

# Tube Weaning Toolkit

*Thank you to the many families who contributed photos and quotes.*

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**National Pediatric Cardiology**  
*Quality Improvement Collaborative*

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*NPC-QIC actively works to support children with complex congenital heart diseases, so they may have the opportunity to enjoy eating their first birthday cake.*

*“I want you to know how truly grateful I am that you have invested your time in my son and have given him this opportunity. As a mom, you just want what's best for your child and to give them every chance to succeed. I know he is challenging, but I do believe he will eat on his own! Thank you for believing in him and not giving up! Thank you for being interested in his future and wanting him to be successful! Thank you for being on this journey with us! I am forever thankful for each of you for all you have done for our family.”*

**Parent** CINCINNATI CHILDREN'S

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*“Being a test center for the tube weaning project has fueled a passion that already existed in our center but has propelled that passion into an actionable process that we have been able to lay out and structure. Seeing the successes of other centers has helped us to pool the resources that we have so we can also do right by these patients and get them enjoying meals with their families.”*

**Nicole Coolidge, Nurse Practitioner** CHILDREN'S HEALTHCARE OF ATLANTA

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*“Our tube wean went above and beyond our expectations. Having the structured program gave us the confidence to take the right steps, and knowing we had our team's support made it all that much more successful. Josh went from being almost completely tube fed to loving every bite of food and often (almost always!) out-eating his twin brother. Weaning from a feeding tube has given us a sense of freedom and “normalcy” that we are so grateful for.”*



**Parent** LURIE'S CHILDREN'S HOSPITAL OF CHICAGO

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## SECTION 1

# Introduction and Background

Supplemental nutrition delivered via feeding tube is often unavoidable in the journey of a patient with single ventricle physiology, which can be provided both as the sole source of nutrition or as a supplement to oral feedings. At the time of development of this project in 2020, aggregate reporting patient data available from the NPC-QIC database indicated that only 53% of patients were exclusively orally fed by their first birthday. There has subsequently been no center line shift to date which suggests no meaningful change in this percentage over time, despite many centers taking an interest in this topic and work being done to wean patients from their tubes.

Many patients with enteral feeding tubes could be considered for weaning prior to age one, but due to the lack of formal process for tube weaning and removal, it is often delayed, sometimes until the child weans him or herself. In the 2021 Winter Semi Annual Survey, only 40% of centers reported using a standardized process for tube weaning post Stage 2 surgery. Of those surveyed centers, 84% stated that if a formal process was available thru the NPC-QIC, they would utilize it.



*Tube dependency does not discriminate by type of feeding tube. Whether fed from a surgical or naso-gastric tube, they become part of the feeding journey for a large majority of our single ventricle patients.*



*Safely administering oral medications is a key part of tube weaning.*

## What is a toolkit?

A toolkit is a concise and practical document that provides ideas and expert guidance. Toolkits focus on a specific condition, care processes that provide background material, summary of evidence and best practices, as well as specific tools, strategies, and examples that can be applied to improvement work. In this instance, on the tube weaning process. Using this toolkit will enhance the effectiveness of QI efforts.

## How was this toolkit developed?

This toolkit was inspired by and grounded in tube weaning research completed using the NPC-QIC database and quality markers. Specifically, aggregate data surrounding the measure of “all oral feeding by first birthday”, along with tools, methods, and approaches developed or tested by NPC-QIC pilot programs and test centers.

The structure of this tube weaning process was developed from an in-depth look at the literature as well as a review of processes and successes from three pilot programs. When developing resources, a sub-group from the Path 2 project on tube weaning extensively reviewed the literature available on tube weaning processes in patients with congenital heart defects, (Slater, N. et al., Weaning from a feeding tube in children with congenital heart disease: A review of the literature. *Progress in Pediatric Cardiology*, 2021). Several key elements for successful weaning were identified:

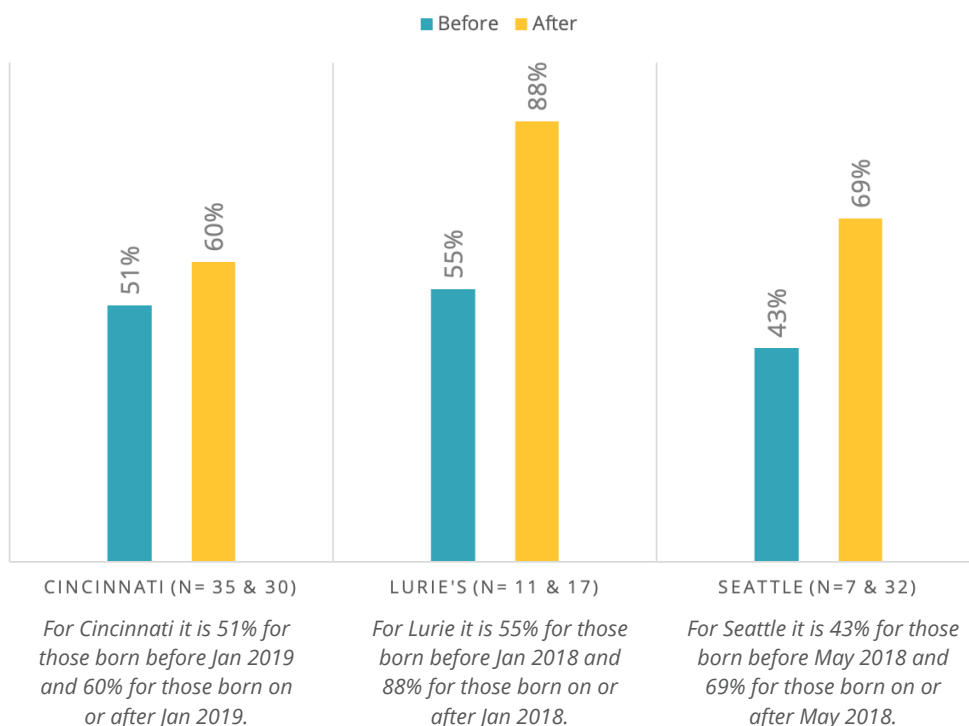
- utilization of a multidisciplinary team
- hunger induction or provocation
- positive mealtime experiences
- behavioral interventions
- early tube weaning goals
- caregiver education and involvement
- follow up interventions



Parent partners ensure improved patient outcomes.

Our pilot centers, including **Cincinnati Children’s Hospital Medical Center**, **Lurie’s Children’s Hospital of Chicago**, and **Seattle Children’s Hospital**, utilized knowledge gained from this literature to establish successful weaning programs that serve as the framework for our education modules.

### ALL ORAL FEEDING AT 1ST BIRTHDAY



*“We are delighted to be involved in the tube weaning project. Families cite the presence of a feeding tube as one of the most stressful experiences in the journey with congenital heart disease, and while cardiologists feel “responsible” for the child needing the tube, we have been ill-equipped to transition off the feeding tube.*

*The tube weaning project has provided structure to an otherwise chaotic clinical management problem. The collaboration with nutrition, speech therapy and the single ventricle team paired with the passionate involvement of families benefits these babies tremendously.*

*We are fortunate that providers have not objected to the approach taken in this project, and in fact are relieved to have help and guidance. And, as is often the case with involvement in the collaborative, other patients in our Heart Center will benefit from this once we have dedicated resources to apply the successful techniques we have learned.”*

**Dr. Martha Clabby** CHILDREN’S HEALTHCARE OF ATLANTA

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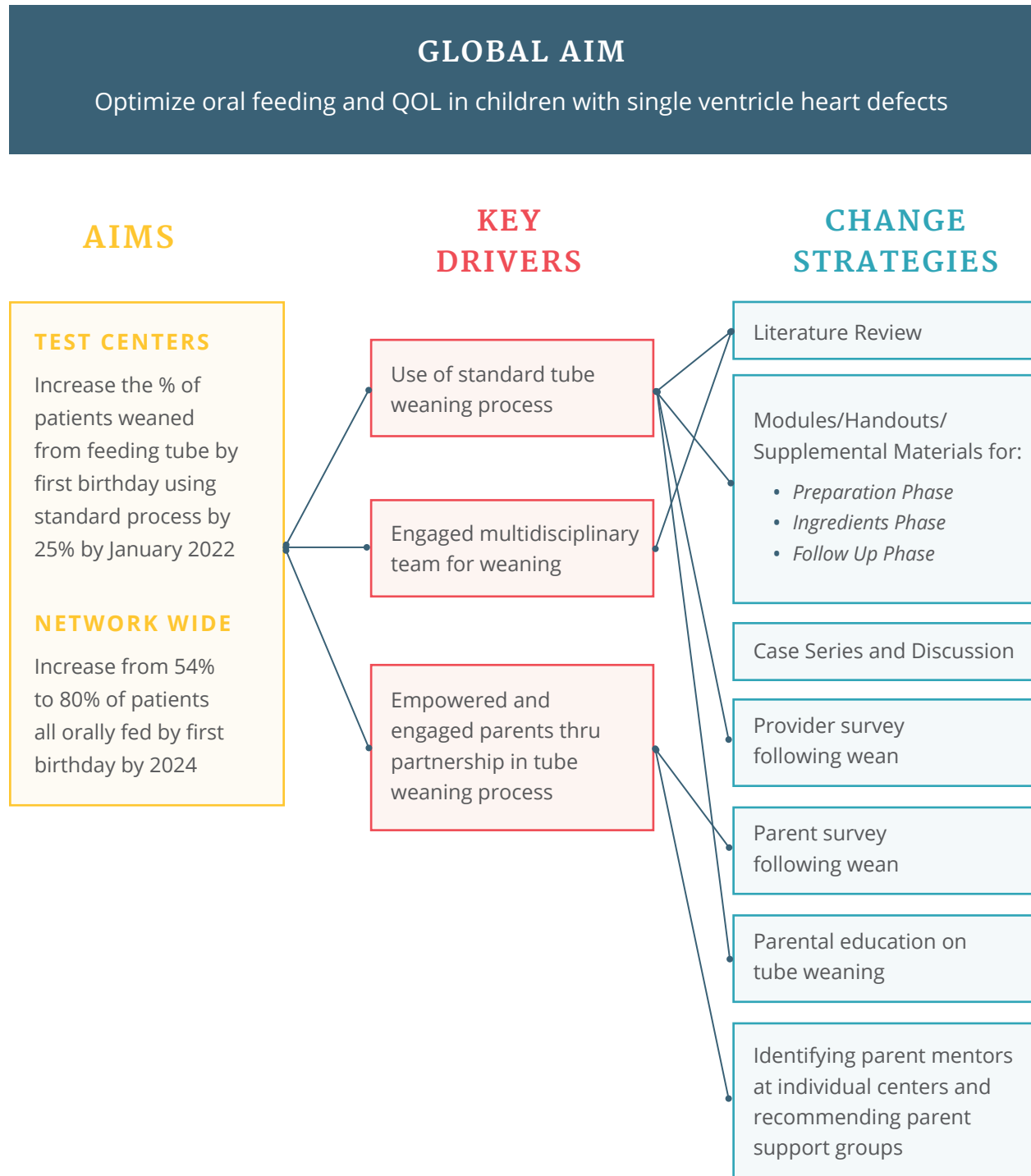
*“We always felt the NG tube was one of the hardest daily battles. The NG tube was a major hindrance of having a “normal” day to day life. Tube weaning gave us the ability to take our child into the world with more ease, it allows our family to feel a sense of normalcy despite every other battle we were facing.”*

**Lauren, Parent** LURIE CHILDREN’S HOSPITAL OF CHICAGO



SECTION 2

# Tube Weaning Key Driver Diagram



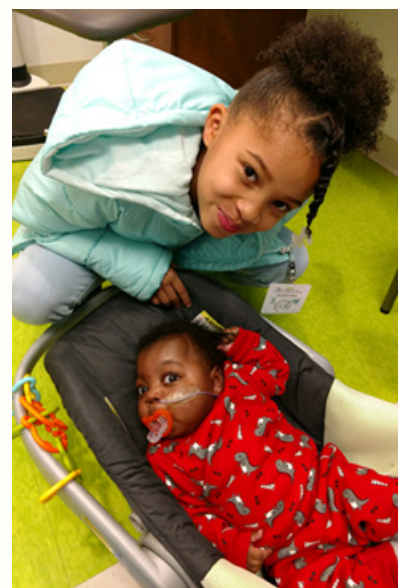
*“Miracles do happen! After seven months of being full NG tube dependent our heart warrior was tube weaned in less than two weeks! I would have thought you were crazy if you told me that the constant vomiting before, during, and after every feed would finally subside. Our boy would know what hunger felt like and would take food and a bottle! That tube wean changed our life. We were no longer living in fear of what the next feeding would bring. It gave us a sense of normalcy and that is all we ever want for our child.”*

**Lindsey, Parent** LURIE CHILDREN'S HOSPITAL OF CHICAGO

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*“Having a feeding tube was both a blessing and a curse. We knew she was getting fed but the vomiting and pulling the tube out and putting it back in was the worst. When we got the green light to start her tube wean I was ecstatic. It took about 3.5 weeks and boom she was done with the tube right before her first birthday and she had been on it since birth. It had challenging days but she is now three almost four thriving, feeding herself and loves food.”*

**Sabrina, Parent** LURIE CHILDREN'S HOSPITAL OF CHICAGO





## SECTION 3

# Change Strategies & Examples of Changes to Test

We have established that weaning can be broken down into three phases, each of which is equally important for successful tube weaning.

1. The **Preparation Phase** starts at the time of tube placement (i.e., when tube feeding begins) through the beginning of a patient's wean. Specific education has been created surrounding:
  - a. *How to prepare families and clinicians for the weaning process*
  - b. *How to evaluate not just a child's growth but their strength to tolerate coming off their feeding tube*
  - c. *Evaluating and optimizing a child's feeding readiness and safety*
  - d. *How and when to manipulate feeding regimens and trouble-shoot feeding intolerance*
  - e. *Additional resources are provided, including a communication checklist for determining if a patient has appropriate cardiac stability and other appropriate criteria for weaning as well as general FAQ for providers*

[See modules and tools in the preparation phase here.](#)

2. The **Ingredients Phase** details the weaning process and how to encourage hunger in combination with developing appropriate oral feeding skills and positive feeding experiences. In this section you will find:
  - a. *How to structure a tube weaning program and the appropriate team members to include and use of parent advocates*
  - b. *Global overview of tube weaning methods including case samples*
  - c. *Anticipatory guidelines including tips and tricks on how to trouble shoot challenges that may arise during the weaning process*
  - d. *Behavioral Interventions that highlight feeding refusal and picky eating behaviors in toddler aged patients and when to bring in additional support*



*Promoting positive experiences with food and encouraging play is beneficial throughout the entire tube feeding journey.*

e. A detailed worksheet for tracking a patient's feeding schedule, phases of the wean, anthropometric information, and potential red flags to encourage organization and communication.

[See modules and tools in the ingredients phase here.](#)

3. Lastly, the **Follow up Phase** includes considerations once the tube wean is complete, including suggested transition communication guidance for parents.

[See modules and tools in the follow up phase here.](#)

For more information, visit: <https://www.npcqic.org/tube-weaning-toolkit>



*First birthday smash cake is delicious!*

## Case Series and Discussion

Adopting a formal tube weaning process can be overwhelming and fear-provoking. Included are recorded presentations of how other centers structured their programs and actively weaned patients. Our Case Series with pilot and test centers (3 participating pilot centers and 5 test centers,) are available on the NPC-QIC share point site located [here](#).



*Self care is an important relationship to soothing and comforting around food.*

## Parental Engagement

Interstage graduation is a huge milestone for families that is often very stressful focusing on daily feeding and growth, survival, and coping with acute and chronic CHD care. Transitioning from a feeding tube requires shifting the focus from the weight on the scale and hypervigilant focus on calorie intake to quality of the feeding behaviors and addressing consequences like constipation. Success includes engaging, coaching, and mentoring families to tube freedom. Centers should be prepared to help coach families regarding appropriate weight change expectations, “normal” baby/child feeding, and managing challenges such as constipation. Connecting families with other families has proven to be very helpful.

[See 'Common Tube Weaning Fears' resource\).](#)





## Change Strategies and Examples of Changes to Test

- Implementing a standard tube weaning process can lead to necessary and ongoing process changes. Utilizing Plan Do Study Act (PDSA) cycles while starting your program and in the early stages of starting to wean patients can be a useful tool to continue to improve your process.

- Regular surveying of both clinicians and families can be useful to improve on your centers experience with tube weaning
  - [Post Tube Weaning Survey for Clinicians](#)
  - [Post Tube Weaning Survey for Patients](#)
- More extensive information can be collected at your local center to track and reflect patient outcomes, an example of this is available [here](#).



PSDA Ramp Planning Tool – Tube Weaning Example

 <p><b>TEST 1</b>          What: Standardized Tube Weaning communication          Who (population): Post Stage 2 Patient          Where: in Person/Virtual          When: 7/1 - 7/23          Who executes: RD/SLP</p> <p>Results: patient 1, successful wean but in need of more formal education and follow up procedures</p> <p>Circle one:          Abandon <b>Adapt</b> Adopt</p>	 <p><b>TEST 2</b>          What: Standardized Tube Weaning expectation communication          Who (population): Post Stage 2 Pt          Where: In Person /Virtual          When: 7/20- 8/1          Who executes: RD/SLP</p> <p>Results: Need for contract vs. more clear expectations for communication with caregiver</p> <p>Circle one:          Abandon <b>Adapt</b> Adopt</p>	 <p><b>TEST 3</b>          What: Tube Weaning introduction standardization          Who (population): Post Stage 2 Pt          Where: in house post stage 2          When: From 8/1-30          Who executes: RD</p> <p>Results: Prior to d/c, given supplement to IMP binder detailing weaning process, parental expectation, who to contact</p> <p>Circle one:          Abandon Adapt <b>Adopt</b></p>	 <p><b>TEST 4</b>          What: Tube Weaning Communication to families          Who (population): Post Stage 2 Pt          Where: in house post stage 2          When: current          Who executes: RD</p> <p>Results: d/c checklist to include those with feeding tube get detail education of parental expectation, weaning process, when it starts, ect.</p> <p>Circle one:          Abandon Adapt <b>Adopt</b></p>
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## SECTION 4

# Acknowledgments

## NPC-QIC Executive Leadership Team

- *Katie Bates, MD*
- *David Brown, MD*
- *Carole Lannon, MD*
- *Stacey Lihn, Parent*

## Tube Weaning Project Members

### Co Leads

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- *Heather Northam, SLP*
- *Nancy Slater, OT*
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- *Michelle Steltzer, NP*

### Pilot Sites

- *Cincinnati Children's Hospital Medical Center*
- *Lurie's Children's Hospital of Chicago*
- *Seattle Children's Hospital*

### Test Sites

- *Arkansas Children's Hospital*
- *Children's Healthcare of Atlanta*
- *Nemours Children's Health of Delaware*
- *Medical University of South Carolina Shawn Jenkins Children's Hospital*
- *Minnesota Children's Hospital*
- *Rady Children's Hospital of San Diego*

## NPC-QIC Network Staff

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**MORE INFORMATION**

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