

APPLICATION PACKET



NATIONAL PEDIATRIC CARDIOLOGY
Quality Improvement Collaborative

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WELCOME |

Thank you for your interest in the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC).

This application packet is to guide you in understanding the Collaborative, and the Collaborative activities and expectations.

After reviewing the packet, please submit the following:

- ☑ Intent to Apply form
- ☑ Care Center Application including:
 - Core Improvement Team Information form
 - Senior Leader/Administrator Agreement

VISION STATEMENT |

Our vision is to dramatically improve the outcomes of care for children with cardiovascular disease.

MISSION STATEMENT |

Our mission is to decrease mortality and improve quality of life for infants with single ventricle congenital heart disease and their families.

THANKS |

We are grateful for the support for NPC-QIC from:

The Children's Heart Association of Cincinnati
The Heart Institute at Cincinnati Children's Hospital Medical Center
NPC-QIC Care Centers



COLLABORATIVE OVERVIEW |

The National Pediatric Cardiology Quality Improvement Collaborative is a pediatric research and quality improvement (QI) network of over 60 pediatric cardiology care centers across the United States and the District of Columbia. NPC-QIC works with a parent partner organization, Sisters by Heart (SBH), to collaborate with families, clinicians, and researchers to dramatically improve outcomes for infants with complex congenital heart disease. NPC-QIC has focused on studying infants with Hypoplastic Left Heart Syndrome (HLHS), a rare, severe and complex congenital condition in which babies are born without a functioning left ventricle, since its inception in 2009.

The collaborative began a partnership with Sisters by Heart in 2011. Sisters by Heart is a national organization, consisting of the mothers of children with HLHS, which provides support, education, and empowerment to families affected by HLHS. Sisters by Heart works with these families from the point of initial diagnosis, and beyond. The members of SBH have been integral to the dissemination of information from the collaborative to parents, through the use of social media and other outlets, to engage members and foster discussion. Through the work with Sisters by Heart, NPC-QIC has embraced essential partnerships with parents and families. Parents participate on the NPC-QIC Executive Leadership Team, help co-lead NPC-QIC Learning Labs, and help with network growth plans.

The initial NPC-QIC phase focused on improving outcomes for infants with Hypoplastic Left Heart Syndrome during the interstage (between discharge from the initial open heart surgery and admission for a bi-directional Glenn procedure). Phase I has been transformational for the field, both because of the improvements accomplished to date and because of the development of a parent, clinician and scientist community that broadly disseminates successful improvement strategies.

Most importantly, data from the registry continues to enable us to document a significant reduction in interstage mortality for infants cared for by teams participating in the collaborative. Cumulative aggregate interstage mortality decreased from 9.5% to 5.1%, a relative reduction of 46%. Performance on key outcome measures also improved and **for the first time we have demonstrated significant reduction in the number of infants experiencing interstage growth failure.** Cumulative aggregate growth failure has been reduced from 18.6% to 13.3%, a relative reduction of 28.4%. There has also been a significant reduction in the number of infants admitted during the interstage for major medical problems.

In 2016 we launched Phase II with our member care centers and expanded the scope of NPC-QIC improvement and research efforts from the interstage period to the first year of life for HLHS patients (pre-natal diagnosis to first birthday.) The following domain areas were identified to structure NPC-QIC's Phase II efforts: Fetal, Surgical & ICU, Neurodevelopmental, Transparency, and Patient & Family Support ([see Key Driver Diagrams](#)). As these new areas of Phase II are being implemented, we continue to work on improving care and outcomes during the interstage period.

INTERSTAGE CHANGE PACKAGE |

The success that was demonstrated during Phase I prompted NPC-QIC to create the Interstage Change Package. The intended audience are care centers who want to improve their interstage processes and outcomes. It is a practical document that includes ideas and inspiration for teams and provides tools, strategies, and examples that can be applied locally. The Interstage Change Package is available on the [website](#).

LEADERSHIP |

Current NPC-QIC Executive Leadership Team

- Katie Bates, MD, Cardiology Co-Chair
- David Brown, MD, Cardiology Co-Chair
- Carole Lannon, MD, MPH, Network Science Lead
- Stacey Lihn, BA, Parent Lead

- Jeffrey Anderson MD, MPH, MBA, Executive Sponsor

PARTICIPATION IN NPC-QIC |

Participation in the NPC-QIC Learning Collaborative

1. Effective participation in NPC-QIC requires a multidisciplinary team including representatives with sufficient authority to effect change in the areas of focus in the [Key Driver Diagrams](#):

A care center's team may consist of:

- Cardiologist
 - NP/RN from clinics responsible for interstage care, parent education and parent management of child with Hypoplastic Left Heart Syndrome.
 - Data coordinator – person who can facilitate data entry into web database, who is familiar with medical record documentation and points of care
 - A parent of a child with Hypoplastic Left Heart Syndrome
 - Representatives from: Neurodevelopmental, ICU, Fetal, Surgery, Social Work, Nutrition, IT
2. Formal commitment by a Senior Leader of your care center or organization to support you in this endeavor and to provide necessary resources and time to devote to testing and implementing changes in the care center. At your request, we will be happy to speak with your leadership to explain the collaborative and its expectations, and how it could fit in with organizational quality improvement goals. The Senior Leader should be someone outside the improvement team that has administrative responsibilities/ oversight for the clinic area.

3. One member of the core team should be designated as the care center's Key Contact. A Key Contact is defined as the individual who is responsible for organizing day-to-day activities, including coordinating regular team meetings, managing improvement responsibilities, and ensuring that reports and/or data are collected and reported by their due date. Because the Key Contact is the care center's primary communicator with the NPC-QIC project team, it is essential that they are easily accessible and can disseminate information quickly to fellow team members.
4. The qualifying elements below are required before your program can claim participation in the National Pediatric Cardiology Quality Improvement Collaborative and for US News & World Report surveys, and to receive Maintenance of Certification credit.

NPC-QIC Participation Expectations

- Annual Fee Paid
- Semi-Annual Report submitted
- Yearly Enrollment Audit submitted and have 90% eligible patients enrolled
- Care center participation at least 3 of 4 AP Calls in the previous 12 months
- Lead MD participates in a minimum of 4 Action Period Calls and/or Learning Lab calls per year
- Lead MD (or physician representative) Participation at least one Learning Session in the previous 12 months
- Data entered and compliant (clean) per the data quality reports through the automated reporting system
- Care center reviews automated quality improvement reports monthly

NPC-QIC Physician Credit for Maintenance of Certification (MOC) Part 4 - Earning Credit

- Be actively involved for at least 12 months
 - Provide care (fetal or post-natal) to single ventricle patients
 - Participate in at least 2 PDSA cycles testing changes designed to improve care, including data collection and review of project data reports
 - Participate in at least 4 Action Period Calls and/or Learning Lab calls
 - Participate in Quality Improvement opportunities (for example participate in Learning Network QI Fundamentals webinar, participate in half day QI training the day before a Learning Session or applicable online module)
5. Participation in a web-based data collection tools (REDCap, Brookes) to populate the Collaborative's registry and ensure that the changes you are making are resulting in improvements.
 6. Willingness and commitment to test and implement changes for improvement via participation in Learning Labs.

The NPC-QIC Collaborative will:

- Provide evidence-based information on care of patients with Hypoplastic Left Heart Syndrome disease
- Offer coaching to improvement teams on applying the Model for Improvement to implement key changes at the Learning Sessions and on Action Period webinars
- Provide each team daily charts/reports on care center and aggregate data

- Provide tools, forms, and other aids to help with implementation of key areas of care
- Provide data entry support and facilitate utilization of the REDCap registry and Brookes online system

PARTICIPATION FEE |

The participant fee of \$15,000 per academic calendar year (July-June) per care center is subject to change.

This fee provides partial support to the Collaborative so that teams can:

- Learn from colleagues about best practices, effective tools, and strategies
- Improve care and outcomes for infants with congenital heart disease
- Learn and apply formal Quality Improvement methods
- Utilize the collaborative to address patient safety and quality improvement metrics
- Earn Maintenance of Certification for participating physicians and colleagues
- Earn Continuing Education credit for Learning Sessions
- Use registry data for research

In addition to demonstrating your cardiology program's commitment to improving care, participation in the Collaborative promotes the involvement of parents, fosters closer relationships and is known to achieve better outcomes. Financial support of the Collaborative from teams also provides a tangible commitment that sends an important message to our present and future funding sources. Added benefits include the ability to satisfy the QI portion of the APB's maintenance of certification requirement and obtaining US News and World Report credit for participation in the Collaborative.

A prorated fee structure has been developed for teams that join the Collaborative mid-year.

We will provide a letter and invoice to your key contact and lead physician after we have received your application.

KEY DRIVER DIAGRAMS |

The [Key Driver Diagrams](#) illustrate the areas in which we are currently working to achieve our improvement goals.

INTENT TO APPLY |

Please complete this brief Intent to Apply Form and email to info@npcqic.org

We intend to apply to participate in the National Pediatric Cardiology Quality Improvement Collaborative.

By submitting this intent to apply, we intend to submit the full application within two weeks.

Organization Name: _____ **Date:** _____

Key Contact Name: _____

Title: _____

Address: _____

City: _____ **State:** _____ **Zip/Postal Code:** _____

Phone: _____ **Fax:** _____

Email: _____

CARE CENTER APPLICATION |

Please complete this brief questionnaire and return to info@npcqic.org

Date: _____ **Care center Name:** _____

Name of person completing this questionnaire: _____

Title: _____

Email: _____ **Phone number:** _____

1. Briefly describe the aspects of your hospital/clinic/organization that relate to care of the infant with univentricular heart disease (including type of organization, size, structure, location).
2. In addition, please complete the Core Improvement Team Information grid on page 12.
3. What does your organization want to accomplish as a participant in this Collaborative?
4. Please estimate the # infants with newly diagnosed Hypoplastic Left Heart Syndrome /year :
5. Please estimate the # infants with congenital heart disease your care center sees each year :
6. Estimate what percentage of your surgery patients are followed elsewhere.
7. Does your pediatric cardiology team utilize a nutritionist as part of your outpatient clinical team on a regular basis? Please describe resources available to you for nutritionist/dietician support.

8. What is the name & position of the Senior Leader who can remove whatever obstacles may arise or to obtain necessary resources during the Collaborative? In addition, please have your Senior Leader complete the Senior Leader/Administrator Agreement.

9. Briefly describe any experience that you or others have in initiating successful improvement activities, participating in a learning collaborative, or any experience with measurement of quality outcomes. In what topic area(s)? Do you have quality improvement support within the unit structure or from the hospital? Examples of this support would be data collection, team facilitation, meeting documentation, and planning for improvement activities aimed at helping you accomplish your goals.

10. Have the members of your proposed core team worked together on a prior project?

11. Is the proposed clinic setting currently involved in a major change process or research study that demands a great deal of time? Is your care center experiencing significant organizational change (e.g., merger, change in leadership, vacancy in leadership, or EHR implementation)? Please explain.

12. Please add any additional information about your setting that may be relevant to your participation in the NPC-QIC collaborative.

13. Do you currently have parent partners engaged and imbedded in your team? If so, to what capacity are parents engaged and involved in your local QI work?

TEAM INFORMATION |

Hospital Name:				
Contacts	Title	Name	Email	Phone
Key Contact:				
Key Contact:				
Data Entry:				
Finance:				
Fetal:				
Intensivist:				
Cardiologist:				
Surgeon:				
Neurodevelopment:				
Dietician:				
Social Work:				
Cardiac ICU Director:				
Cardiac Care Coordinator:				
Other [please list]:				
Other [please list]:				
Other [please list]:				
Other [please list]:				
Other [please list]:				
Other [please list]:				

SENIOR LEADER/ADMINISTRATOR AGREEMENT |

Name: _____

Title: _____

Organization: _____

Direct Phone: _____ Direct Fax: _____

Email: _____

★As the Senior Leader*, I fully understand the Collaborative's objectives and expectations. Furthermore, I agree to support the team and will work with them to remove any barriers and/or provide the resources necessary for them to achieve their improvement goals.

Senior Leader Signature: _____

* The Senior leader should be someone outside the improvement team that has administrative responsibilities/oversight for the cardiology clinic.

Please email this Senior Leader signature page to info@npcqic.org

AFTER APPLICATION IS APPROVED |

AFTER APPLICATION IS APPROVED CARE CENTER WILL BE SENT:

- Regulatory Documents (Protocol, Consent, Neurodevelopment materials)
- Legal Document (Data Use Agreement)
- Invoice for participant fee
- Action Period call and Learning Session meeting invites

AFTER INVOICE IS PAID:

- New team orientation call will be scheduled

AFTER RECEIPT OF IRB LETTER OF APPROVAL, SIGNED DATA USE AGREEMENT, AND PAYMENT OF INVOICE:

- SharePoint access will be given
- Team will be provided with security access forms for access to REDCap data base
- A care center profile will be created for ASQ in Brookes website
- Database & ASQ orientation call will be scheduled