



Grow Baby, Grow

Creating an
Environment of
Success at Home for
High-Risk Congenital
Heart Babies

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Akron Children's Hospital

Objectives

- Explain the history of the National Pediatric Cardiology Quality Improvement Collaborative and how it has shaped the standard of care for high risk cardiac patients
- Describe our experiences with home monitoring and demonstrate the importance of the primary care provider in the team approach to caring for high risk patients
- Illustrate the process of using MyChart for data collection and evaluation of high risk patients



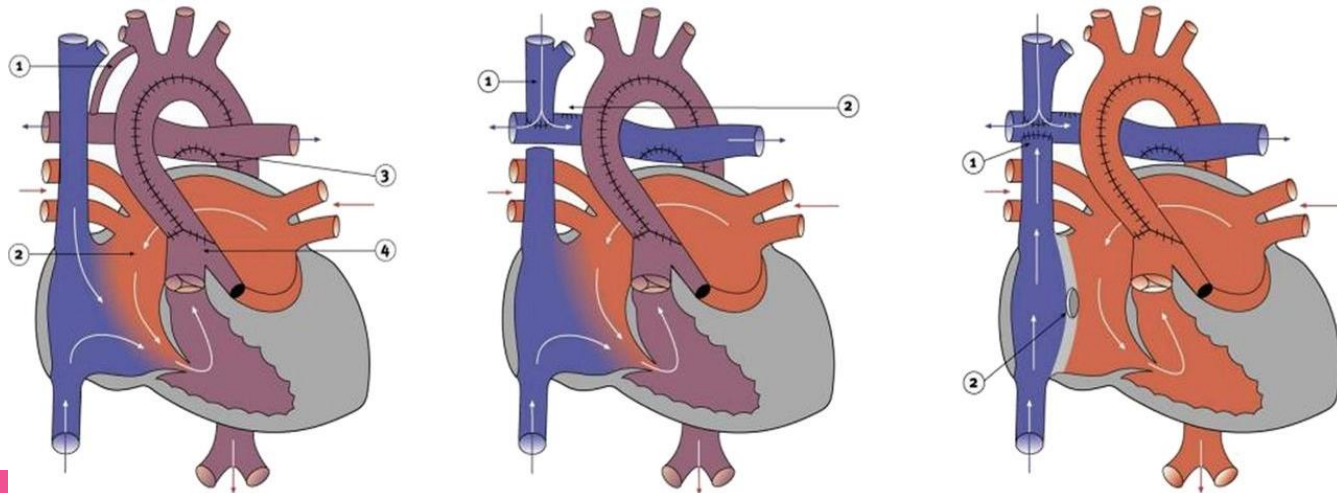
The Basics

- Approximately 40,000 infants in the US are born with CHD each year
- Single ventricle defects are the most complex and have the highest rates of morbidity and mortality
- Hypoplastic Left Heart Syndrome accounts for approximately 2-3% of congenital heart defects overall
 - 960 births per year
 - 1 in every 4,344 births



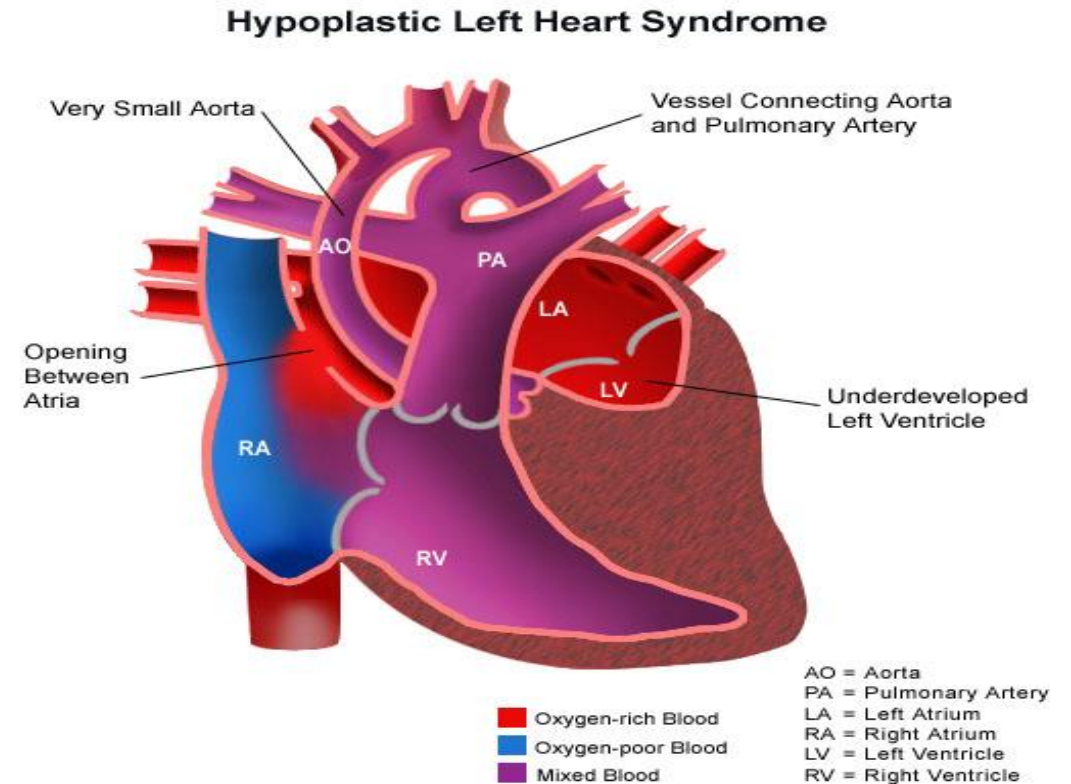
Hypoplastic Left Heart Syndrome

- A small percentage of children with HLHS receive heart transplants, while the large majority receive a series of three cardiac surgeries to survive:
 - Stage I (Norwood) procedure occurs within a few days of birth
 - Stage II (Glenn) typically occurs within 4-6 months of birth
 - Stage III (Fontan) procedure occurs between 2-4 years of age



Hypoplastic Left Heart Syndrome

- Mortality risk of children with HLHS is 10-20% at the Norwood stage
- **Interstage mortality is 10-15%**
 - **Occurring between discharge from Norwood (Stage 1) until Glenn (Stage 2)**
- 3-5% mortality at the Glenn
- 3-5% mortality at the Fontan
- **30-45% mortality risk overall in the first 4 years of life**





NATIONAL PEDIATRIC CARDIOLOGY

Quality Improvement Collaborative

- Joint Council on Congenital Heart Disease formed in 2003 related to need for Quality Improvement Work
- Focus on a clinical area that involves most areas of cardiology and is in need of significant improvement





NATIONAL PEDIATRIC CARDIOLOGY
Quality Improvement Collaborative

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

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





NATIONAL PEDIATRIC CARDIOLOGY *Quality Improvement Collaborative*



NPCQIC

68 sites

Over 1,000 patients enrolled

Advocate Children's Hospital	Cook Children's	Primary Children's Medical Center
Akron Children's Hospital	Doernbecher Children's Hospital	Rady Children's Hospital
Ann and Robert H. Lurie Children's Hospital of Chicago	Duke University Medical Center	Riley Hospital for Children
Arkansas Children's Hospital	Evelina London Children's Healthcare	Seattle Children's Hospital
Arnold Palmer Children's Hospital	Inova Children's Hospital	SSM Health Cardinal Glennon Children's Hospital
Blair E. Batson Children's Hospital, University of Mississippi Medical Center	Johns Hopkins All Children's Hospital	St Louis Children's Hospital
Boston Children's Hospital	Kravis Children's Hospital at Mount Sinai	Sutter Medical Center - Sacramento
Children's Healthcare of Atlanta	Le Bonheur Children's Hospital - Memphis	Texas Children's Hospital
Children's Hospital and Medical Center, Omaha	Levine Children's Hospital - Sanger Heart and Vascular Institute	The Children's Hospital of Montefiore
Children's Hospital Colorado	Lucile S. Packard Children's Hospital at Stanford	The Hospital for Sick Children
Children's Hospital Los Angeles	Mayo Clinic	UC Davis Children's Hospital
Children's Hospital of Philadelphia	Medical University of South Carolina	UCLA Mattel Children's Hospital
Children's Hospital of Pittsburgh of UPMC	Monroe Carrell Jr Children's Hospital at Vanderbilt	University Hospitals Case Medical Center - Rainbow Babies & Children's Hospital, Pediatric Heart Center
Children's Hospital of Wisconsin	Nationwide Children's Hospital	University of Florida, UFHealth
Children's Mercy Hospitals and Clinics - Kansas City	Nemours Cardiac Center, A.I. DuPont Hospital for Children	University of Iowa Stead Children's Hospital
Children's of Alabama	New York Presbyterian - Morgan Stanley Children's Hospital	University of Maryland Children's Hospital
Children's Hospitals and Clinics of Minnesota	Nicklaus Children's Hospital	University of Michigan C.S. Mott Children's Hospital
Children's Medical Center Dallas	Norton Children's Hospital	University of Minnesota Masonic Children's Hospital
Children's National Medical Center	NYU Medical Center	University of Rochester Medical Center
Cincinnati Children's Hospital Medical Center	Ochsner Hospital for Children	University of Texas Health Science Center, San Antonio (UTHSCSA) at University Hospital
Cleveland Clinic Children's Hospital	Penn State Hershey Children's Hospital	University of Wisconsin, American Family Children's
Cohen Children's Medical Center Northwell Health	Phoenix Children's Hospital	UVA Children's Hospital



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NPCQIC Early Data

- Schidlow, et al, 2011
- First 100 patients enrolled
 - “Wide variation in care practices, and it clearly discloses a general lack of identified best clinical practices for these infants.”
- Drove the Initial Key Drivers
 - Optimize Patient and Family Support
 - Provide Effective Care Transitions and Care Coordination (inpatient and outpatient)
 - Achieve Optimal Oral Feeding and Adequate Growth
 - Optimize Development
- Each child requires care that is tailored to their and their family’s needs and circumstances, and the NPC-QIC is not suggesting that care for infants with HLHS is a “one size fits all” proposition.



NPCQIC Improvements

- Anderson, et al, 2014
 - Infants with single ventricle heart disease often experience growth failure

NPC-QIC Nutrition Bundle
Interstage weight monitoring with home scales
Use of "Red Flags" for interstage weight monitoring
Regular contact with families at home regarding weight gain and feeding
Availability of a Dietician to manage interstage nutrition questions
Standardized evaluation of feeding ability post-Norwood prior to discharge to interstage

- Compared patients before and after bundle based on weight for age Z scores
- 407 patients from 15 sites
 - 158 before bundle
 - 249 after bundle
 - Improved weight for age z-score in all patients, most improvement in sites with poorest baseline

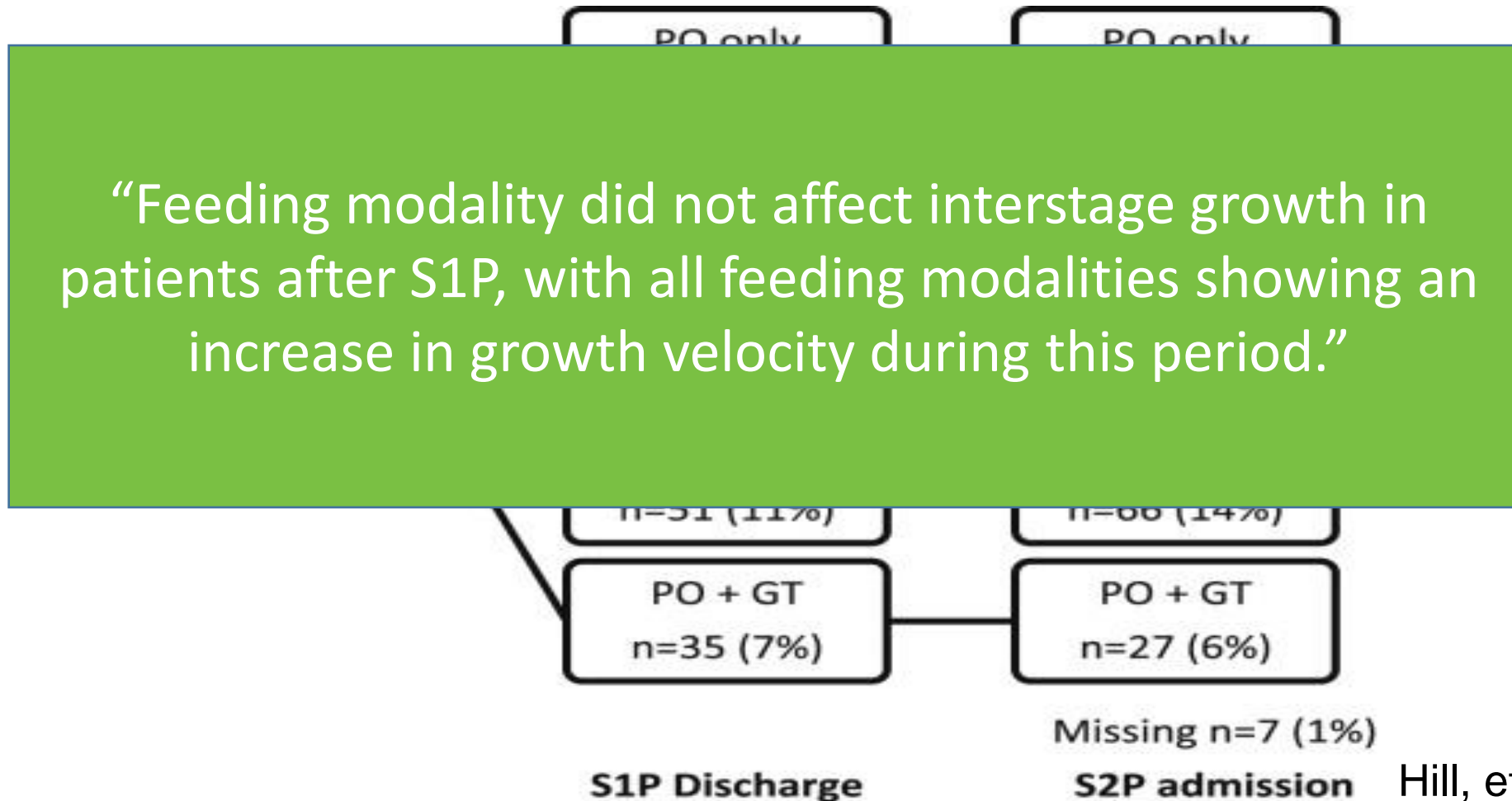


NPCQIC

- Anderson, et al, 2012 – Variation in growth of HLHS patients
 - “The **combination of standard post-operative feeding evaluation before Norwood discharge and close weight monitoring in the interstage period with the use of home scales and specific weight gain/loss red flags resulted in the greatest effect**, with an increase of change in [weight for age z-scores] WAZ of 0.98, compared to sites that did not use these monitoring interventions. **Several factors seemed to have little effect on interstage WAZ changes, including feeding modality** and the use of standard gastrointestinal medications such as H2 blockers, proton pump inhibitors or promotility agents.”
- Carlo, et al, 2017 - Practice trends over time in the care of infants with HLHS
 - Data including demographic, operative, discharge, and follow-up variables from the first 100 patients (6/2008–1/2010) representing 18 centers were compared with the most recent 100 patients (1/2014–11/2014) from these same centers
 - 89% went home with oral feeds in early era, and only 74% in later era
 - Use of NG was similar, 45% in early era, 47% in later era
 - Frequency of Gastrostomy tube was similar, 11% in early, 16% in later era



Effect of feeding modality on interstage growth after stage I palliation



Hill, et al, 2016



NPCQIC

- Slicker, et al, 2016
 - Voluntary survey, included data from 46 centers
 - Only 7% (3/46) reported using the NPCQIC published recommendations for feeding evaluation prior to oral feeding
 - 52% (24/46) followed a written feeding evaluation guideline
 - 33% utilized an “informal shared practice”
 - 15% had no evaluation process
 - Reasons for choosing one feeding modality over the other were similar amongst centers
 - Provider/parent preference
 - Complications associated with procedure
 - Projected length of time feeding tube would be needed

Slicker et al, 2016



Akron Children's Hospital

Tools for Change

RED FLAGS CALL OUR OFFICE IF YOUR CHILD

- Your child's oxygen saturations change
 - drop consistently below 70% or change of 5% up or down
 - increase suddenly >90%
- Your child is breathing harder, faster or fussy.
- Your child is unable to meet maintenance goal volume for 24 hours
- Your child is unable to attain goal to grow volume/24 hours
- Your child does not gain .02 Kg or 20 grams over a 3 days
- Your child loses .03kg or 30 grams or more over 3 days
- Your child is fussy and difficult to calm
- Your child has a fever > 101° F (taken under the arm)
- Your child is turning more blue than usual
- Your child has diarrhea or vomiting (More than 3 times in 24 hours)
- Your child has fewer wet diapers in 24 hours
- Your child has to go to the Emergency Room
- You have any questions or concerns.



INTERSTAGE CHANGE PACKAGE



72 hours prior to Rooming In	Responsible Group	Staff Initials
Obtain proposed discharge date. Write on white board in room.	Clinical Attending, NICU	
Communicate proposed discharge date to parents and staff.	Attending RN, CT	
Send prescriptions to patient's pharmacy.	Pharmacy Attending NP	
Order home care equipment supplies.	Cardiology Attending, NICU	
Communicate rooming in expectations with parents and decrease date and time of rooming in period.	Attending, CT/NP/Cardiology NP	
24 hours prior to Rooming In	Responsible Group	Staff Initials
Medication teaching, including providing family with administration schedule.	RN	
Formula preparation teaching.	RN	
Wound care supplies and teaching.	RN	
48 hours prior to Rooming In	Responsible Group	Staff Initials
Top medications from pharmacy.	Medication RN	
Order for administration of home meds in med room all post and tubes.	CT/NP	
Formula order.	Responsible Group	
Wash and scrub water for formula preparation.	Parents	
24 hours prior to Rooming In	Responsible Group	Staff Initials
Change or continue Vt per protocol.	CT/NP	
Bring by staff when they are ready to room.	Bedside RN	
Provide family with bag of home meds and demonstrate how to use.	Parents with observation of Bedside RN	
Diaper changed by bedside RN.	RN	
Rooming to observe specific:	Parents with observation of Bedside RN	
Rooming to observe all hour.	Parents with observation of Bedside RN	
Rooming to observe all day.	Parents with observation of Bedside RN	
Rooming to observe all night.	Parents with observation of Bedside RN	
Rooming to observe all weekend.	Parents with observation of Bedside RN	
Rooming to observe all holiday.	Parents with observation of Bedside RN	
Rooming to observe all vacation.	Parents with observation of Bedside RN	
Rooming to observe all emergency.	Parents with observation of Bedside RN	
Rooming to observe all other.	Parents with observation of Bedside RN	

Home Monitoring at Akron Children's Hospital

- Collaboration amongst Cardiologists, Nurse Practitioners, Nutrition and Speech and Primary Care Providers
 - Communication at discharge
 - Ongoing concerns and plans to address
 - Other services involved
 - Current medications
 - Immunization plan
 - Developmental concerns/planning
 - Social concerns



MyChart Tyler

Health Visits Messaging Billing Resources

Track My Health (Tyler)

You have been assigned the flowsheets below by one or more health professionals.

Active Flowsheets

Flowsheet

- Daily Feeding
Breast Feeding (minutes), Bottle Amount, NG/GT Amount, Total Amount this Feeding
- Daily Monitoring
Today's Weight (kg), Weight Change (kg), Pulse Ox, Heart Rate, Daily Total Intake

What's in My Record?

- Plan of Care
- Test Results
- Health Summary
- Current Health Issues
- Medications
- Allergies
- Preventive Care
- Medical History
- Immunizations

Medical Tools

- MyChart Central
- Document Center
- Who's Accessed My Record?
- Health Trends
- Growth Charts
- Questionnaires
- Track My Health 1/2019
- Share My Record

Add Daily Feeding Data (Tyler)

Step 1 of 2: Enter readings

Click **Add Another Reading** if you would like to enter data for more than one reading at this time.

When you are finished entering data, click **Continue**. Click **Cancel** if you do not want to save the data you entered.

Medical Questions Call (330) 543-8521 and state you are a "High Risk Home Monitoring Patient" and need to speak with a nurse. All Medical Emergencies Call 911

Reading 1

Date: **NOW**

Time: : **AM** **PM**

Breast Feeding (minutes):

Bottle Amount (ml or cc):

NG/GT Amount (ml or cc):

Total Amount this Feeding (ml or cc):

Time Spent this Feeding (minutes):

CONTINUE **ADD ANOTHER READING** **CANCEL**

Add Daily Monitoring Data (Tyler)

Step 1 of 2: Enter readings

Click **Add Another Reading** if you would like to enter data for more than one reading at this time.

When you are finished entering data, click **Continue**. Click **Cancel** if you do not want to save the data you entered.

Medical Questions Call (330) 543-8521 and state you are a "High Risk Home Monitoring Patient" and need to speak with a nurse. All Medical Emergencies Call 911

Reading 1

Date: **NOW**

Time: : **AM** **PM**

Today's Weight (kg):

Weight Change (kg):

Pulse Ox (%):

Heart Rate:

Daily Total Intake (ml or cc):

CONTINUE **ADD ANOTHER READING** **CANCEL**



Flowsheet Report

Select Flowsheets to View		
MYCHART PATIENT ENTERED HC DAILY MONITC		
MYCHART PATIENT ENTERED HC DAILY FEEDIN		

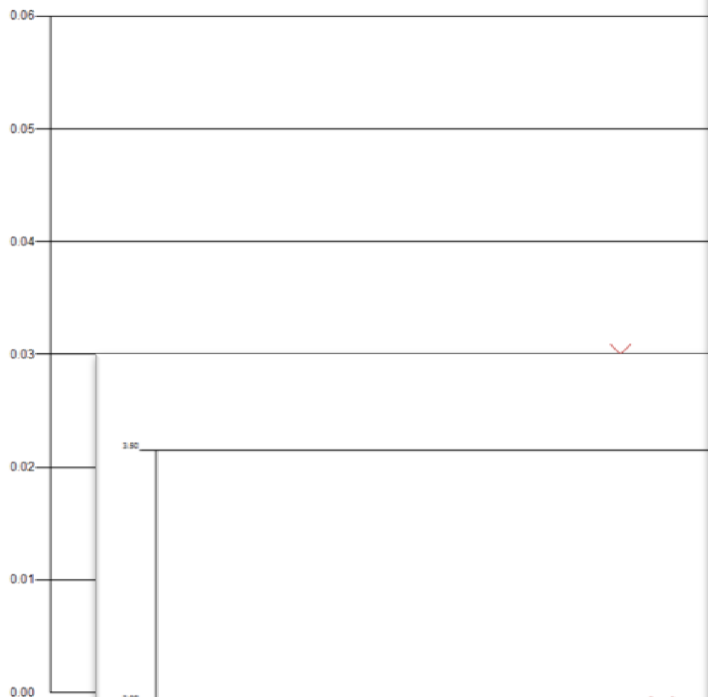
Load More

	Units	8/24/2019	8/24/2019	8/24/2019	8/24/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019
Time			10:14 AM	6:00 PM	9:00 PM								9:00 AM	9:44 PM					9:00 AM	1:01 PM	6:30 PM
Today's Weight (kg)			2.99										2.99						3.05		
Weight Change (kg)			0.02										0						0.06		
Pulse Ox	%		80	80	80									80					82	76	80
Heart Rate			146	140	146									148					152	160	157
Daily Total Intake	ml or cc																				
	Units	8/24/2019	8/24/2019	8/24/2019	8/24/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/25/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019	8/26/2019
Time		12:00 PM	3:00 PM	6:00 PM	9:00 PM	12:00 AM	3:00 AM	6:00 AM	9:00 AM	12:00 PM	3:00 PM	6:00 PM	9:00 PM	12:00 AM	3:00 AM	6:00 AM	9:00 AM	12:00 PM	3:00 PM	6:00 PM	9:33 PM
Bottle Amount	ml or cc	5	5		6				6	8	10	10	2						5	6	10
NG/GT Amount	ml or cc	50	45	50	44	50	50	50	44	42	40	45	48	50	50	50	55	45	42	50	40
Total Amount this Feeding	ml or cc	55	50	50	50	50	50	50	50	50	50	55	50	50	50	50	55	50	50	50	50
Time Spent this Feeding (minutes)		15	15		10				15	15	20	15	5						15	10	15

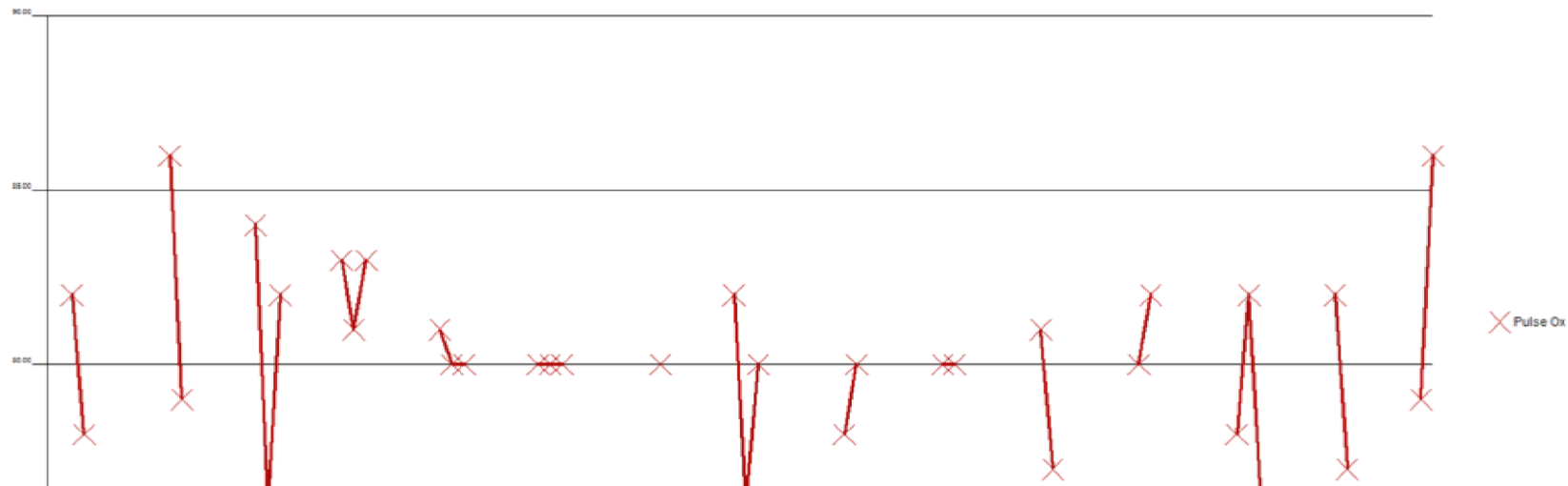
Weekly in-basket message, or sooner if outside of set parameters



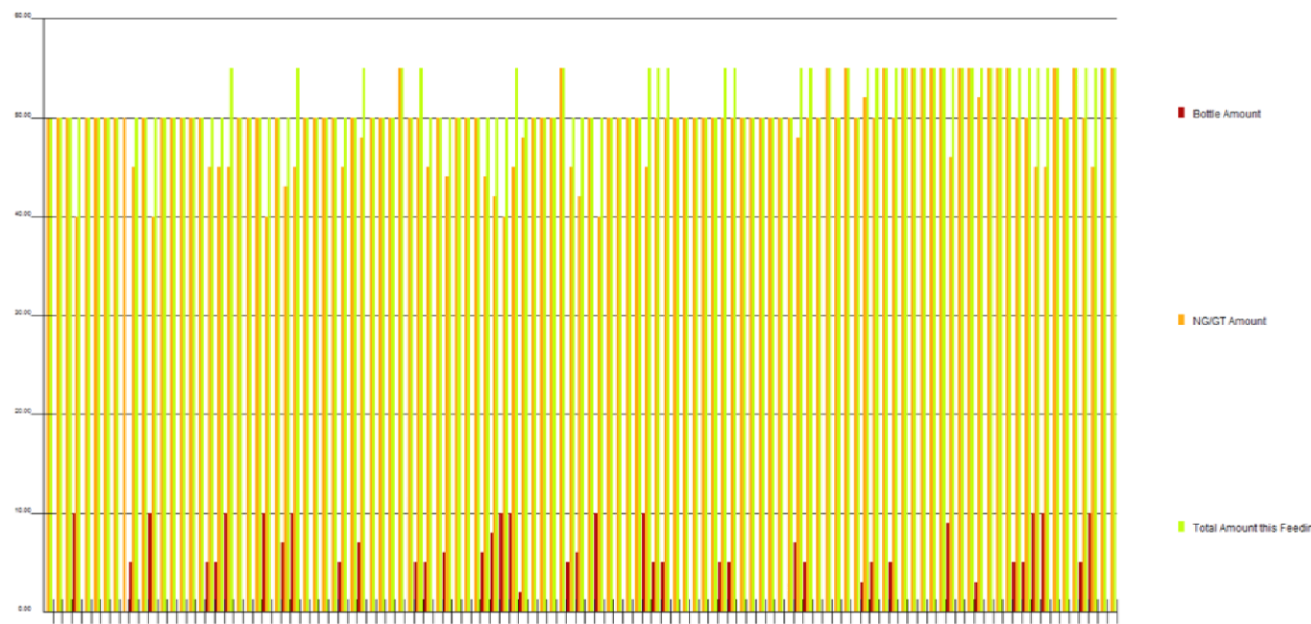
Flowsheet Data



Flowsheet Data



Flowsheet Data



The graph shows the data in chronological order (8/19/2019 - 9/3/2019)

The graph shows the data in chronological order (8/19/2019 - 9/3/2019)



Our Goals



Our Achievements



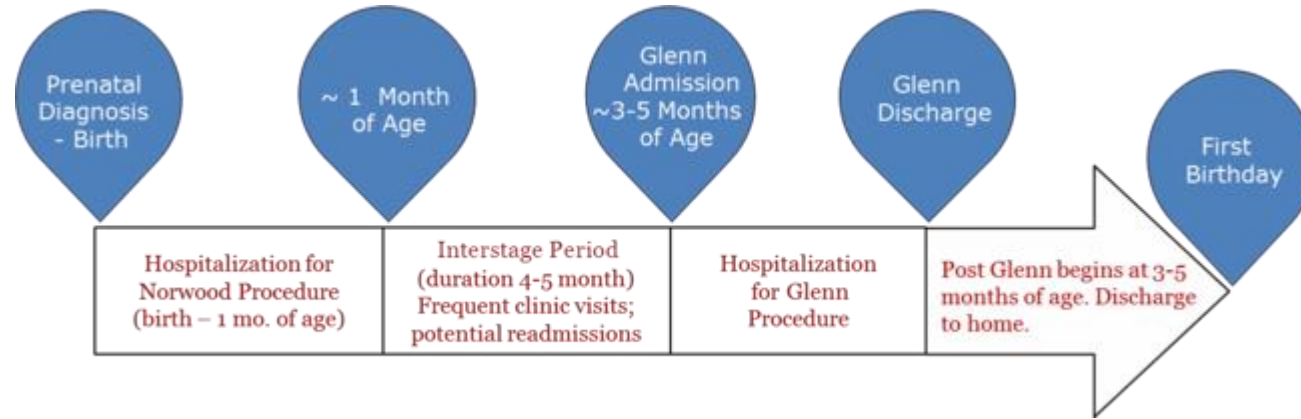
Our Team



Data represented from August 2016 through December 2018.
For more information visit npcqic.org or email info@npcqic.org



The Future of Collaboration



- Phase II Launched in August 2016 with an aim **to improve outcomes between diagnosis and first birthday**
 - Continued focus on nutrition and feeding
 - Neurodevelopmental outcomes
 - Routine Neurodevelopmental screening and early intervention with Neuropsychology and Developmental Pediatrics
 - Fetal
 - Family
 - Transparency
 - Surgical/ICU
- Phase III – New Fontan Project





References

- Anderson, J. B., Beekman, R. H., Kugler, J. D., Rosenthal, G. L., Jenkins, K. J., Klitzner, T. S., Martin, G. R., Neish, S. R., Darbie, L., King, E., Lannon, C. and , (2014), Improved Interstage Weight Gain. *Congenit Heart Dis*, 9: 512-520. doi:[10.1111/chd.12232](https://doi.org/10.1111/chd.12232)
- Anderson JB, Iyer SB, Schidlow SN, Williams R, Varadarajan K, Horsley M, Slicker J, Pratt J, King E, Lannon C; National Pediatric Cardiology Quality Improvement Collaborative. *Journal of Pediatrics* ,2012 Jul;161(1):16-21. doi:10.1016/j.peds.2012.01.009.
- Carlo WF, Cnota JF, Dabal RJ, Anderson JB. Practice trends over time in the care of infants with hypoplastic left heart syndrome: A report from the National Pediatric Cardiology Quality Improvement Collaborative. *Congenital Heart Disease*. 2017;12:315–321. <https://doi.org/10.1111/chd.12442>
- El-Sayed Ahmed MM, Alfares FA, Hynes CF, Ramakrishnan K, Louis C, Dou C, et al. Timing of Gastrostomy Tube Feeding in Three-stage Palliation of Single-ventricle Physiology: G-tube Timing for Single-Ventricle Palliation. *Congenital Heart Disease* 2016;11:34–8. doi:10.1111/chd.12272.
- Cross RR, Harahsheh AS, McCarter R, Martin GR, for the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC). Identified mortality risk factors associated with presentation, initial hospitalisation, and interstage period for the Norwood operation in a multi-centre registry: a report from the National Pediatric Cardiology-Quality Improvement
- Hill GD, Hehir DA, Bartz PJ, Rudd NA, Frommelt MA, Slicker J, et al. Effect of feeding modality on interstage growth after stage I palliation: A report from the National Pediatric Cardiology Quality Improvement Collaborative. *The Journal of Thoracic and Cardiovascular Surgery* 2014;148:1534–9. doi:10.1016/j.jtcvs.2014.02.025.
- Slicker J, Sables-Baus S, Lambert LM, Peterson LE, Woodard FK, Ocampo EC, et al. Perioperative Feeding Approaches in Single Ventricle Infants: A Survey of 46 Centers: Perioperative Feeding in Single Ventricle Infants. *Congenital Heart Disease* 2016;11:707–15. doi:10.1111/chd.12390.
- Schidlow, D. N., Anderson, J. B., Klitzner, T. S., Beekman III, R. H., Jenkins, K. J., Kugler, J. D., Martin, G. R., Neish, S. R., Rosenthal, G. L., Lannon, C. and , (2011), Variation in Interstage Outpatient Care after the Norwood Procedure: A Report from the Joint Council on Congenital Heart Disease National Quality Improvement Collaborative. *Congenital Heart Disease*, 6: 98-107. doi:[10.1111/j.1747-0803.2011.00509](https://doi.org/10.1111/j.1747-0803.2011.00509)

