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2024

# Can a Learning Network Improve Outcomes?

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# OBJECTIVES

- Describe a Learning Network
- Define the concept of collaboration
- Provide examples/tools of learning improvement

# WHAT IS A LEARNING NETWORK?

- Members work together to study a health condition and improve patient care
- Gathering data about treatments through QI and research
- Members include:
  - Patients/families and community organizations
  - Healthcare providers
  - Researchers




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# WHAT IS THE VALUE OF A NETWORK?

- Expands knowledge
- Help to grow/educate teams
- Provide higher quality, safer, more efficient care for your patients
- Collaboration between sites allow best practices to be identified and improvement to made across sites



## Power of a Learning Network in Congenital Heart Disease

Jeffrey B. Anderson, MD, MPH, MBA<sup>1,2</sup>, David W. Brown, MD<sup>3</sup>, Stacy Lihn, BS<sup>2,4</sup>, Colleen Mangeot, MS<sup>5</sup>, Katherine E. Bates, MD<sup>6</sup>, Andrew H. Van Bergen, MD<sup>7</sup> , Nancy A. Rudd, MS, CPNP<sup>8</sup>, Samuel Hanke, MD<sup>1,2</sup>, Jim Tweddell, MD<sup>1</sup>, and Carole Lannon, MD<sup>2</sup>; for the National Pediatric Cardiology Quality Improvement Collaborative

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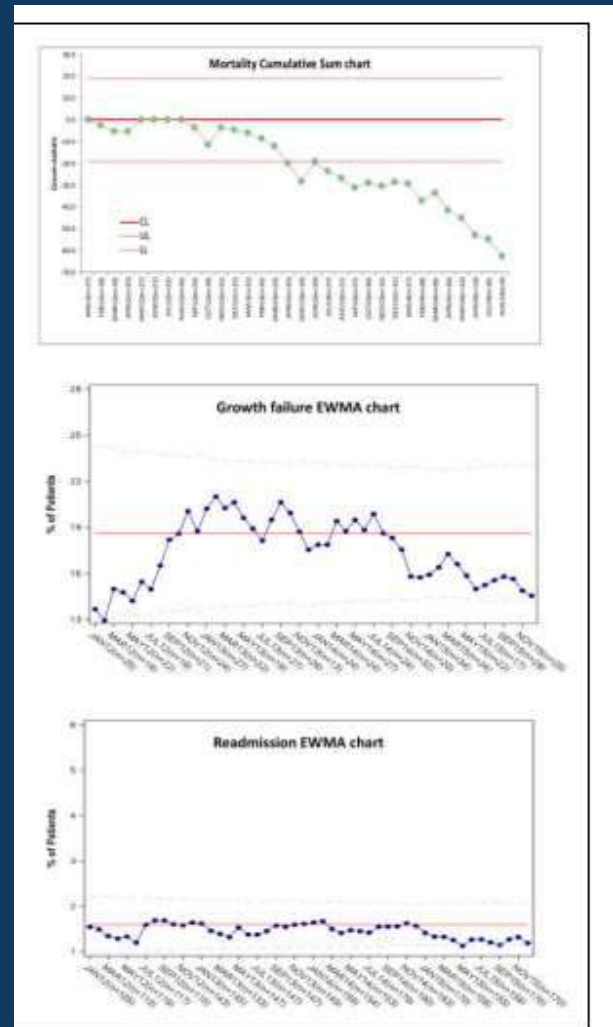
National Pediatric Cardiology  
Quality Improvement Collaborative

“The NPC-QIC's initial efforts led to improvements in interstage growth and mortality. The NPC-QIC has modeled the use of data for improvement and research, the value of co-production with parents, and the concept "all teach, all learn," demonstrating the power of the learning network model.”

-Interstage Mortality decreased by 40% from 9.5% to 5.3%

-Use of the nutrition bundle improved growth a 28% reduction in growth failure

-Serious hospital readmissions was low and did not significantly change





[J Am Heart Assoc.](#) 2016 Jan; 5(1): e002376.

Published online 2016 Jan 11. doi: [10.1161/JAHA.115.002376](#)

PMCID: PMC4859359

PMID: [26755552](#)

## Digoxin Use Is Associated With Reduced Interstage Mortality in Patients With No History of Arrhythmia After Stage I Palliation for Single Ventricle Heart Disease

[David W. Brown](#), MD,<sup>1</sup> [Colleen Mangeot](#), MS,<sup>2</sup> [Jeffrey B. Anderson](#), MD,<sup>2</sup> [Laura E. Peterson](#), BSN, SM,<sup>3</sup> [Eileen C. King](#), PhD,<sup>2</sup> [Stacey L. Lihn](#), BA, [Steven R. Neish](#), MD,<sup>4</sup> [Craig Fleishman](#), MD,<sup>5</sup> [Christina Phelps](#), MD,<sup>6</sup> [Samuel Hanke](#), MD,<sup>2</sup> [Robert H. Beekman, III](#), MD,<sup>2</sup> [Carole M. Lannon](#), MD, MPH,<sup>2</sup> and the National Pediatric Cardiology Quality Improvement Collaborative



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Randomized Controlled Trial

► [Pediatr Cardiol.](#) 2018 Aug;39(6):1200-1209.

doi: [10.1007/s00246-018-1884-x](#). Epub 2018 May 24.

## Digoxin Use in Infants with Single Ventricle Physiology: Secondary Analysis of the Pediatric Heart Network Infant Single Ventricle Trial Public Use Dataset

[Dongngan T Truong](#)<sup>1</sup>, [Shaji C Menon](#)<sup>2</sup>, [Linda M Lambert](#)<sup>3</sup>, [Phillip T Burch](#)<sup>4</sup>, [Xiaoming Sheng](#)<sup>5</sup>, [L LuAnn Minich](#)<sup>2</sup>, [Richard V Williams](#)<sup>2</sup>





# INTERSTAGE CHANGE PACKAGE



NPC-QIC Toolkit

Patient Management Strategies  
for Interstage Care

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- Improve care and outcomes during the “Interstage” Period
- Outlines strategies for clinicians, parents and researchers to advance QI improvement efforts

► *Pediatr Cardiol.* 2022 Jun;43(5):1141-1155. doi: 10.1007/s00246-022-02837-9. Epub 2022 Feb 14.

## Assessing the Association Between Pre-operative Feeding and the Development of Oral Feeding Skills in Infants with Single Ventricle Heart Disease: An Analysis of the NPC-QIC Dataset

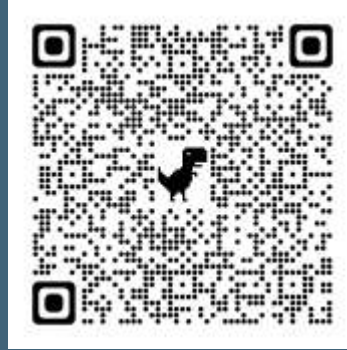
E Sagiv <sup>1</sup>, Y L Tjoeng <sup>2 3</sup>, M Davis <sup>4</sup>, E Keenan <sup>5</sup>, J Fogel <sup>4</sup>, K Fogg <sup>6</sup>, N Slater <sup>7</sup>,  
S Prochaska-Davis <sup>8</sup>, K D Frontier <sup>9</sup>, J Fridgen <sup>2</sup>, T Chan <sup>2 3</sup>



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“Pre-operative feeding of infants with single ventricle heart disease was not associated with early achievement of tube-free feeding in the first year of life. However, pre-operative oral feeding was also not associated with increased risk of NEC, suggesting that it can be safely offered among appropriate patients”

NPC-QIC Toolkit



# Oral Feeding Prior to Stage 1 Palliation

“The “Preoperative Feeding Project” was established to improve the quality of life for infants with single ventricle heart disease and their families by increasing opportunities for nutritional and neurodevelopmental oral feeding experiences prior to Stage I surgical palliation”

> Cardiol Young. 2020 Nov;30(11):1603-1608. doi: 10.1017/S1047951120003522. Epub 2020 Oct 23.

## Variations in practice in cardiac neurodevelopmental follow-up programs

Thomas A Miller<sup>1</sup>, Anjali Sadhwani<sup>2</sup>, Jacqueline Sanz<sup>3</sup>, Erica Sood<sup>4</sup>, Dawn Ilardi<sup>5</sup>,  
Jane W Newburger<sup>2</sup>, Caren S Goldberg<sup>6</sup>, David Wypij<sup>7</sup>, J William Gaynor<sup>8</sup>, Bradley S Marino<sup>9</sup>



- In response to clinical need and published guidelines, many centers have established formal cardiac neurodevelopmental follow-up programs
- Centers vary considerably in their approaches to routine screening and objective testing, with many focusing their resources on younger age patients

# GROSS MOTOR IMPROVEMENT PROJECT

Improve quality of life for infants with single ventricle congenital heart disease and their families through the development of gross motor skills in the first year

Key Driver Diagram:

## Gross Motor Improvement Project

Revised 10/16/2021

### GLOBAL AIM

Optimize development for single ventricle infant survivors s/p Stage 1 palliation all of whom are at high risk for developmental delay and / or developmental deficits

### SMART AIM

Primary: Increase the % of patients on target at 12 months on ASQ gross motor domain from 30% to 60% by August 2022  
Secondary: Increase the % of patients improving or staying on target between 6 and 12 months on ASQ gross motor domain from 40% to 70% by August 2022

### POPULATION

HLHS infants at CRT-IN NPC-QIC centers

### DRIVERS

Patient-centered, individualized developmental care practices while inpatient

Knowledgeable and empowered parents

Referral to and participation in appropriate therapies

### CHANGE/PRACTICES

Receive PT/OT services during inpatient stay

Infants held out of bed by family in ICU

Initiate tummy time practices to promote development while inpatient and practice with families so tummy time is continued after discharge to home

Counsel family on how to interpret their child's ASQ results with recommended next steps

Send toolkit home with simple activities for families to work on developmental progression with their infant at home

Developmental Plans (part of discharge S1 and S2)  
Developmental Plans (weekly)

Evaluation at a neurodevelopmental clinic by 9-12 months of age

If ASQ-GM score in "refer" or "borderline" range at 6 months, refer to Physical Therapy and/or Early Intervention Program

Standardize practices for sternal precautions as evidence is available

Current Focus

Future Focus

Foundational Requirement: Adhere to ASQ Screening



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**Strengthening Hearts And Bodies: A Multi-center Quality Improvement (qi) Initiative To Improve Gross Motor Skills In Infants With Single-ventricle Congenital Heart Disease Participating In The National Pediatric Cardiology Quality Improvement Collaborative (npc-qic)**

**Author Block:** S. C. Butler<sup>1</sup>, L. Malik<sup>2</sup>, P. Kuhnell<sup>3</sup>, L. Lambert<sup>2</sup>, N. Kasparian<sup>3</sup>, J. Briend<sup>4</sup>, J. Anixt<sup>3</sup>;

<sup>1</sup>Boston Children's and Harvard Medical, Boston, MA, <sup>2</sup>Primary Children's Hospital, Salt Lake City, UT, <sup>3</sup>Cincinnati Children's Medical Center, Cincinnati, OH,

<sup>4</sup>Sisters by Heart, El Segundo, CA.

- Increase in the rate of developmental plan provision:
  - 4 weeks post Stage 1 surgery (61% to 71%)
  - Stage 2 surgery discharge (54% to 76%)
- Referral to early intervention by age 6 months (65% to 82%)
- All sites with a shift in the centerline indicating significant improvement
- Protocols created to support infant holding and mobilization in CICU
  - 81% of sites engaging in mobilization efforts (20% prior to project)

# NEURODEVELOPMENT AND SUPPORTING INFANT GROSS MOTOR



“Parents are eager to support their baby’s development. Too often parents feel that their concerns about development are not prioritized by care teams. Development takes the back seat when babies have such serious heart conditions. Parents want strategies and therapies to support their babies as early as possible.”  
— Jennie Briend, Parent



> Ann Thorac Surg. 2020 Jul;110(1):221-227. doi: 10.1016/j.athoracsur.2019.09.078.  
Epub 2019 Nov 21.

## Center Variation in Chest Tube Duration and Length of Stay After Congenital Heart Surgery

Katherine E Bates<sup>1</sup>, Nicolas L Madsen<sup>2</sup>, Lara Khadr<sup>3</sup>, Zhiqian Gao<sup>2</sup>, Karl Crawford<sup>4</sup>, Michael Gaies<sup>3</sup>, Margaret Graupe<sup>2</sup>, Samuel P Hanke<sup>2</sup>, Anthony M Hlavacek<sup>5</sup>, Evonne Morell<sup>6</sup>, Sara K Pasquali<sup>3</sup>, Jennifer L Russell<sup>7</sup>, Susan K Schachtner<sup>8</sup>, Ronn E Tanel<sup>9</sup>, Adam L Ware<sup>10</sup>, Alaina K Kipps<sup>11</sup>

doi: 10.1161/JAHA.121.020730. Epub 2021 Oct 29.

### Successful Reduction of Postoperative Chest Tube Duration and Length of Stay After Congenital Heart Surgery: A Multicenter Collaborative Improvement Project

Katherine E Bates<sup>1</sup>, Chloe Connelly<sup>2</sup>, Lara Khadr<sup>1,2</sup>, Margaret Graupe<sup>4,5</sup>, Anthony M Hlavacek<sup>6</sup>, Evonne Morell<sup>7</sup>, Sara K Pasquali<sup>1,2</sup>, Jennifer L Russell<sup>8</sup>, Susan K Schachtner<sup>9,10</sup>, Courtney Strohacker<sup>1,2</sup>, Ronn E Tanel<sup>11,12</sup>, Adam L Ware<sup>13</sup>, Sharyl Wooten<sup>2</sup>, Nicolas L

**Session CHA.05.708 - Multicenter Research in Pediatric Cardiology**  
**323 - Sustaining and Spreading Success: Longer Term Outcomes and Spread of a Multi-Center Quality Improvement Project to Reduce Post-operative Chest Tube (CT) Duration (on Behalf of the Pediatric Acute Care Cardiology Collaborative and Pediatric Cardiac Critical Care Consortium)**

on-demand

#### Topics

2020 Pediatric Congenital Heart Disease

#### Keywords

Pediatric cardiology Quality improvement Postoperative Outcomes Congenital heart surgery pediatric

#### Authors

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Variation in CT removal practices after congenital heart surgery across centers. One site appeared to be a + deviant with ↓ CT duration, which was associated with ↓ LOS and no ↑ CT re-insertion. Utilizing this model site project aimed at ↓ CT duration ↓ and LOS

“We successfully lowered postoperative CT duration and LOS across 9 centers using collaborative learning methodology. We plan to spread this project to other PAC3-PC4 centers”

In this multicenter prospective interventional cohort study, reductions in CT duration and LOS were sustained in 9 centers following a collaborative learning model, without adverse events



# CONCLUSION

- Learning networks provide a platform for continuous improvement for children with CHD
- Collaboration between all stakeholder-clinicians, researchers, parents and families is key
- Integration of the various networks provides the ability in pediatric and congenital heart disease to foster novel science and accelerate translation of discovery to improvements in care

# THANK YOU!



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