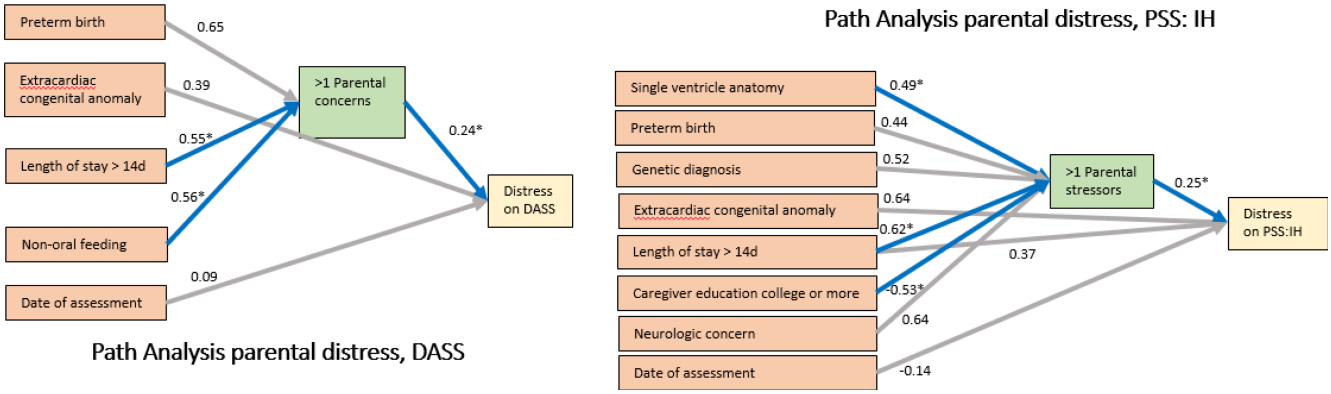



**Figure 2: Path Analysis for parent distress**




## 29. Cerebrovascular Stability Index is Associated with Concurrent Neurodevelopmental Outcomes in 18-Month-Old Infants with Congenital Heart Disease

*Imran Ahmad MS[1], Ashok Panigrahy MD[2], Ashley Ibrahim MS[1], Emma Salmon BS[3], Vidya Rajagopalan PhD[4], Jodie K. Votava-Smith MD[4] and Nhu N. Tran PhD[5]*

*[1]Keck School of Medicine of University of Southern California (KSOM USC); [2]Department of Pediatric Radiology, Children's Hospital Los Angeles (CHLA), and KSOM USC and University of Pittsburgh Medical Center, Children's Hospital of Pittsburgh; [3]CHLA; [4]Division of Cardiology, Department of Pediatrics, CHLA and KSOM USC; [5]Division of Neonatology, Department of Pediatrics, CHLA, and KSOM USC*

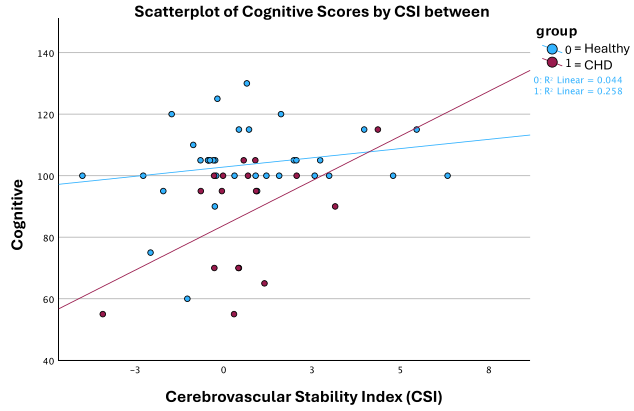
*Introduction:* We sought to identify factors that lead to an increased risk for impaired neurodevelopmental outcomes (NDOs) in children with congenital heart disease (CHD). Cerebrovascular autoregulation (CA) is thought to be dysregulated in infants with CHD and may contribute to poorer NDOs. Therefore, we investigated the association of cerebrovascular stability index ([CSI], a proxy for CA), with NDOs between infants with CHD and healthy controls (HC) at 18 months of age. We hypothesized that CSI would be associated with NDOs at 18 months of age and that the association of CSI and NDOs would vary significantly between the HC and CHD groups.

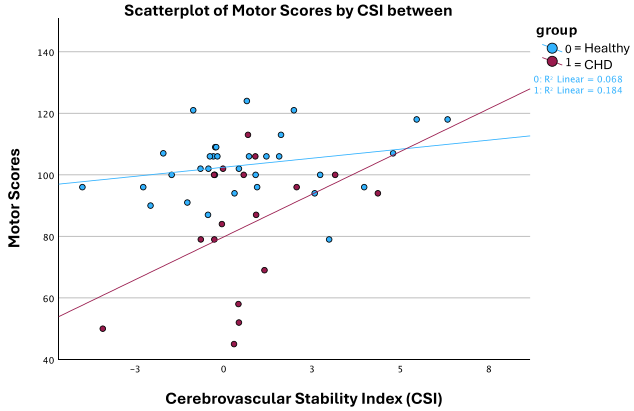
*Methods:* This study was a sub-analysis of a prospective, longitudinal study in CHD and HC infants. Visits occurred at 5 time points (neonatal, 3, 6, 9, and 18-months of age), and we focused on the 18- month time point for this analysis. Our innovative technique for CSI measured cerebral oxygenation ($rcSO_2$) using near-infrared spectroscopy during 3 tilts (moving the infant from supine to sitting postures). We then subtracted the average 2-minute sitting rcSO2 from the 2-minute supine rcSO2 for each posture and averaged those values across all three tilts to obtain CSI. NDOs were measured with the Bayley-4. We used separate regression models to examine the association of CSI with NDOs (i.e., cognitive, language, and motor scores) and a group-by-CSI interaction on the NDOs to examine group differences in this

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

association. We performed subgroup analyses in each group separately to assess their association with NDOs. *Results:* We examined a total of 57 infants (40 HC and 17 CHD). Mean CSI for HC=0.73, SD±2.28 and CHD=0.60, SD±1.65. We found a statistically significant association between CSI and cognitive (β=0.28, 95% CI 0.29–4.33, p=0.03), language (β=0.29, 95% CI 0.08–4.78, p=0.04), and motor scores (β=0.25, 95% CI 0.08–4.18, p=0.04) when controlling for group and sex in the sample overall (Figure 1). We did not find a significant difference in the association of CSI with NDOs between groups, however the cognitive (β=-4.61, 95% CI -9.48–0.26, p=0.06) and motor scores (β=-4.38, 95% CI -9.21–0.45, p=0.07) trended towards significance. The CHD group showed significant associations of CSI with cognitive scores (β=0.53, 95% CI 0.50–11.68, p=0.04) and trends towards significance for language and motor scores.

*Discussion:* CSI, our novel noninvasive measurement of CA, predicted cognitive, language, and motor development scores in 18-month-old infants. Moreover, reduced CSI associated significantly with decreased cognitive scores in the CHD group. Our findings suggests that dysregulated cerebral blood flow in infants with CHD persists into toddlerhood and may lead to impaired NDOs. Future studies can explore whether interventions to enhance cerebrovascular hemodynamics may improve NDOs and whether CSI can identify infants at higher risk for developmental delays.




### 30. Exploring the Intersection of Neurodevelopmental Outcomes and Socioeconomic Status in Young Children with Hypoplastic Left Heart Syndrome: A Pilot Study

*Allegra X. Campagna PhD[1], Eric S. Semmel PhD[1], Sarah R. McCarthy PhD, ABPP[1] and Adam R. Cassidy PhD, ABPP[1,2]*
*[1]Department of Psychiatry & Psychology, Mayo Clinic, Rochester, MN USA; [2]Department of Pediatric and Adolescent Medicine, Mayo Clinic, Rochester, MN USA*

*Introduction:* Socioeconomic status (SES) is an important predictor of neurodevelopmental (ND) outcomes among children in the general population, as well as those with chronic medical conditions such as hypoplastic left heart syndrome (HLHS). Despite growing recognition of the multi-faceted nature of SES, most prior investigations have focused on SES at the level of the family (e.g., household income, number of people in the home), rather than at the level of the neighborhood (e.g., access to schools, healthy food). Therefore, it remains unclear which of these SES factors may be more strongly predictive of child ND outcomes. In this study, we examined differential associations between family- and neighborhood-level indicators of SES, and a range of child ND outcomes in a sample of young children with HLHS.

*Methods:* Participants were recruited via social media into a larger study of ND outcomes among children with HLHS. Family income and number of people in the house were used to calculate an income-to-needs ratio (INR). Family home address was used to derive a Childhood Opportunity Index (COI) score. Parent-report versions of the Behavior Assessment System for Children, Third Edition (BASC-3), Behavior Rating Inventory of Executive Function-Preschool Version (BRIEF-P), Adaptive Behavior Assessment System, Third Edition, and Social Responsiveness Scale, Second Edition (SRS-2) were administered to assess child psychosocial adjustment, executive function, adaptive, and social communication skills, respectively. Multiple regression analysis was conducted to examine associations between SES factors and ND outcomes.

*Results:* ND outcomes data were provided by 37 participants; four did not report income and two did not report number of people in the home ($n$=31; 74% male; 94% White, mean age: 44 months). The correlation between INR and COI was not significant ($r$=.16, $p$=.40). Regression models were statistically significant for BASC-3 Externalizing, BASC-3 Behavioral Symptoms Index, BRIEF-P Inhibitory Self-Control, and SRS-2 Total Composite. Whereas INR was significantly associated with ND outcomes across all models, COI did not account for significant unique variance (Table).

*Discussion:* Family-level SES was more strongly associated with ND outcomes than neighborhood- level SES within a small sample of 2-5-year-old, predominantly white children with HLHS. Children from higher family SES backgrounds were described by their parents as exhibiting fewer behavioral problems, and having better self-regulatory and social skills, than children from lower family SES backgrounds. In contrast, neighborhood-level SES was not associated with any ND outcomes, suggesting that the SES status of the family may exert a greater influence on early childhood ND outcomes than neighborhood-level SES. Additional research including larger and more diverse samples of children and adolescents with congenital heart disease is necessary to determine the generalizability of these findings.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**TABLE: Hierarchical Regression Analyses of SES Predicting ND Outcomes**

| | INR | | | | COI | | | | Model | |
|---|---|---|---|---|---|---|---|---|---|---|
| **ND Composite** | B | SE | beta | *p* | B | SE | beta | *p* | Total $R^2$ | Cohen's $f^2$ |
| BASC-3 Externalizing | -3.57* | .75* | -.68* | <.001* | .03 | .06 | .08 | .56 | **.45*** | 0.82 |
| BASC-3 Internalizing | .13 | .86 | .03 | .88 | -.08 | .07 | -.23 | .24 | .05 | 0.05 |
| BASC-3 Behavior Symptoms | -2.06 | .74 | -.55 | .001* | -.03 | .06 | -.08 | .60 | **.33*** | 0.49 |
| BASC-3 Adaptive Skills | 1.84 | 1.0 | .33 | .08 | .02 | .08 | .06 | .75 | .12 | 0.14 |
| BRIEF-P Inhibitory Self-Control | -2.80 | .98 | -.48 | .01* | -.02 | .07 | -.04 | .83 | **.23*** | 0.30 |
| BRIEF-P Flexibility | -1.14 | 1.01 | -.21 | .27 | -.05 | .08 | -.11 | .56 | .06 | 0.06 |
| BRIEF-P Emergent Metacognition | -2.86 | 1.20 | -.42 | .02 | .03 | .09 | .07 | .71 | .17 | 0.20 |
| BRIEF-P General Executive Composite | -2.59 | 1.05 | -.43 | .02 | .01 | .08 | .01 | .94 | .18 | 0.22 |
| ABAS-3 General Adaptive Composite | 3.02 | 1.55 | .35 | .06 | -.03 | .12 | -.05 | .80 | .12 | 0.14 |
| ABAS-3 Conceptual | 2.96 | 1.68 | .32 | .09 | .05 | .13 | .08 | .68 | .12 | 0.14 |
| ABAS-3 Social | 2.23 | 1.60 | .26 | .17 | -.05 | .12 | -.08 | .69 | .07 | 0.08 |
| ABAS-3 Practical | 3.22 | 1.57 | .37 | .05 | .003 | .12 | .004 | .98 | .14 | 0.16 |
| SRS-2 Total | -3.10 | 1.13 | -.52 | .01* | -.01 | .12 | -.01 | .97 | **.28*** | 0.39 |

COI = Childhood Opportunity Index, INR = income-to-needs ratio, BASC-3 = Behavior Assessment System for Children, Third Edition, BRIEF-P = Behavior Rating Inventory of Executive Function-Preschool Version, ABAS-3 = Adaptive Behavior Assessment System, Third Edition, SRS-2 = Social Responsiveness Scale, Second Edition

*p < .05

**31. Implementing Social Determinants of Health Screening in Cardiac Neurodevelopmental Clinic**

*S. Tewar[1,2], H. Watson[2], H. Pillert[2], A. Escapita[3] and T. Johnson[1,2]*
*[1]Pediatrics, University of Arkansas Medical Sciences (UAMS); [2]Pediatrics, Arkansas Children's Hospital; [3]Neurobiology and Developmental Sciences, UAMS*

*Introduction:* Social determinants of health (SDoH) influence health outcomes and adherence to care for children with special health-care needs. Children with congenital heart disease (CHD) have long term medical needs that put a strain on family resources and impact care. Identifying and addressing these unmet SDoH can improve care and long-term outcomes in children with CHD. We implemented SDoH screening at Arkansas Children's Hospital Cardiac Neurodevelopmental Program (CNP) to identify and address unmet SDoH.

*Methods:* Using QI Methodology, SDoH screening was implemented in Spring 2022. SDoH screener was assigned in the Electronic Medical Record (EMR) two weeks prior to child's appointment in the CNP clinic. A paper screener was administered if not completed in EMR. SDoH screening was implemented hospital- wide starting November 2022, with it being auto assigned in EMR if not completed in the past 12 months. If family reported

Table 1. Unmet Needs identified on SDoH Screening

| **Domain** | **2023** | **Jan – April 2024** |
|---|---|---|
| Food Insecurity | 8% | 11% |
| Housing | 12% | 8% |
| Financial Resource Strain | 14% | 37% |
| Transportation | 3% | 3% |
| Internet Access | 0% | 1% |
| Child Education | 18% | 6% |
| Adolescent Education | 0% | 0% |
| Adolescent Socialization | 77% | 73% |

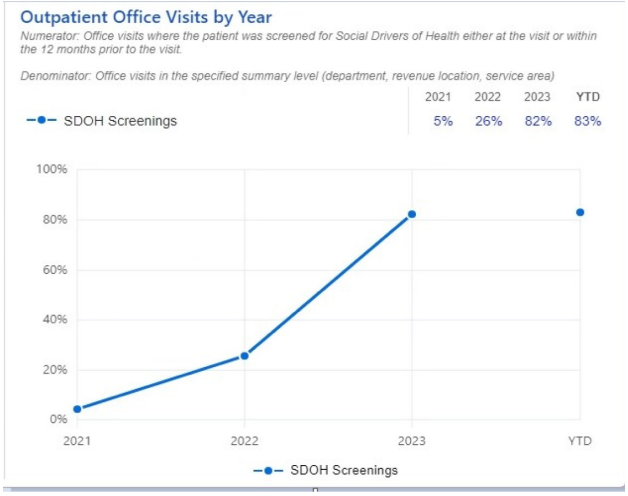
https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

unmet needs on SDoH screening, it was automatically reassigned at subsequent outpatient visits. We tracked completion of SDoH questionnaires over time, most common unmet needs identified, and resources needed to address these needs between November 2022 to April 2024.

*Results:* Between November 1, 2022 and April 30, 2024, 195 children were auto assigned the SDoH screener in the CNP clinic. With EMR implementation, completion of SDoH screening increased from 60% at the start of hospital wide screening to 83% at the end of 2023 in the outpatient setting within 365 days of their CNP appointment (Figure1). This trend has continued in the first quarter of 2024. Families of children with CHD identified unmet needs for child education, housing, and financial resource strain as the top three concerns (Table 1). Parents of adolescents with CHD reported unmet needs in opportunities for adolescent socialization. Clinical staff provided resources using Resource Connect. For more complex social needs, a social work consult was initiated.

*Discussion:* Families of children with CHD have high levels of unmet socioeconomic needs that can impact accessing healthcare in this population. Implementing routine SDoH screening in CNP can improve identification of unmet social needs and allows the healthcare team to provide a more personalized and effective plan of care.

Figure 1 SDOH Screening by Year




### 32. Improving Quality of Care for Young Children with Complex Congenital Heart Disease through Development of a Therapist Mentorship Program

*Emily H. Maloney PT, DPT, PCS, Andrea Gerk OTD, OTR/L, BCP, Caelah Clark MS, CCC-SLP, Sherrill D. Caprarola MD and Kelly R. Wolfe PhD ABPP-CN*

*Introduction:* With the ever-growing evidence of neurodevelopmental impacts on patients with congenital heart disease (CHD) and benefits of direct therapy services, the need for education to outpatient therapists was identified. Children's Hospital Colorado (CHCO) is a large hospital-system with 4 outpatient therapy locations in the Denver-metro area, serving not only Colorado, but a 7-state region. With this unique geographical span, many patients must remain local for medical access and are followed by outpatient therapies. Through implementation of an educational and mentorship series, we aimed to increase confidence of clinicians who are treating children with CHD, increase access to therapy services, and improve continuity and quality of care across the continuum.

*Methods:* A series of educational sessions were completed in Fall 2023 to engage outpatient Physical Therapists (PTs), Occupational Therapists (OTs), and Speech Language Pathologists (SLPs) in understanding the brain-heart connection, neurodevelopmental impact in CHD, and treatment practices in the cardiac population. After these sessions, four outpatient PTs, voiced interest in ongoing mentorship and working to adapt current outpatient practices for children with CHD. Monthly meetings were established in January 2024 and focused on diagnoses, special considerations for PT with children with CHD, and program growth ideas.

*Results:* After 4 months of mentorship, an informal questionnaire was sent to the participating PTs. They reported that, through education, mentorship and shadowing opportunities, they had a better understanding of a patient's medical course and complexity, impact of CHD on neurodevelopment, and diagnosis specific implications. The cohort also identified gaps in access to equipment in the outpatient setting and areas for growth in the outpatient therapy services. An infant pulse oximeter was acquired, allowing for safer progression of activity for children with CHD during outpatient PT. The Baby Intensive, a 3 time per week for 4 weeks outpatient program for children 0-2 years of age at CHCO, expanded its inclusion criteria to include children with CHD, allowing for improved access to care, as well as supporting gross motor development and parent coaching following hospital discharge.

*Discussion:* Developing an expert cohort of PTs, when outpatient is best fit for a patient, allows for improved continuity of care for children with CHD, as well as excellent access to care while families remain local before returning home to rural or underserved areas with poor access to therapy services. Future goals include developing outpatient therapy competencies, expanding mentoring to SLPs and OTs interested in treating this population, improving the referral process from inpatient to outpatient setting, and studying the impact of this mentorship program and program development on patient/family outcomes.

### 33. Neuroimaging Practice Variation across CNOC Member Sites

*Rachel Leon[1], Cynthia Ortinau[2], Caitlin Rollins[3], Marie Brossard-Racine[4], Lynn Boswell[5], Sarah Schlatterer[6], Nadine Kasparian[7], Anjali Sadhwani[3], Anton Corinne[8], Kavita Sharma[1], Ortega Christina[9], Kalpana Norbisrath[10], Whitnee Hogan[11], Ashok Panigrahy[12], Stephen Miller[13], Mike Seed[14] and Vidya Rajagopalan[15]*

*[1]University of Texas Southwestern Medical Center, Dallas, TX; [2]Washington University, St. Louis, MO; [3]Boston Children's Hospital, Boston, MA; [4]McGill University Health Centre, Montreal, QC, Canada; [5]Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL; [6]Children's National Hospital, Washington, DC; [7]Cincinnati Children's Hospital, Cincinnati, OH; [8]Children's Health, Dallas, TX; [9]Joe DiMaggio Children's Hospital, Hollywood, FL; [10]UT Health Houston, Houston, TX; [11]University of Utah, Salt Lake City, UT; [12]University of Pittsburgh, Pittsburgh, PA; [13]University of British*

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*Columbia, Vancouver, BC, Canada; [14]Hospital for Sick Kids, Toronto, Ontario, Canada; [15]Children's Hospital Los Angeles, Los Angeles, CA*

*Introduction:* Research has established an association between fetal and postnatal neuroimaging and later neurodevelopmental outcomes (NDO) for high-risk infants. However, no standard of care exists regarding neuroimaging practices for fetuses and neonates with congenital heart disease (CHD). The Developing Fetal Brain Special Interest Group of CNOC aimed to describe current neuroimaging practices across CNOC member institutions. These institutions are optimal to survey because they are high volume cardiac surgical centers of excellence with a commitment to improving NDO.
*Methods:* A 45-item survey was administered via REDCap to all CNOC member sites after Institutional Review Board and the CNOC Steering Committee approval. The survey queried sites regarding brain imaging of fetal and neonatal CHD patients, including the modality, timing, prevalence, institutional guidelines or criteria, and rationale for neuroimaging. Site champions were asked to seek multi-disciplinary input for survey items related to imaging technology, cardiac lesion-specific care, and logistic and cultural barriers in clinical and/or research domains.
*Results:* A total of 12 sites submitted responses to date to our comprehensive survey on neuroimaging practices. Overall, there is significant variability in timing, modality, and patient selection for neuroimaging in fetal and neonatal CHD patients. Most centers (>80% of respondents) utilize head ultrasound in the pre-operative time period while half of those surveyed have protocols for pre-operative brain MRI. Uniform access to the resources and expertise to perform fetal and neonatal neuroimaging in CHD patients is lacking at some centers. All respondents agree that pre- and post-operative brain MRI have clinical utility at least sometimes. Half of all centers are performing neuroimaging in CHD patients as part of research studies.
*Discussion:* In contrast to best-practices that govern other aspects of clinical care for patients with CHD, there are no standard guidelines for neuroimaging. Large practice variations in neuroimaging impede research and clinical advancements in cardiac neurodevelopmental care. This survey is the first step towards developing and implementing a best-practice consensus statement regarding the use of neuroimaging for fetuses, neonates, and infants with CHD. A recent CNOC-led report shows relatively low return rates for outpatient neurodevelopmental follow- up among patients with even the most complex and high-risk forms of CHD. Moreover, triage for neurodevelopmental evaluation is a critical need. Information from standardized neuroimaging could strengthen models of risk-stratification, which may streamline neurodevelopmental surveillance, identify deficits earlier, and help guide utilization of therapeutic services and other resources.

### 34. Establishing a New Multidisciplinary Cardiac Neurodevelopmental Follow-up Clinic: A Single- Center Experience

*Louisa Keith MD, Jessica Pliego PhD, Margaret Goss MS, MS, APRN, CPNP-PC, Yingchao Yuan MA, Alexandra Lamari-Fisher PhD, Marian Morris PhD, MPH, RN, Sarah Schukei MSN-NI, CPN, CNRN, Janelle Gritsko RNC-NIC, BSN, RN and Austin Adair MD*
*UT Health Austin Pediatric Neurosciences at Dell Children's Medical Center and the University of Texas at Austin Dell Medical School; Texas Center for Pediatric & Congenital Heart Disease, at Dell Children's Medical Center and the University of Texas at Austin Dell Medical School; Department of Neurology, University of Texas at Austin Dell Medical School*

*Introduction:* The American Heart Association and American Academy of Pediatrics have published and recently updated guidelines for optimizing neurodevelopmental care for infants and children with congenital heart disease (CHD). In this study, we outline the establishment of a new multidisciplinary program aimed at improving neurodevelopmental follow-up care for CHD patients and families. Notably, our program has seen a higher follow-up rate than the recently published national average of 29%, underscoring the potential benefits of our approach.
*Methods:* The Cardiac Neurodevelopmental Follow- Up Program at Dell Children's Medical Center was started in spring 2021 and has a collaborative, multidisciplinary approach. Weekly inpatient neurodevelopmental rounds held in the Cardiac Intensive Care Unit identify patients at high risk for neurodevelopmental impairment1. The rounding team includes members from the cardiac, neurosciences, psychosocial, and rehabilitation therapy departments. The neurodevelopmental rounds also serve to address active neurodevelopmental, neurological, and psychosocial concerns, ensure the transition to outpatient care using a "warm hand-off" led by a neurology nurse practitioner, and place referrals for outpatient follow- up. Outpatient assessments adhere to CNOC guidelines, with clinic visits scheduled at critical developmental stages and transition points. We report here our follow-up rate for the multidisciplinary neurology and neuropsychology clinic visit for toddlers 18 to 24 months of age.
*Results:* Since July 2021, there have been 594 total outpatient visits, for patients ranging from 6 months to 18 years old. This includes 143 multidisciplinary visits for children age 18-24 months. The follow-up rate for the 18-24 month age group from July 2021 to April 2024 was 67%.
*Discussion:* The success of our clinic is reflected in the high follow-up rate for patients at our multidisciplinary toddler age visit. Factors contributing to this success include proactive inpatient identification of patients, interdisciplinary collaboration, and effective outpatient transition practices. Despite these achievements, we acknowledge the need for further program development to reach the remaining eligible patients. Barriers include need for enhanced awareness among care team members and existence of separate electronic medical record systems. Immediate future goals include completing analysis of characteristics of those who have attended vs not attended clinic to better understand factors impacting attendance. Our experience offers valuable insights for other institutions aiming to establish similar programs.

### 35. Trauma Informed Care for Parents in the PCICU through Digital Screening of Post Traumatic Stress Symptoms

*Althea P. Wroblewski PhD[1], Xavier Bledsoe[2], Kayla Buttafuoco MD[3], Daniel Ragheb MD[3], Gabrielle Reimann MS[4], E. Leighton Durham MA[4], Valerie Shaffer APRN[5], Neill Broderick PhD[6] and Jamie N. Colombo DO[5]*
*[1]Division of Psychology, Department of Pediatrics Vanderbilt University Medical Center and Monroe Carell Jr. Children's Hospital, Nashville, TN; [2]Medical Scientist Training Program, Vanderbilt University, Nashville, TN; [3]Vanderbilt University School of Medicine, Nashville, TN; [4]Vanderbilt University Clinical Science Doctoral Program, Nashville, TN; [5]Division of Cardiology, Department of Pediatrics Vanderbilt University Medical Center and Monroe Carell Jr. Children's Hospital, Nashville, TN; [6]Division of Developmental Medicine, Department of Pediatrics Vanderbilt University Medical Center and Monroe Carell Jr. Children's Hospital, Nashville, TN*

*Introduction:* Parents of infants with congenital heart disease (CHD) experience high rates of anxiety, depression, and post-traumatic

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

stress symptoms following the weeks and months after their child's surgery. Infants born with single ventricle (SV) physiology pose additional stressors for parents including initial diagnosis, prolonged hospitalizations, post-operative complications, and uncertainty around their survival. Despite the availability of the pediatric cardiac intensive care unit (PCICU) to serve as a setting in which to provide trauma informed care to families, integration of these services has received limited focus and attention. Digitized screening and assessment of mental health symptoms among parents in the PCICU offers an efficient way to systemically identify parents and provide individualized family- centered care.

*Methods:* Participants in this quality improvement project included parents of neonates with SV physiology admitted to the PCICU following initial palliative surgery. Parents consented prior to completing a trauma symptom screener using the Impact of Events Scale, Revised (IES-R). Parents deemed at high risk for experiencing PTSD symptoms were identified based on clinical cut-off scores (>24) on the IES-R. High scores prompted inpatient support services for families with a licensed clinical psychologist within 72 hours of screening. Community resources packets were distributed to all families regardless of their participation in the project. Administration of survey and resource packet materials transitioned from paper to a digitized form in November 2023 for ongoing feasibility of the project and to increase screening efficiency. A quick response (QR) code was provided to parents to complete the survey on their cell phone.

*Results:* From May 2023 to May 2024, 73% of parents (27 out of 38 eligible families) completed either paper or electronic versions of the survey. More parents completed the survey electronically (93%) compared to paper administration (56%). Reasons for missed screenings included parents not at bedside or discharge (n=5), death (n=3), declining to participate (n=2), and incompletion (n=1). The median IES-R score was 28 (range 4-56). Parents identified the following stressors as being most impactful in contributing to their levels of distress: initial diagnosis (n=13, 81.3%), delivery/birthing experience (n=6, 37.5%), surgical intervention (n=10, 62.5%), post-operative complications (n=5, 31.3%), prolonged hospitalization (n=12, 75.0%), family separation (n=10, 62.5%), and having their own prior mental health history (n=3, 18.8%).

*Discussion:* This project offers an efficient manner to screen for traumatic stress response symptoms in parents in the PCICU setting using a digitized survey. Parents were more likely to complete the survey when it was offered electronically. Follow-up questions on the survey also highlight specific stressors that are most impactful on parents' levels of post-traumatic stress. Many of these stressors were noted to occur within the PCICU and underscore the need for integration of trauma-informed services prior to discharge.

### 36. CINCO Improves Delirium and Neurodevelopmental Outcomes

*Sherrill D. Caprarola MD[1], Emily Maloney PT, DPT, PCS[2], Sarah L. Kelly PsyD[1], Caelah Clark MS, CCC- SLP[3], Andrea Gerk OTD, OTR/L, BCP[3], Jesse Davidson MD[1] and Kelly R. Wolfe PhD, ABPP-CN[1]*

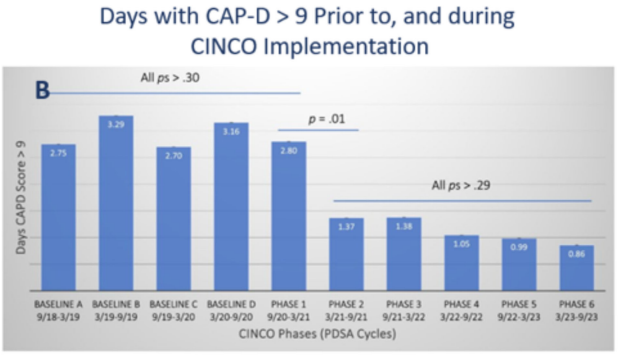
*[1]University of Colorado School of Medicine, Aurora, CO; [2]Children's Hospital Colorado, Aurora, CO; [3]Children's Hospital Colorado, Aurora, CO*

*Introduction:* Children with congenital heart disease (CHD) are at risk for poor neurodevelopmental (ND) outcomes. Risk factors include genetic syndromes, prematurity, CHD severity, and longer lengths of inpatient stay. In hospital, children with CHD often spend significant time alone, not being held, and therapeutic resources can be limited. Our ND program (CINCO) was developed to standardize inpatient cardiac ND care and improve long-term ND outcomes. While cardiac inpatient ND care practices are recommended, few studies have demonstrated improved outcomes. Therefore, we evaluated relationships between CINCO interventions and associated developmental therapies (physical [PT], occupational [OT] and speech/language pathology [SLP]) with incidence of delirium and ND outcomes 3 years after CINCO implementation.

*Methods:* CINCO was implemented in September 2020 for children 0-2 years who were admitted for ≥7 days to the cardiac intensive and progressive care units. Using electronic health record data from 9/1/18- 9/1/23, Cornell Assessment of Pediatric Delirium (CAP-D) and Bayley Scales of Infant and Toddler Development, 4th edition (Bayley-4) scores were obtained and evaluated in relation to receiving CINCO care including PT, OT, and SLP services, developmental kits, developmental care rounds (DCR), parent mental health support, and developmental plans. Trends of Bayley-4 scores over time were examined, by q6month phases. If patients had multiple admissions, only their first hospitalization was used for analyses. Associations were adjusted for CHD severity (STAT score), genetic syndrome, hospital length of stay, and premature birth.

*Results:* The average number of days per patient with CAP-D >9 decreased since CINCO was implemented (Figure 1; $n = 847$ admissions). For patients 0-3 months of age ($n = 53$) receiving, PT, OT, and SLP orders was correlated with higher Bayley-4 Expressive Communication scores at 4-9 months of age ($p = <0.001$, 0.006, and 0.037, respectively). OT orders at 0-3 months of age were correlated with higher Receptive Communication scores at 4-9 months ($p = 0.031$) and having OT and SLP orders was correlated with higher Fine Motor scores ($p = 0.005$ and 0.047, respectively). For patients 0-9 months of age ($n = 35$), participating in DCR and receiving developmental kits correlated with higher Bayley-4 Cognitive Index at 19-42 months ($p = 0.026$ and 0.031, respectively). Cognitive scores at 12+ months of age at our center increased after CINCO implementation ($n = 58$, $p < 0.05$).

*Discussion:* Implementation and maintenance of CINCO was followed by improved delirium and ND outcomes as evidenced by decreased number of days with CAP-D >9 and increased Bayley-4 scores. Future research is warranted to include larger sample sizes and evaluate the impact of CINCO on pre-school and school-age ND outcomes.




Note. CAPD = Cornell Assessment of Pediatric Delirium. Data shown are average number of days with CAPD score > 9 per patient, across six-month periods. Baselines A through D were prior to the launch of the CINCO program. Phases 1-6 represent the six Plan-Do-Study-Act quality improvement cycles of the CINCO program to date.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

### 37. Improving Quality of Care for Young Children with Complex Congenital Heart Disease through Development of a Therapist Mentorship Program

*Emily H. Maloney PT, DPT, PCS[1], Andrea Gerk OTD, OTR/L, BCP[1], Caelah Clark MS, CCC-SLP[1], Sherrill D. Caprarola MD[2] and Kelly R. Wolfe PhD, ABPP-CN[2]*
*[1]Children's Hospital Colorado, Aurora, CO; [2]University of Colorado, Aurora, CO*

*Introduction:* With the ever-growing evidence of neurodevelopmental impacts on patients with congenital heart disease (CHD) and benefits of direct therapy services, the need for education to outpatient therapists was identified. Children's Hospital Colorado (CHCO) is a large hospital-system with 4 outpatient therapy locations in the Denver-metro area, serving not only Colorado, but a 7-state region. With this unique geographical span, many patients must remain local for medical access and are followed by outpatient therapies. Through implementation of an educational and mentorship series, we aimed to increase confidence of clinicians who are treating children with CHD, increase access to therapy services, and improve continuity and quality of care across the continuum.
*Methods:* A series of educational sessions were completed in Fall 2023 to engage outpatient Physical Therapists (PTs), Occupational Therapists (OTs), and Speech Language Pathologists (SLPs) in understanding the brain-heart connection, neurodevelopmental impact in CHD, and treatment practices in the cardiac population. After these sessions, four outpatient PTs, voiced interest in ongoing mentorship and working to adapt current outpatient practices for children with CHD. Monthly meetings were established in January 2024 and focused on diagnoses, special considerations for PT with children with CHD, and program growth ideas.
*Results:* After 4 months of mentorship, an informal questionnaire was sent to the participating PTs. They reported that, through education, mentorship and shadowing opportunities, they had a better understanding of a patient's medical course and complexity, impact of CHD on neurodevelopment, and diagnosis specific implications. The cohort also identified gaps in access to equipment in the outpatient setting and areas for growth in the outpatient therapy services. An infant pulse oximeter was acquired, allowing for safer progression of activity for children with CHD during outpatient PT. The Baby Intensive, a 3 time per week for 4 weeks outpatient program for children 0-2 years of age at CHCO, expanded its inclusion criteria to include children with CHD, allowing for improved access to care, as well as supporting gross motor development and parent coaching following hospital discharge.
*Discussion:* Developing an expert cohort of PTs, when outpatient is best fit for a patient, allows for improved continuity of care for children with CHD, as well as excellent access to care while families remain local before returning home to rural or underserved areas with poor access to therapy services. Future goals include developing outpatient therapy competencies, expanding mentoring to SLPs and OTs interested in treating this population, improving the referral process from inpatient to outpatient setting, and studying the impact of this mentorship program and program development on patient/family outcomes.

### 38. CNOC Talk: Development of a Podcast for the Cardiac Developmental Outcome Collaborative

*Scott W. Osborne MD, MS[1], Caroline K. Lee MD[2], Karli Negrin MS[3] and Chetna Pande MD[4]the Cardiac Neurodevelopmental Outcome Collaborative Communications Committee*
*[1]Department of Pediatrics, Section of Neonatology, Baylor College of Medicine/Texas Children's Hospital, Houston, TX; [2]Department of Pediatrics, Division of Cardiology, Washington University of St. Louis/St. Louis Children's Hospital, St. Louis, MO; [3]Therapeutic and Rehabilitative Services, Nemours Children's Hospital, Wilmington, Delaware; [4]Department of Pediatrics, Section of Critical Care Medicine, Baylor College of Medicine/Texas Children's Hospital, Houston, TX*

*Introduction:* Technological advancements in computers and communication devices have enabled almost anyone to create and distribute information to a wide audience. "iPod broadcasts" (or podcasts) are digital audio files that are recorded, edited and distributed to a listener's personal device for listening at any time. The Cardiac Neurodevelopmental Outcomes Collaborative (CNOC) Communications committee is responsible for optimizing communication to CNOC members; creating and overseeing content to communicate to the larger heart community distributed through various modalities. To expand the reach of CNOC, the Communications Committee developed a bimonthly podcast, "CNOC Talk", for patients, parents, and professionals to discuss all aspects related to cardiac neurodevelopment across the lifespan, as well as provide education and inspiration to all working towards improving the quality of life for pediatric heart patients. The committee hypothesized that such a product could reach a global audience to better spread awareness of the neurodevelopmental issues among the pediatric cardiac and congenital heart disease (CHD) populations.
*Methods:* A multidisciplinary group of practitioners involved in cardiac neurodevelopmental care and families affected by CHD participated in virtual discussions during the planning phase to determine needs, the cadence of podcasts, topics to be discussed, and podcast guests. Talking points and questions were reviewed prior to these sessions to maximize time efficiency and content. Recordings of these sessions were edited and uploaded to a podcast hosting service for distribution and download. Analytics are provided by the podcast hosting service.
*Results:* The time from conception of CNOC Talk to distribution of the first episode took 5 months, with 2 episodes currently available. CNOC Talk has over 100 unique listens since release. The bulk of initial listeners were from North America (USA 78%, Canada 15%), but listeners downloaded the podcast from 6 other primarily non-English speaking countries. Mobile device and listening via web browser were most common.
*Discussion:* The availability of sophisticated, but easy to use, software makes creation of a podcast a relatively easy, but time-consuming task. Topics of importance and interest can easily be identified, and files distributed globally to educate and inform individuals interested in or affected by neurodevelopmental challenges because of congenital heart disease. Further refinements in editing and distribution will reach a broader audience and additional investigation into the listener characteristics will allow provide more detail on topics for the future.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**39. Experiences of Loss and Grief in Parents of Children with Congenital Heart Disease**

*Erin Moorman PhD[1], Conrad Williams MD[2], Jennifer Christofferson MS[3], Linda G. McWhorter PhD[4], Abigail C. Demianczyk PhD[5], Anne E. Kazak PhD, ABPP[6], Allison Karpyn PhD[6] and Erica Sood PhD[1]*

*[1]Nemours Children's Hospital, Wilmington, DE, US; [2]Medical University of South Carolina, Charleston, SC, US; [3]Cleveland Clinic Children's Hospital, Cleveland, OH, US; [4]Widener University, Chester, PA, US; [5]Cleveland Clinic, Cleveland, OH, US; [6]University of Delaware, Newark, DE, US*

*Introduction:* Parents of children with congenital heart disease (CHD) are at risk for anxiety, depression, and traumatic stress, which may negatively influence family and child outcomes. Non-death losses and experiences of grief can impact mental health, but are understudied among parents of children with CHD. The current study used online crowdsourcing, an innovative methodology to generate ideas and solve problems by soliciting contributions from a large online community, to characterize loss and grief experienced by parents of children with CHD.

*Methods:* Eighty parents of children with CHD (ages 1-7) with a prior history of infant cardiac surgery across 43 US hospitals responded to 37 open-ended questions over a period of 6 months on a private social networking site. Data were coded by 2 coders using a hybrid inductive-deductive approach and emergent themes regarding loss and grief were identified.

*Results:* Six broad themes were identified from the qualitative data: 1) Loss of Identity was an overarching theme that cut across the other themes; 2) Loss of Sense of Security/Predictability, 3) Loss of "Normal/Healthy" Pregnancy, Birth, and Child, 4) Work/Financial Loss, 5) Loss of Parent-Infant Bonding and Parenting Experiences, and 6) Loss of/Impact on Relationships (Table 1). Recommendations from parent participants to support families around the experiences of non-death losses included acknowledging and normalizing experiences of loss and grief, providing memory and meaning making opportunities, supporting parents in establishing a bond with their baby, and providing general psychosocial support (e.g., offering in-hospital psychological support, connecting parents to grief counseling resources and support groups).

*Discussion:* Acknowledging and normalizing non- death losses and experiences of grief is paramount to supporting families of children with CHD. A thorough understanding of the types of losses experienced by parents of children with CHD is necessary to better support parents and promote healthy family and child outcomes.

Table 1. Themes and Representative Quotes

| Theme | Representative Quote |
|---|---|
| Loss of identity | I can wake up tomorrow and things can be very different than they are today and they can deteriorate quickly. I also feel like I have lost part of myself, because the effects of the trauma, stress, PTSD and anxiety that I live with everyday has changed me as a person. (ID 92)<br><br>The hardest loss at first for me was losing myself and my identity. I left a job that I loved to take care of my Heart Warrior. I felt like I fell off the face of the earth and I had no one anymore. (ID 30) |
| Loss of sense of security/predictability | The worrying about his future is overwhelming at times. Prior to his diagnosis I used to think that no matter, everything would be alright. I don't feel that way anymore. (ID 117)<br><br>We lost the feeling of security and stability when our daughter almost died after a successful surgery. We lost our ability to not worry all the time about our daughter's health, her healthcare coverage, our finances. (ID 23) |

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**Table 1 (Continued)**

| | |
|---|---|
| Loss of "normal/healthy" pregnancy, birth, and child | When you are preparing to have a child, you never think that you will be the one to have a "sick" child. I often find myself grieving the loss of what a "normal life" may look life. Not always do I feel as if life would be better this way, but I often wonder what it is like to not have to be in the doctor's office so often or to have to focus so much on what the care plan looks like for my child. (ID 77)<br><br>My wife and I lost the "healthy child " we thought we were having and we lost the " normal" pregnancy we were in the middle of having. (ID 44) |
| Work/financial loss | We have also lost our financial security, since the mounds of medical bills and other expenses associated with this journey have eaten up our savings and lessened our ability to save for the future, because we are just trying to survive today. (ID 122)<br><br>I have also had a loss in my career. I have been passed up for promotions and projects due to having to care for my child. (ID 82) |

**Table 1 (Continued)**

| | |
|---|---|
| Loss of parent-infant bonding and parenting experiences | In the hospital, people failed to understand how much the task of providing milk for him meant to me. I tried so hard to provide breastmilk for a kid with a gut that I knew was broken. It was so heartbreaking to me to know that I had what he needed and couldn't give it to him. (ID 52)<br><br>One of the most difficult things about his recovery was not being able to hold him at first. It took a few days, and it seemed that me being near him, touching him and talking to him in an effort to comfort him only made him cry harder and make his heart rate faster. My attempts were hurting more than they were helping. He was in pain and I couldn't hold, shush, bounce, pat or nurse him into comfort. (ID 109) |
| Loss of/impact on relationships | I feel like I lost a piece of my marriage -- while we have grown a lot because of CHD, it has also changed the nature of our relationship. (ID 81)<br><br>I feel sometimes that family time has been stolen from us by CHD because I feel like we are always doing medications, tube feedings, therapy appointments and other appointments instead of being able to play and do normal family stuff. (ID 55) |

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

**40. Implementation of CINCO Program Improves Frequency and Earlier Initiation of Therapy Orders**

*Sarah Oriolo Watson M.S., CCC-SLP, CBS[1], Reagan Broach MOT, OTR/L[1], Caelah Clark M.S., CCC-SLP[1], Andrea Gerk OTD, OTR/L, BCP[1], Emily Maloney PT, DPT, PCS[2], Ariann Neutts PT, DPT, PCS[2], Sherrill D. Caprarola MD[2], Sarah L. Kelly PsyD[2] and Kelly R. Wolfe PhD, ABPP-CN[2]*

*[1]Childrens Hospital Colorado, Aurora, CO, USA; [2]Children's Hospital Colorado, Aurora, Colorado*

*Introduction:* With improving medical outcomes and increased life expectancy in patients with congenital heart disease (CHD), there is increased understanding of the impact of CHD on neurodevelopmental (ND) outcomes and the importance of ND-supportive care to improve outcomes in this population. The Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) program was implemented at Children's Hospital Colorado in 2020 to systemize and expand upon existing ND care practices. While automatic physical therapy (PT), speech/language pathology (SLP), and occupational therapy (OT)orders have existed at our institution since 2012, data collected between 2018 and 2020 indicated many patients did not receive orders for therapy or orders were delayed. We sought to evaluate whether CINCO impacted the number of patients receiving therapy orders and the length of time from admission to initiation of therapies.

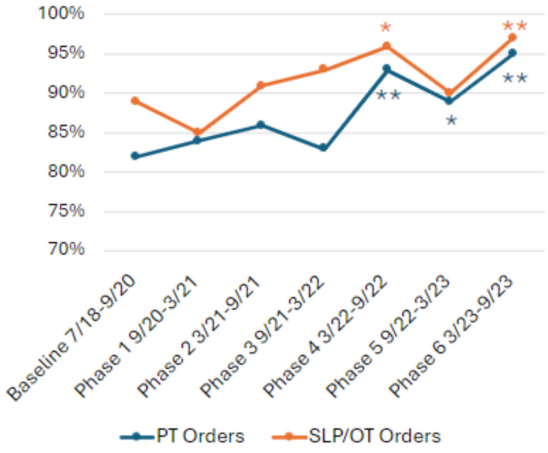
*Methods:* Inclusion criteria were all patients aged 0–2 years admitted for ≥7 days to the cardiac intensive or progressive care units, from 9/1/2020–9/1/2023 ($N = 1{,}257$ admissions). Data regarding placement and timing of therapy orders was collected from the electronic health record. At our institution, SLP and OT orders are typically combined; thus, we combined these orders for analysis. Baseline data was collected between 7/1/2018 and 9/1/2020 and compared to data collected after CINCO implementation.

*Results:* There was a change in the percentage of patients receiving therapy orders over time, (Figure 1). Specifically, during baseline phases, 75–85% of patients received PT orders; by phase 6 of CINCO, 95% of patients received PT orders. Similarly, during baseline phases, 85–92% of patients received SLP/OT orders; by phase 6 of CINCO, 97% of patients received SLP/OT orders. The length of time from admission to initiation of therapies decreased for both order sets. Specifically, time to PT orders decreased from 6–11 days at baseline to less than 1 day by phase 6 of CINCO, and time to SLP/OT orders decreased from 3- 6 days to 1.6 days.

*Discussion:* In 2023, the American Heart Association released a science advisory describing a "critical need" for "targeting early factors" influencing developmental outcomes "after birth and during the neonatal hospitalization for CHD patients". We found that implementation of the CINCO program increased the number of PT, SLP, and OT orders and decreased the time to therapy initiation. Integrated, multidisciplinary cardiac inpatient ND care programs such as CINCO can leverage existing therapy personnel, resources, and infrastructure to improve outcomes for children with CHD and their families.

1A) PT/OT/SLP Orders Frequency

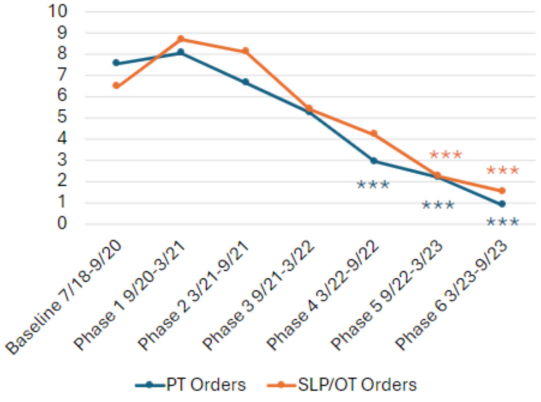
Figure 1A. Percentage of patients receiving therapy orders




Note. Follow-up contrasts comparing CINCO Phases to Baseline: *p<.05; **p<.01

B) PT/OT/SLP Days to Order Initiation

Figure 1B. Number of days post-admission when therapy orders were placed




Note. Follow-up contrasts comparing CINCO Phases to Baseline: *p<.05; **p<.01; ***p<.001

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

### 41. Implementation of a Gastrostomy Tube (G- tube) Weaning Protocol in Patients with Complex Congenital Heart Disease

*Amanda Hogan RD, CNSC, Kelly Ross Wolfe Ph.D ABPP-CN, Caelah Clark M.S.,CCC-SLP, Andrea Gerk OTR/L, BCP OTD, Sherrill D. Caprarola M.D., Sarah L. Kelly PsyD and Sarah Oriolo Watson M.S., CCC-SLP, CBS*
*Children's Hospital Colorado, Aurora, CO*

*Introduction:* Many children with congenital heart disease (CHD) require a feeding tube to achieve adequate intake for growth. Feeding issues from CHD can include dysphagia, oral aversion, and feeding intolerance which interfere with the natural progression of oral feeding development. Standardization of practice in weaning from feeding tubes has been shown to support oral feeding success. Without a standardized method to reintroduce oral feeding and initiate weaning from the feeding tube, patients sustain delays in oral feeding progression which compromises their ability to reach developmental milestones. We sought to implement a multidisciplinary G-tube weaning protocol to promote full oral feeds. Using a tube weaning toolkit created for single ventricle patients, we expanded the use of the toolkit to include all children with CHD at Children's Hospital Colorado.
*Methods:* The goal of this single-center quality improvement project was to help medically stable, tube-dependent patients with any form of CHD reach 100% oral intake through implementation of the National Pediatric Cardiology-Quality Improvement Collaborative (NPC-QIC) Tube Wean Toolkit. Patients were weaned by hunger provocation with caloric reductions of tube feedings every 3-5 days until volume was eliminated. The children were also receiving weekly feeding therapy either via home or telehealth. We defined tube weaning as: 100% of the child's nutrition and hydration being delivered via oral intake without use of the G-tube for a minimum of one month.
*Results:* Fourteen patients (4-42 months, *M*=13 months) with complex congenital heart disease were enrolled in the tube weaning program. At the time of enrollment, 10 patients (45%) were taking less than 10% of their nutrition by mouth. Over the course of the protocol, 93% of patients successfully transitioned from G-tube feeds to full oral feeds; the average time to achieve full oral feeds was 14.9 days from initiation of the tube weaning protocol. Complications included constipation and dehydration and were managed proactively throughout the wean. Weight loss following caloric reduction was minimal, and all patients demonstrated weight gain from baseline within 1 month post-wean (average gain 3.6%; weight for-age z-score change -0.12). Parents reported decreased anxiety around mealtimes and achievements in new developmental milestones including language, motor and cognitive skills.
*Discussion:* Patients with various types of CHD can safely and successfully transition from G-tube feeds to full oral feeds using a standardized treatment protocol with multidisciplinary support without significant weight loss or complications when proactively managed. The NPC-QIC protocol can be expanded beyond single ventricle patients to include a variety of CHD diagnoses. Further research is warranted to assess the relationship between G-tube wean protocols and neurodevelopmental outcomes of patients with CHD.

### 42. Developing new approaches to mental health care integration in congenital heart centers: a qualitative study exploring the views and experiences of health professionals from three countries.

*Julia Baenziger[1,2], Emily Jones[2], Madeleine Pidcock[2], Daniel Tobler[3], Alexander R. Opotowsky and NadineA. Kasparian[1,2]*
*[1]Heart and Mind Wellbeing Center, Heart Institute and Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center and the Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, OH, United States; [2]Heart Centre for Children, The Sydney Children's Hospitals Network, Sydney, NSW, Australia; [3]Department of Cardiology, University Hospital Basel, University of Basel, Basel, Switzerland*

*Introduction:* Internationally, there is increasing focus on the mental healthcare needs of individuals with congenital heart disease (CHD). We investigated health professionals' views and experiences of integrated mental health services to identify current practices, better understand facilitators and barriers to embedding mental health care within CHD services, and identify strategies to promote future recommendations and service implementation.
*Methods:* Healthcare professionals from five congenital heart centers in the United States, Australia, and Switzerland, each with a distinct health system and model of mental health care integration, were invited to take part in a qualitative interview study. Interviews focused on mapping currently available mental health services, facilitators and barriers to mental health program development, and staff education, training, and resource needs. Interviews were recorded, transcribed verbatim, and analyzed using MAXQDA software (Berlin, Germany). We applied thematic analysis, a qualitative approach that involves systematically identifying, organizing, and interpreting themes within data to provide nuanced understanding of the content. Data interpretation was theoretically guided by the Consolidated Framework for Implementation Research.
*Results:* Forty-six health professionals representing cardiology, cardiothoracic surgery, neonatology, cardiac intensive care, nursing, psychology, psychiatry, allied health, and healthcare administration participated (58% response rate, 72% women, mean length of professional experience: 15.5±8.0 years, mean interview duration: 47.9±18.8 minutes). Five key themes relevant to the design and implementation of integrated mental health services in congenital heart care were identified: (1) Universal recognition of the high need and demand for mental health care among individuals with CHD and their families; (2) Patient and family lack of awareness of existing services, and socioeconomic and cultural barriers to mental health care, including stigma, and financial cost; (3) Center- based barriers to mental health care integration, including fiscal, workforce, and time constraints; (4) Integration promotion strategies, including interdisciplinary teamwork, regular and reliable communication, closed feedback loops, skills-based mental health education and training, and professional role clarity; (5) Factors to improve patient and family access to mental health care, including service flexibility and co-location with CHD care, routine psychosocial screening, and adoption of a proactive and preventive approach with multiple entry-points to mental health care across the medical trajectory. These findings were largely consistent across the three countries.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*Discussion:* Our results highlight the need for innovative strategies to overcome common and widespread barriers at community, center, system, and societal levels. Sustainable business models, coupled with workforce capacity-building initiatives and skills-based education and training opportunities, are critical to accelerating equity in access to mental health care for individuals with CHD across the lifespan.

### 43. Integrating Developmentally Supportive Care Practices in the Cardiac Intensive Care Unit Through Nasotracheal Intubation

*Lizzy Mekler SLP, Kimberly DiMaria DNP, Kevin De Bear OT, Amanda Peck OT, Evan Goldart MD, Adrian Dantzer, Stephen Else RN, Bishr Haydar MD, Susan M. Smith RRT and Dan Ehrmann MD*

*Introduction:* Infants with congenital heart disease (CHD) are at increased risk of neurodevelopmental delays (ND) and feeding challenges, which may negatively impact growth and caregiver bonding. Partial or complete dependence on tube feeding presents significant challenges for neonates and families, and results in substantial increases in healthcare utilization. Cumulative sedation exposure in the intensive care unit (ICU) and oral aversion from prolonged oral endotracheal intubation have been shown to contribute to dependence on tube feeding. Nasotracheal intubation has been shown to decrease overall sedation exposure, prevent oral aversion, and reduce time to achievement of full oral feeds. Nasal intubation may allow earlier initiation of developmentally appropriate activities including positive oral stimulation, holding, and engagement during developmentally appropriate positions with less discomfort.

Neonates undergoing cardiac surgery with cardiopulmonary bypass (CBP) at the University of Michigan Congenital Heart Center are exclusively orally intubated and have relatively low rates of percent of oral feeds at discharge (21%). We hypothesized that transitioning to nasal intubation would increase oral feeding at hospital discharge (primary outcome). We also hypothesized that nasal intubation would decrease overall opioid and benzodiazepine exposure and time to SLP/OT evaluation while increasing frequency of feeding/ND interventions (secondary outcomes).

*Methods:* We performed a single center prospective quality improvement study beginning in 1/2024. Nasotracheal intubation was offered to all term neonates over 2.5 kg undergoing cardiac surgery with cardiopulmonary bypass (CPB) without any anatomical contraindications. As part of this practice change, SLP/OT consultation orders were placed upon admission from the OR to encourage earlier intervention by the dysphagia team instead of after extubation or transfer to the acute care unit. Primary and secondary outcomes were ascertained via data pull from PC4/PAC3 registries and retrospective electronic medical record review. Statistical analysis includes pre-post analysis of % of PO feeds at discharge and SPC charts to evaluate change over time for SLP/OT consultation and cumulative sedation (opioid and benzodiazepine) exposure. Results from an interim analysis of available data are presented with further analyses ongoing.

*Results:* Since implementation, 95% (n= 18 of 19) eligible patients were nasally intubated and the percentage of oral feeds at hospital discharge increased from 21% to 49%. Demographic data for the 18 patients included in Table 1. No major complications have been observed. Prior to nasal intubation, dysphagia consults only occurred after extubation and once tolerating appropriate enteral nutrition and respiratory supports to initiate oral feeds. Since implementation of nasal intubation, dysphagia consults are received POD 1 and services initiated within an average of 4.7 days post-operatively, with therapy targets including positive oral stimulation, non-nutritive sucking and pacifier dips as appropriate.

*Discussion:* Nasal intubation for neonates undergoing cardiopulmonary bypass is safe and effective at increasing the percent of PO intake at hospital discharge. Next steps include secondary data analysis to evaluate the impact of nasal intubation on additional ND interventions to decrease incidence of oral aversion; quantification of cumulative sedation exposure for patients; and time to NG removal.

| | n= 18 |
|---|---|
| Gender | 39% Male; 61% Female |
| Mean Gestational Age | 38.98 days |
| Ethnicity | 83% White; 11.1% African American; 5.6% Hispanic |
| Mean Duration of Mechanical Ventilation | 5.2 days |

### 44. Three-Year Review of the Implementation and Sustainability for the Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) Program

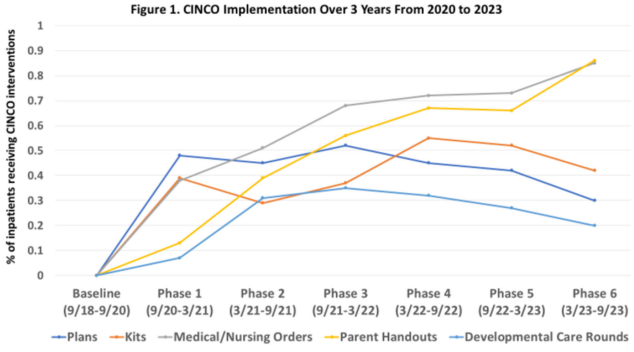
*Sarah L. Kelly, Sherrill D. Caprarola MD, Emily H. Maloney PT, DPT, PCS, Caelah Clark, Andrea Gerk, Foster Rosemund, Hilary Patteson, Sarah Riessen, Kelly R. Wolfe, Rachel Lindgren, Andrea Rees, Lain Jackson, Katie Arora-Frank and Jesse Davidson*

*Introduction:* Children with congenital heart disease (CHD) are at risk for neurodevelopmental (ND) delays. CINCO was developed to standardize inpatient cardiac ND care using an interdisciplinary model with 5 pillars of program interventions: Medical/Nursing Order Panels (for holding/activity and clustering cares), Weekly Developmental Plans and Bedside Kits, Parent/Caregiver Education and Mental Health Support Handouts, Weekly Bedside Developmental Care Rounds (DCR), and cardiac-specific Volunteer Program.

*Methods:* This study assessed the sustainability of implementing CINCO over 6 phases across a 3-year span, q6 months from 9/20-9/23, for children 0-24 months of age admitted for ≥7 days to the cardiac intensive (CICU) and progressive care units (CPCU) using Electronic Health Record data (compared to baseline 9/18-9/20). One-way ANOVAs and follow-up simple contrasts tracked utilization of interventions across the phases. Exploratory bivariate analyses examined whether utilization differed by demographic and medical variables. The Volunteer Program was measured by number of 3-hour shifts completed.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*Results:* During the study timeframe, there were 1257 qualifying admissions. CINCO implementation was sustained over the 3 years with Figure 1 demonstrating the percentage of patients receiving orders, plans, kits, handouts, and DCR from baseline through Phase 6. Younger age at admission and higher STAT surgical scores were associated with an increased likelihood of each intervention (Age: rs = -.074 to -.182; ps = .036 to <.001; STAT score: rs = .166 to .313; all ps <.001). Patients with longer CICU length of stay (LOS) were more likely to receive orders, plans, kits, and DCR (rs = .223 to .315; all ps <.001). Those with longer hospital LOS were more likely to receive plans and DCR (rs = .103 to .202; all ps <.01), though slightly less likely to receive handouts (r = -.081; p <.05). Females were more likely to receive DCR, and patients born prematurely were more likely to receive kits but less likely to receive orders, plans and handouts. Volunteer shifts increased from 0 at baseline to 110 when started at Phase 3 (delayed due to pandemic) and finally 134 in Phase 6 (M = 112 shifts per phase).
*Discussion:* Inpatient cardiac ND care is broadly recommended, but studies describing and evaluating implementation practices are scarce. We demonstrated sustainability of a comprehensive, interdisciplinary ND program for CHD. Generally, implementation of CINCO interventions has been sustained, with each pillar increasing or maintaining since implementation. Small decreases were observed during times of reduced staffing, team member turnover, or overflow inpatient census (e.g., decreased adherence with documentation of interventions related to volume and acuity). Future research will focus on maintaining ongoing sustainability and improvement, optimizing staffing and practice models, and tracking longer-term outcomes of cardiac inpatient ND care.



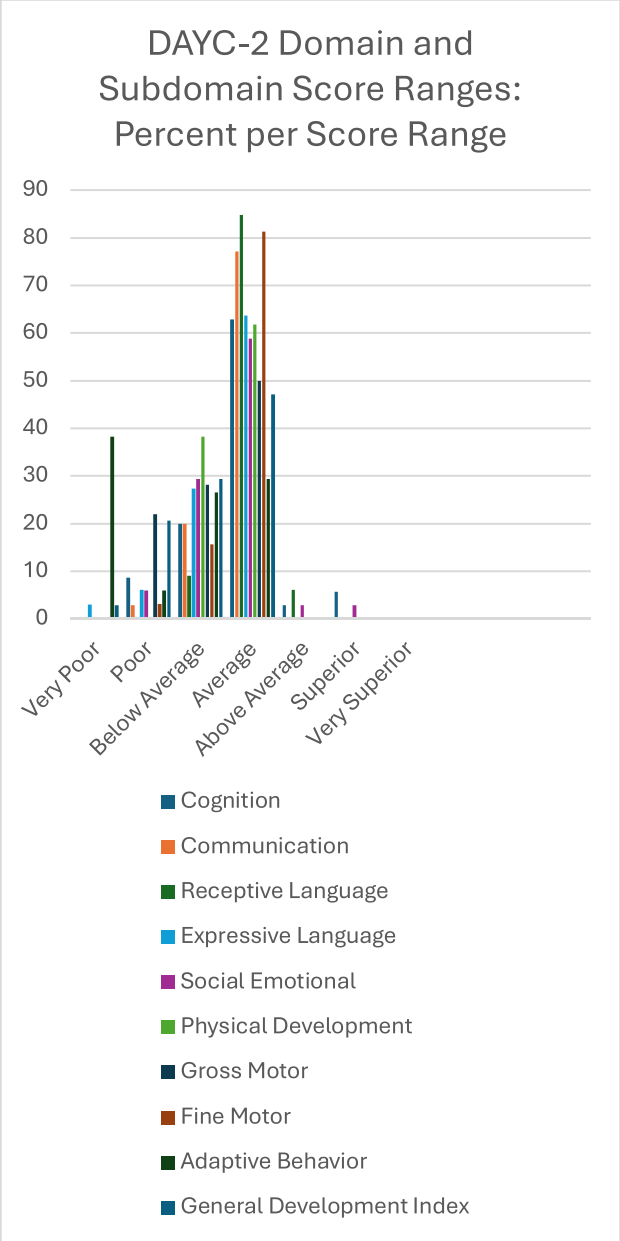

## 45. Developmental Screening for Infants in Interstage Period at ≤ 4 months of age with Single Ventricle Congenital Heart Disease

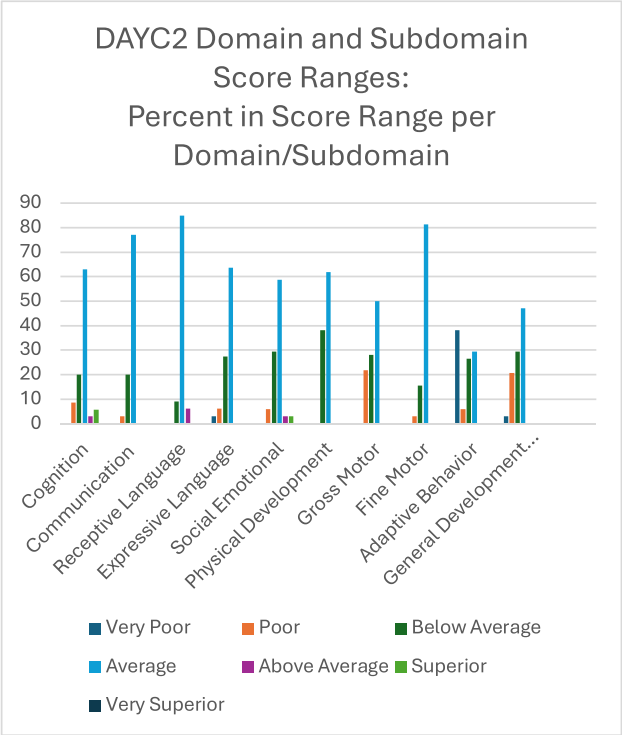
*Neill Broderick PhD[1], V. Angie Shaffer APPN[2], Althea Wroblewski PhD[3] and Jamie N. Colombo DO[2]*
*[1]Division of Developmental Medicine, Department of Pediatrics Vanderbilt University Medical Center and Monroe Carell Jr. Children's Hospital, Nashville, TN; [2]Division of Cardiology, Department of Pediatrics Vanderbilt University Medical Center and Monroe Carell Jr. Children's Hospital, Nashville, TN; [3]Division of Psychology, Department of Pediatrics Vanderbilt University Medical Center and Monroe Carell Jr. Children's Hospital, Nashville, TN*

*Introduction:* Single ventricle congenital heart disease (SVCHD) is one of the most severe forms of congenital heart disease (CHD). Children with SVCHD are at high risk for behavioral, emotional, cognitive, and motor developmental delay. Brain injury is reported in up to 40% of infants with CHD prior to the first surgical intervention with possible additional post-surgical complications, including delirium (acute brain dysfunction), stroke, seizure, long-term narcotic exposure, and/or prolonged hospitalization (> 2 weeks), all of which are known risk factors for neurodevelopment. Following stage 1 palliation, infants with SVCHD may require up to 6 months inpatient care with necessary focus on cardiopulmonary recovery, yet receive limited emphasis on care that promotes ongoing neurodevelopmental recovery and/or progress during this critical period. The benefits of developmental care on early psychomotor and cognitive development in premature infants are well known; however, there is currently limited knowledge surrounding these practices for infants with complex CHD. We have conducted, and will continue to administer, family-centered developmental assessment on all newborn and infant inpatients with SVCHD after surgical stage I palliation and prior to stage 2 palliation. This project aims to 1) characterize the developmental profiles of these patients 2) inform neurodevelopmental care decisions during inpatient stay as well as at discharge and 3) guide care pathways and procedures within the PCICU, step down floor, and home monitoring/neurodevelopmental follow up settings.
*Methods:*Demographics ; Within clinical care, a multidisciplinary team of providers implemented strategies for early identification of developmental differences/delays in infants with SVCHD, including the NeoNatal Neurobehavioral Scale-II (NNNS-II) and the Developmental Assessment of Young Children, Second Edition (DAY-2) instruments. The DAYC-2 domains and subdomains are the primary variables of interest for the current project. Patient related variables, including medical course and demographics, are also pertinent. All infant *inpatients* with SVCHD who underwent a surgical stage I palliation were eligible for inclusion. Parental or guardian permission was obtained. 35 patients were enrolled between July 2022 and April 2024. Patients were excluded from screening if they were mechanically ventilated or clinically unstable. Developmental screening was completed by one of two clinical psychologists using observation as well as parent/primary caregiver report. A medical provider (i.e., nurse or nurse practitioner) served as surrogate if caregivers were unavailable.
*Results:* Demographics: Of the 35 enrolled patients, 20 were eligible for the current study regarding medical stability and timing of developmental assessment. The participants range in age from 15 days to four months 25 days of age (median age = two months) at time of assessment. Preterm birth (<37 weeks gestational age) occurred for six (30%) of the participants. Birthweights range from 2.13 to 4.58kg (mean = 3.12kg). 55% are male, and 45% are female. They are 80% white, 10% Hispanic, 5% Black, and 5% Multiracial. Three of the 20 (15%) participants displayed a genetic anomaly. The participants received varying stage 1 palliation procedures, including Norwood/Sano (45%), BTT Shunt (20%), PDA stent (10%), Hybrid (10%), Norwood/BTT (5%), or other palliation (10%). It is notable that two of the patients (10%) required ECMO during their hospital course, and two (10%) experienced stroke. One of the patients who required ECMO also experienced stroke. The reporters for testing varied. Most (80%) reporters were parents, while 10% were medical staff. Another 10% represented "other." It is also notable that two of the participants had partially completed DAYC-2 activities. Some domains or subdomain scores were missing.

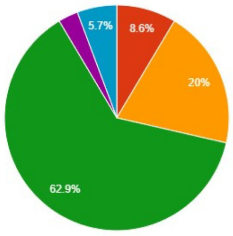
https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

Developmental Testing Data



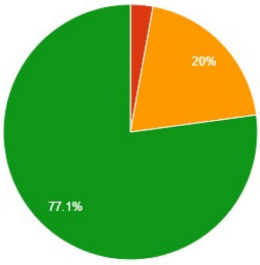

Cognition
Mean Score = 90
**Counts/frequency:** Very Poor (0, 0.0%), Poor (3, 8.6%), Below Average (7, 20.0%), Average (22, 62.9%), Above Average (1, 2.9%), Superior (2, 5.7%), Very Superior (0, 0.0%)




https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

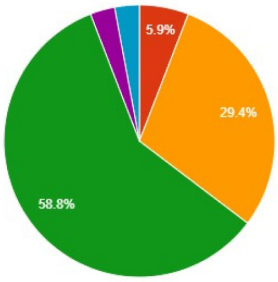
Communication
Mean Score = 94.5

**Counts/frequency:** Very Poor (0, 0.0%), Poor (1, 2.9%), Below Average (7, 20.0%), Average (27, 77.1%), Above Average (0, 0.0%), Superior (0, 0.0%), Very Superior (0, 0.0%)

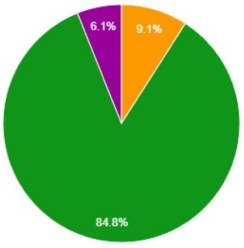



Social Emotional

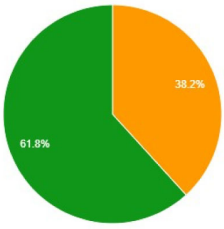
Mean Score = 90.21
**Counts/frequency:** Very poor (0, 0.0%), Poor (2, 5.9%), Below Average (10, 29.4%), Average (20, 58.8%), Above Average (1, 2.9%), Superior (1, 2.9%), Very Superior (0, 0.0%)



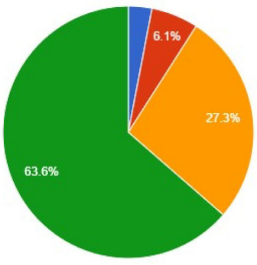

Receptive Language
Mean Score = 98.26
**Counts/frequency:** Very Poor (0, 0.0%), Poor (0, 0.0%), Below Average (3, 9.1%), Average (28, 84.8%), Above Average (2, 6.1%), Superior (0, 0.0%), Very Superior (0, 0.0%)



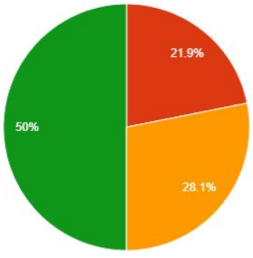

Physical Development
Mean Score = 91
**Counts/frequency:** Very poor (0, 0.0%), Poor (0, 0.0%), Below Average (13, 38.2%), Average (21, 61.8%), Above Average (0, 0.0%), Superior (0, 0.0%), Very Superior (0, 0.0%)




Expressive Language
Mean Score = 90.79
**Counts/frequency:** Very Poor (1, 3.0%), Poor (2, 6.1%), Below Average (9, 27.3%), Average (21, 63.6%), Above Average (0, 0.0%), Superior (0, 0.0%), Very Superior (0, 0.0%)




Gross Motor
Mean Score = 89.78
**Counts/frequency:** Very Poor (0, 0.0%), Poor (7, 21.9%), Below Average (9, 28.1%), Average (16, 50.0%), Above Average (0, 0.0%), Superior (0, 0.0%), Very Superior (0, 0.0%)

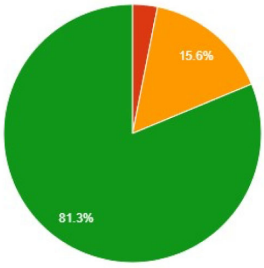



https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

Fine Motor

Mean Score = 93.44

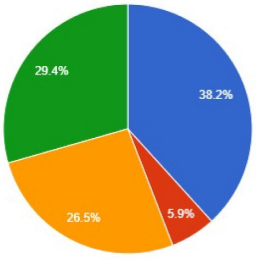
**Counts/frequency:** Very Poor (0, 0.0%), Poor (1, 3.1%), Below Average (5, 15.6%), Average (26, 81.3%), Above Average (0, 0.0%), Superior (0, 0.0%), Very Superior (0, 0.0%)




Adaptive Behavior

Mean Score = 77.26

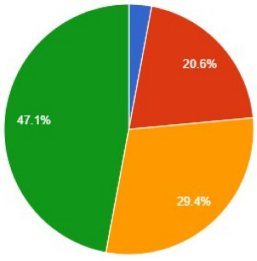
**Counts/frequency:** Very Poor (13, 38.2%), Poor (2, 5.9%), Below Average (9, 26.5%), Average (10, 29.4%), Above Average (0, 0.0%), Superior (0, 0.0%), Very Superior (0, 0.0%)




General Development Index

Mean Score = 84.89

**Counts/frequency:** Very Poor (1, 2.9%), Poor (7, 20.6%), Below Average (10, 29.4%), Average (16, 47.1%), Above Average (0, 0.0%), Superior (0, 0.0%), Very Superior (0, 0.0%)




**46. Fostering Neurodevelopmental Support within the CVICU: A Novel Interdisciplinary Approach to Enhance Development for A Toddler with Mitochondrial Disease and A Berlin Heart**

*Molly K. King MSN/MPH, PNP-AC, CVICU and Sarah Anais Mejia Ph.D., Psychologist*

*Pediatric Nurse Practitioner & Heart Center Neurodevelopmental Lead, Phoenix Children's; Center for Heart Care, Phoenix Children's, Assistant Professor, University of Arizona College of Medicine Phoenix*

*Introduction:* Hospitalization during infancy presents a critical period for neurodevelopment. While much attention is directed towards medical management, the opportunities to support the neurodevelopmental needs during this vulnerable time are essential. There are few well-described interdisciplinary approaches targeting the medical, physical, socioemotional wellbeing of young children during hospitalization. There is little known about support for young children with dilated cardiomyopathy secondary to SDHA autosomal dominant mitochondrial complex type II deficiency with history of VA-ECMO bridging to biventricular VAD support. This case illustrates the power of integrating an interdisciplinary team— medical team, occupational therapy, physical therapy, speech therapy, nutrition, infant mental health therapy, child life therapy, and expressive arts therapies to support the unique needs and ongoing development during prolonged hospitalization.

*Case Report:* A typically developing 10 mo (AG) was referred to our institution 10 days after presenting to an outlying center in cardiac arrest. Shortly after admission, he was urgently placed on VA-ECMO. His ECMO course was complicated by compartment syndrome in his left upper extremity requiring fasciotomies. He was diagnosed with dilated cardiomyopathy secondary to SDHA autosomal dominant mitochondrial complex type II deficiency. After 28 days of VA-ECMO, he was converted to biventricular VAD support with Berlin Heart. He was extubated after 98 days of ventilation. Since that time he has continued to recover and gain developmental milestones while awaiting a suitable donor. Given the various medical constraints to movement, engagement, social interaction, bonding, feeding, and typical child interactions, specific attention was placed on using a dyadic approach to support the child-parent relationship during hospitalization. AG received ongoing PT, OT, and speech therapy throughout his hospitalization. With the integration of trauma-informed, developmentally appropriately engagement and play, he has made significant developmental gains. He regained all his prior milestones and is now walking with one-handed assist, demonstrating advanced fine motor grasps, saying 2-5 words, progressing in his oral feeding skills with subsequent reductions in his tube feedings. Additionally, he weaned from all habituation medications 2 months after extubation, save gabapentin. The neurodevelopmental team meets weekly to discuss his progress and develop creative strategies for supporting AG and his mother in reaching his next milestone. The development of concerning behaviors prompted the initiation of interdisciplinary therapy sessions that incorporate novel co-treatment approaches, such as OT with art therapy, PT with child life, music therapy with speech language therapy, and infant mental health therapy with medical counseling. With these modifications in his treatment plan, he continues to flourish as he awaits transplantation.

*Discussion:* Here we explore pivotal points of development, interdisciplinary interventions used to support ongoing development during hospitalization, and ways to promote this understanding in a cardiac intensive care unit. This abstract highlights novel strategies to prioritize neurodevelopmental support during a traumatic hospitalization.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

### 47. Utilizing the Infant Positioning Assessment Tool (IPAT) improves developmentally supportive positioning of neonates in the Heart Center

*Molly K. King MSN/MPH, PNP-AC, CVICU, Latoya Olusoji OTR/L, Jena Buck OTD, OTR/L, Miranda Hopper PT, DPT, Kelly McKenna M.S., CCC-SLP, Mary Baglieri MSN MBA CCRN CPN, Stacy Stravitz DNP, PNP-AC, CVICU and Josh Koch MD Pediatric Nurse Practitioner & Heart Center Neurodevelopmental Lead, Phoenix Children's; Pediatric Nurse Practitioner; Critical Care Division Chief Phoenix Children's*

*Introduction:* Congenital heart disease (CHD) is the most common birth defect, affecting 1 in 101 live births. A small percent (~1%) of these births will require surgical intervention during the neonatal period (0-60 days of life). Surgical mortality has decreased dramatically over the last 40 years. Licht, et al found prior to any surgical or catheter-based intervention neonates with CHD had brain maturation scores 5 weeks behind their unaffected peers. Families affected by CHD continue to experience high rates of morbidity in many areas (technology dependence, gross & fine motor delays, cognitive delays, speech & feeding delays, and prolonged opioid & benzodiazepine exposure.) Critical care environments often find neonates positioned in developmentally unsupportive positions which increases stress, decreases self-soothing abilities, decreases time in deep sleep, & potentially increases need for interventions. The NICU literature demonstrated consistent developmentally supportive positions improve these intermediate outcomes. The Infant Positioning Assessment Tool (IPAT) is a validated, reliable, simple pictorial tool used to evaluate posture of premature infants in six body areas.

We sought to increase the average IPAT score for infants who were in a developmentally supportive position admitted to the Phoenix Children's Inpatient Heart Center from 7.67 to 9 by June 6, 2024.

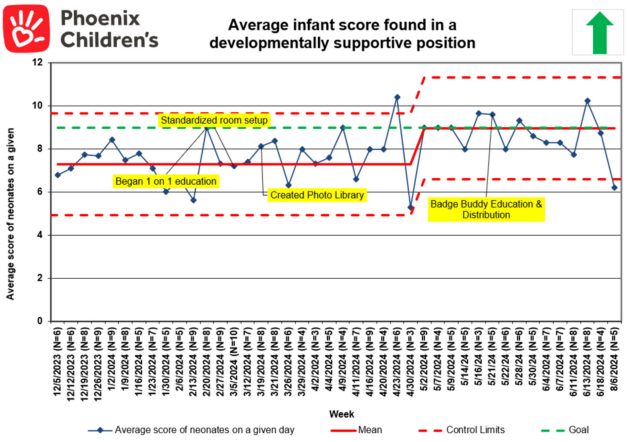
*Methods:* This Quality Improvement effort spanned 7 months including 11 weeks of baseline data. PDSA cycles include just-in-time training with CVICU nurses resulting in increased individual scores. Other PDSA ramps included additional just-in-time training with more complex infants including those who are intubated, open sternums following CT surgery, and on ECMO; group training; hands-on practice during skills day; creating photo journals of "before & afters" to support long-term memory retention; and creating an IPAT badge buddy.

Biweekly measurement of IPAT score on all infants < 60 days admitted to the inpatient Heart Center care areas (CVICU, Stepdown, & Cardiology.) Scores can be 0-12. The individual IPAT scores are used to determine the mean for the that day. Describe total opioid & benzodiazepine doses received 12 hours prior to and after assessment & measurement. Balancing measures: frequency of unplanned extubations, significant escalations in care, staff assists/codes, and Rapid Responses alerts on Cardiology inpatient infants.

*Results:* This project demonstrates that developmental positioning is feasible, simple & safe in the high-risk CVICU population. There were no serious safety events or near misses related to positioning in this population since beginning this work, including self- extubations, central line dislodgement, and CPR.

This project was full received at by the bedside nurses. We noted a center line shift around the 6$^{th}$ of the project reaching our target IPAT score of 9. We are moving toward sustainability with intermittent re-education. Additionally, we are looking to apply some of these principles more broadly in the Heart Center.

*Discussion:* The IPAT is a simple tool showing developmentally supportive positions in neonates. This nonpharmacologic intervention increases comfort and decreases physiologic & psychologic stress. It is also a key component in trauma informed care. Welcoming caregivers into this work decreases their own physiologic & psychologic stress.




### 48. Cardiac Neurodevelopmental Program Enrollment: Leveraging the Electronic Medical Record and Healthy Planet for Patient Enrollment & Follow-up

*Abigail C. Demianczyk[1], Jenna Kolschetzky[2], Katherine Myers[2], Michelle Hughes[2], Kelly Campbell[2], Meghan Siegfried[2], Mayme Marshall[2], Bradley S. Marino[2] and Rashmi Rao[1]*
*[1]Cleveland Clinic Children's, Cleveland, OH; [2]Cleveland Clinic Children's, Cleveland, OH*

*Introduction:* Neurodevelopmental (ND) monitoring is standard of care for patients with congenital heart disease (CHD) who meet high-risk criteria for developmental delay per American Heart Association CHD ND guidelines. Many centers have established cardiac ND programs, but the participation rate of high-risk patients varies; average attendance rate 29.0%. Identifying high-risk patients for ND follow- up remains difficult. Implementation of standardized surveillance practices may increase referrals for ND follow-up but places the burden of identification on providers. The aim of this project was to demonstrate how the electronic medical record (EMR) may be used to identify cardiac patients who meet high-risk criteria for ND follow-up.

*Methods:* This quality improvement project utilized the Epic Healthy Planet (HP) module to create a report identifying patients in our hospital that met high-risk criteria for ND follow-up from July 2023 to March 2024. Table 1 describes HP Search methodology. High-risk status was confirmed, and patients were contacted via phone and/or EMR message. Pediatric cardiology providers were educated about high-risk criteria for ND follow-up and asked to refer eligible patients. Results of scheduling attempts were tracked. Patient demographics and clinical characteristics were compared for HP identified versus provider referred patients.

*Results:* HP identified 1118 patients who met high- risk criteria. Of those identified, 376 (34%) patients were contacted, resulting in 123 (32%) responses and 95 (25%) patients with scheduled clinic visits. Simultaneously, providers referred 60 eligible patients; 100% were contacted and scheduled. Clinic visits were completed by 110 patients: 65 (59%) HP- identified; 42 (38%) provider-

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

referred; and 3 (2%) self-referred. Patient demographics and clinical characteristics were similar across referral sources.
*Discussion:* HP is an effective way to leverage the EMR to quickly and easily identify cardiac patients who are at high-risk and eligible for ND follow-up. Despite two-thirds of HP-identified patients not responding to scheduling attempts, over half of patients scheduled and seen for ND follow-up in our clinic were initially identified using HP, resulting in more scheduled and attended clinic visits than provider referral of high-risk patients. Referral by primary cardiologist remains important as some patients may need targeted education about their personal risk factors and need for follow-up. Additionally, HP may not capture patients whose risk factors are not extractable from the EMR.

Table 1. Creating a Healthy Planet Report of Cardiac Patients at High-Risk for Neurodevelopmental Differences

| | |
|---|---|
| **Request Healthy Planet Build** | • Healthy Planet (HP) is an Epic Module that can be used to optimize outcomes for a patient population.<br>• A build request was submitted via the Information Technology team or Epic team.<br>• HP report was built with Epic support. |
| **Identify Cardiac Diagnoses to Include in the HP Build** | • 158 ICD 10 diagnosis codes related to congenital heart disease, acquired heart disease, heart failure, rhythm issues, cardiac genetic conditions, and cardiac procedure codes were included in search<br>• Patients included in the report if they had one or more of these diagnoses listed (1)on their problem list, (2) as the encounter diagnosis on at least two encounters, (3) and/or included in data extractable from the electronic medical record (EMR) |
| **Clarify Clinical Risk Factors** | Once appropriate cardiac diagnosis identified, patients were included on the HP report if at least one of the following risk factors were listed on their problem list, as the encounter diagnosis in at least two encounters, and/or in data that is extractable from the EMR:<br>• Prematurity – gestational age <37 weeks<br>• Any of the following with the first year of life:<br>○ Cardiac surgery or catheterization<br>○ >2 week hospitalization in the PCICU, PICU, NICU, or associated step-down units<br>• Genetic Diagnosis<br>○ Alagille/JAG1, CHARGE/CHD7, Trisomy 21, 22q11.2 deletion, Jacobsen/11q23 deletion, Noonans, Turner, VACTERL, Williams/7q11.23<br>• History of Mechanical Circulation (ECMO or VAD)<br>• History of Cardiac Arrest and/or Cardiopulmonary Resuscitation<br>• History of Heart Transplantation<br>• Abnormal electroencephalogram or neuroimaging<br>• Perioperative seizures |

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

| | |
|---|---|
| **Create HP Report Logic** | HP report included all patients between the age of 0 and 21 who met high-risk criteria using the following logic:<br>• Patient with cardiac diagnosis **AND** one or more clinical risk factor described above<br>**OR**<br>• Patient had a heart transplant<br>**OR**<br>• Patient is status post Fontan<br>The additional logic for Heart Transplant and Fontan physiology was included to ensure that we captured all of our highest risk patients regardless of where they received their surgical care. |
| **Create Documentation Templates with *Smart Data Elements*** | • We also built a contact note that tracks attempts at contact (1st, 2nd, 3rd), outcome of contact (enrolled, deferred, declined), and when patients are due for follow up (date).<br>• Our program coordinator contacts eligible patients and documents using the smart data element note, which then feeds into the report to reduce burden of chart review. |

**49. Real-World Differences in Pharmacological Treatment of ADHD among Children and Adolescents with and without Congenital Heart Disease**

*Anna N. Pressel[1], Julianne M. Giust[2], Gillian S. Mayersohn[3], Cynthia M. Ortinau[4] and Kara E. Garcia[5]*

*[1]Indiana University School of Medicine; [2]Indiana University School of Medicine, Department of Psychiatry; [3]St. Louis University, Department of Psychology; [4]Washington University School of Medicine, Department of Pediatrics; [5]Indiana University School of Medicine, Department of Radiology and Imaging Sciences*

*Introduction:* Patients with congenital heart disease (CHD) are at increased risk for psychiatric disorders including Attention-Deficit/Hyperactivity Disorder (ADHD). However, stimulant medications, the first- line treatment for ADHD, can induce cardiovascular side effects such as change in heart rate or blood pressure. Available studies do not indicate significant risk of sudden cardiac death in children with CHD, but evidence is limited. Since 2008, the American Heart Association and American Academy of Pediatrics have recommended "use of clinical judgement" regarding cardiovascular evaluation and monitoring of children and adolescents receiving medication for ADHD. The current study sought to characterize real world differences in pharmacological treatment of ADHD among children and adolescents with CHD, compared to the broader ADHD population, using a national, multispecialty electronic medical record database.

*Methods:* Retrospective analysis was conducted using the Indiana University School of Medicine-Evansville Real World Evidence Psychiatric Database, which contains de-identified electronic medical records for 4.89 million patients with psychiatric diagnoses across the United States (Sidus Insights, last update 2024). Selection criteria included patients with current age 20 years or younger, as well as diagnoses of both CHD and ADHD or ADHD only. Primary analysis compared medication history for CHD+ADHD and ADHD only groups, based on identification of common ADHD stimulant or non-stimulant medications.

*Results:* Selection criteria resulted in 110,465 pediatric and adolescent patients with ADHD and 713 with CHD+ADHD. Age and gender were comparable across groups. Of the CHD+ADHD group, the most common cardiac diagnoses were atrial septal defects (39%), congenital insufficiency of the aortic valve (16%), congenital malformation of the aortic and mitral valves (15%), and ventricular septal defects (13%). Only 11% had moderate to severe CHD diagnoses recorded (27 tetralogy of Fallot, 17 coarctation of aorta, 11 transposition of the great arteries, 9 hypoplastic left heart syndrome, 12 other). ADHD diagnoses were similar across groups, with unspecified type most commonly recorded, followed by inattentive then hyperactive or combined types.

Among patients with ADHD but no CHD, 48% had medication histories containing common stimulants (e.g., Adderall, Concerta, Vyvanse, Ritalin), and 23% had medication histories containing

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

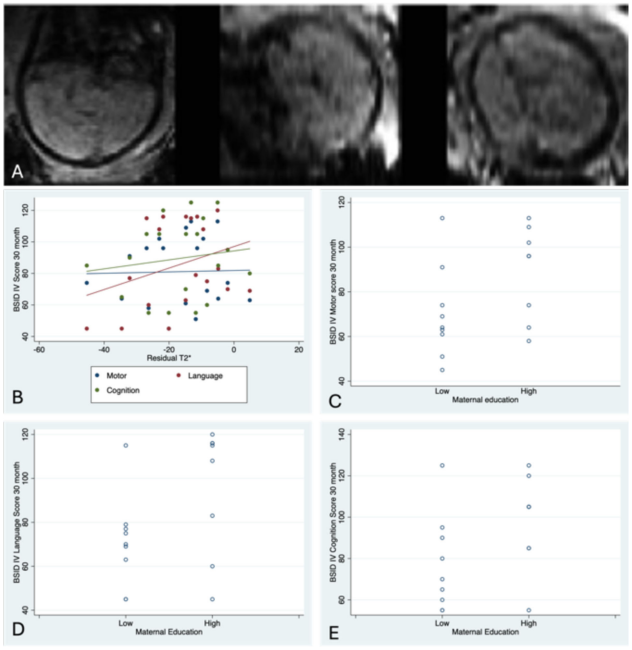
common non- stimulants (e.g., Kapvay, Strattera, Intuniv). However in patients with CHD+ADHD, only 26% had medication histories containing the same stimulants and 15% had medication histories containing the same non-stimulants.
*Discussion:* The current findings, obtained from a large national sample, suggest that both stimulant and non-stimulant pharmacological treatments are less likely to be prescribed in children and adolescents with CHD. This disparity suggests potential barriers to access for, or prescription of, pharmacological treatment of ADHD. Future work should assess the specific barriers to access, including provider education and referrals regarding the safety of pharmacological treatments, as well as treatment- related outcomes for the CHD population with ADHD.

### 50. Fetal Brain T2* mapping and Infant Neurodevelopmental Outcomes in Congenital Heart Disease

*Elizabeth George, Jing Liu, Duan Xu, Lauren Christopher, Patrick McQuillen, Shabnam Peyvandi UCSF and San Francisco CA*

*Introduction:* Fetal T2* mapping has demonstrated altered brain oxygenation in fetuses with congenital heart disease (CHD) compared to normal controls. We sought to assess the association of fetal T2* relaxation time with neurodevelopmental (ND) outcomes among infants with CHD requiring a neonatal intervention.
*Methods:* 48 fetuses with transposition of great arteries (TGA) or single ventricle physiology (SVP) underwent fetal brain MRI in the 3rd trimester including T2*mapping. T2* relaxation time was adjusted for gestational age (GA) at time of MRI and sex and a residual T2* was calculated which reflects the difference between the subject's T2* and the expected value based on normal controls. ND outcome was assessed at 18- and 30-months using Bayley Scales of Infant and Toddler Development (BSID, version III or IV). Due to the differences in BSID versions, the primary outcomes at 18 months were abnormal motor, cognition, or language defined as a score < 85 in the corresponding domain (BSID III or IV). The primary outcomes at 30 months were the motor, cognitive, language scores on BSID version IV. Race/ethnicity, GA at birth, cardiac lesion type, length of neonatal hospital stay, maternal education (college graduate or higher vs. partial college or specialized training or lower), and fetal total brain volume (TBV) were included in univariate analysis. Multivariate (MV) analysis included residual T2* and those variables with $p<0.1$ on univariate analysis (after excluding highly correlated variables).
*Results:* The study population was 73% (24/33) male with a median gestational age at birth of 39.1 (IQR: 38.3-39.3) weeks. The median GA at fetal brain MRI was 34.1 (IQR: 33.5-34.6) weeks and median residual T2* was -13.2 (IQR: -26.3- -7.9) msec. On MV analysis, abnormal language at 18 months was associated with low maternal education (OR: 6.51 (0.97-43.54, p=0.5), and there was a trend for abnormal motor and cognition outcome to be associated with cardiac lesion type (SVP relative to TGA, OR: 8.46 (0.82-86.97, p=0.07) and low maternal education (OR: 8.57 (0.72-102.02, p=0.09), respectively. On MV analysis, 30-month motor, language, and cognition scores were associated with cardiac lesion type (β =-19.97- -23.16, p=0.03-0.04) and maternal education (β=-19.59- -30.61), p=0.01- 0.04).
*Discussion:* Fetal brain T2* is not associated with 18- or 30-month ND outcomes. Maternal education is associated with 18-month language outcome, while both cardiac lesion type and maternal education are associated with 30-month motor, language, and cognition scores.
Fetal brain T2* is not associated with early ND outcomes, while cardiac lesion type and the home environment have a greater impact on outcome.

Figure: T2* mapping of the fetal brain (A). Residual T2* was not associated with 30-month BSID scores in any domain (B), while maternal education was associated with all domain BSID scores (C-E).




### 51. The Heart of Feeding: Enhancing Parental Involvement in the First Oral Feeding for Infants with Complex Congenital Heart Disease (cCHD)

*Karli Negrin MS CCC-SLP, Jessica A Davis PhD, RN, CCRN, IBCLC, Elizabeth Mekler MA CCC-SLP, CLC, Susan Willette MS, CCC-SLP, Kimberly Morris MS CCC-SLP, BCS-S, IBCLC, Nancy Slater OTR/L, CLC, NTMTC, Michelle M Steltzer CPNP-AC/PC (APP), Elizabeth Ziegler MS, CCC-SLP, Sofia Carretero MS, PA-C, Lauren Malik PT, MSPT, Courtney Jones MS CCC-SLP, Paula Bartlett MA, OTR/L, CLEC, SWC, Hema Desai MS CCC-SLP, BCS-S, CLEC, David Segar MD MS, Eliza K Harley PhD, Chetna K. Pande MD MPH, Adam Kortis MA, James M Anderson, Jodi Smith Esq, Kristin Elgersma PhD, Caelah Clark SLP and Samantha Butle PhD*
*Speech Language Pathologist, Department of Rehabilitative Services, Nemours Children's Health, Wilmington Delaware; Department of Pediatrics, Division of General Academic Pediatrics, School of Medicine, University of Pittsburgh; Cardiac Intensive Care Unit, Heart Institute, UPMC Children's Hospital of Pittsburgh; Speech Language Pathologist, Department of Speech Language Pathology, CS Mott Children's Hospital at the University of Michigan; Speech Language Pathologist, Department of Speech-Language Pathology, Ann and Robert H. Lurie Children's Hospital of Chicago, Chicago, IL; Speech Language Pathologist, Department of Speech- Language Pathology, Rady Children's Hospital*

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press

*San Diego; Rehabilitation Clinical Specialist for Cardiovascular Care Services, Physical Medicine and Rehabilitation Services, Children's Minnesota; Program Coordinator for the Single Ventricle Center of Excellence, Ann and Robert H Lurie Children's Hospital of Chicago, Chicago, IL.; Speech Language Pathologist, Therapy and Audiology Services, Saint Louis Children's Hospital, Saint Louis, MO; Advanced Practice Provider, Division of Critical Care Medicine, Texas Children's Hospital, Houston TX; Physical Therapist, Rehabilitation Services, Dell Children's Medical Center, Austin, TX; Speech Language Pathologist, Acute Therapy, Primary Children's Hospital, Salt Lake City, UT; Occupational Therapist, Division of Pediatric Rehabilitation Medicine, Children's Hospital Los Angeles; Speech Language Pathologist, Rehabilitation Services, Children's Hospital of Orange County, Orange CA; Assistant Professor of Pediatric Cardiology, Herma Heart Institute, Children's Wisconsin and Medical College of Wisconsin; Clinical Psychologist, Perinatal, Infant-Family, and Cardiac Mental Health Program, Cardiothoracic Intensive Care and Cardiovascular Acute Units, Heart Institute, Department of Pediatrics, Children's Hospital Los Angeles, Los Angeles, CA; Pediatric Cardiac Intensivist, Department of Pediatrics, Division of Critical Care Medicine, Baylor College of Medicine, Texas Children's Hospital; Economics, Analyst II; Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center, Cincinnati, OH; Parent Representative; University of Minnesota, School of Nursing, Minneapolis, MN; Department of Speech Language Pathology, Children's Hospital of Colorado; Pediatric Psychologist, Department of Psychiatry and Behavioral Sciences, Cardiac Neurodevelopmental Program, Boston Children's Hospital, Harvard Medical School.*

*Introduction:* Infants with cCHD have altered feeding experiences, including delayed oral feeding introduction and family separation. Positive, family- centered early feeding experiences are important for infant attachment and neurodevelopment (ND), and for improved parent emotional health. The Cardiac Newborn Neuroprotective Network (CNNN), a SIG of the Cardiac Neurodevelopmental Outcome Collaborative (CNOC), established a Quality Improvement (QI) study to further understand parent engagement during the first oral feeding (FOF) experience for hospitalized infants with cCHD. The aim was to identify baseline parent engagement in FOF and to improve parent presence at the first oral feed within the inpatient setting.

*Methods:* CNNN sites (n=15) with multidisciplinary representation created process measures and a key 1driver diagram focused on the FOF. Prospective baseline data for infants receiving their FOF <3 months of age was collected in REDcap starting 10/2022 and included medical record review of medical complexity, parent engagement, and human milk use for infants admitted to the CICU. A Plan-Do- Study-Act (PDSA) cycle one was implemented beginning 2/2024. Data was reviewed and control charts created. The content of cycle one was health care provider (HCP) education, designed to provide information on the importance of parent participation in FOF. Didactic education was created collaboratively and sites tailored implementation.

*Results:* Participating sites varied in location of infant birth (50% inborn), size (56% 20+ bed ICU), number of infant surgeries (63% 300+ per year), prior HCP oral feeding training (63%), developmental rounds (63%), and dedicated cardiac ND program (88%). Baseline data (n=819 records) revealed parent engagement in the FOF at 51% across the collaborative, with individual sites ranging from 25% to 83% (Figure 1). Feeding team and lactation support were involved in 49% of FOF experiences and 73% of infants received human milk. Following PDSA cycle one and HCP education, parent engagement in FOF was 69% for the collaborative, with individual sites ranging 40% to 86%. Sites with higher rates of parent engagement in the FOF implemented education including didactics, utilization of clinical nurse educators, and FOF discussions during program meetings.

*Discussion:* This multicenter, multidisciplinary QI project addressed an overlooked aspect of cardiac care. Parent engagement in the FOF impacts infant outcomes and supports parent-infant relationships and was noted to be limited with opportunity for improvement. This collaborative set out to understand variables surrounding FOF to guide stakeholders with interventions to support early parental engagement in FOF. Future plans include examining individual data for associations between medical factors, developmental care practices, parent attachment, and infant feeding outcomes, along with creation of interventions to specifically increase parent engagement in FOF. Distribution of techniques to improve parental engagement in FOF will be provided across cardiology.

https://doi.org/10.1017/S1047951125000708 Published online by Cambridge University Press