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Tracheostomy-Related Care in the NICU Clinical Pathway

Johns Hopkins All Children's Hospital
Maternal, Fetal, and Neonatal Institute

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Rationale:

Pediatric tracheostomy is known to have a high rate of morbidity and mortality as it is commonly performed in medically fragile children with complex conditions (Amin, 2025; Brenner, 2020; Muller, 2019; Overman, 2013; Perez-Ruiz, 2012). Since 2017, the interprofessional approach of the multidisciplinary Tracheostomy Team at Johns Hopkins All Children's Hospital (JHACH) NICU has improved survival among tracheostomy patients (Machry, 2024). This clinical pathway addresses the care of patients being considered for long-term ventilation and/or tracheostomy. The areas covered are:

- Multidisciplinary team approach for tracheostomy decision making and management
- Pre-operative preparation
    - Assessment of indications and timing for tracheostomy
    - Family engagement
    - Patient qualifications for multiple procedures under the same anesthesia
    - Clinical stability for tracheostomy
    - Tracheostomy tube size
- Tracheostomy care since its initial placement
- Post-operative pain and sedation
- Discharge planning/transition to home care
- Parent/caregiver education
- Patient handoff to Pediatric Intensive Care Unit (PICU) providers
- Outside Hospital transfer acceptance to JHACH NICU for patients with or undergoing evaluation for tracheostomy

Background / Published Data and Levels of Evidence:

I. Tracheostomy outcomes:

a. Despite advances in care and improved survival of extremely premature infants, current published data reveal that a small subset will develop severe bronchopulmonary dysplasia (BPD) and remain ventilator dependent beyond corrected term age, possibly being discharged home with a tracheostomy (0.7%) (Bell, 2022).

b. Since 2015 in the JHACH NICU, over half of the patients (51.5% [34/66]) undergoing tracheostomy placement were extremely premature infants with BPD (Machry, 2024).

i. All BPD patients who survived to hospital discharge required long-term mechanical ventilation, placement of a gastrotomy tube (GT), and gastric fundoplication, and were discharged on medication for pulmonary hypertension (PHTN), and 56.3% (9/16) were diagnosed and treated for pneumonia/tracheitis after tracheostomy placement.

ii. To a lesser degree, non-BPD tracheostomy patients experienced similar complexity and required long-term mechanical ventilation (26%), GT placement (91%), gastric fundoplication (43%), and medication for PHTN upon discharge (13%).

c. After completing three Plan-Do-Study-Act (PDSA) cycles of a multidisciplinary quality improvement (QI) initiative launched in 2017, the observed in-hospital survival rate among patients with tracheostomy improved from a baseline of 66.7% to 100%, with sustained 100% survival over the last 3 years of the project (Machry, 2024).

II. Indications and timing for tracheostomy/long-term ventilation (LTV):

a. The decision to place a tracheostomy tube and/or commit an infant to chronic ventilator support can be difficult. It must involve extensive discussions among care providers and family members. There is a need for a standardized decision-support process that is consistent with a child's best interests and family-shared decision-making. Strategies for optimizing communication and mechanisms for managing disputes are needed (Amin, 2025; Mack, 2024). Providers should present families with comprehensive, balanced information on the impact of long-term ventilation, and when the child has a profoundly serious and life-limiting condition, explore the option not to initiate long-term ventilation (Amin, 2025; Edwards, 2020). The literature suggests that information about tracheostomy is better received when introduced early and in phases (Bushroe, 2024). Tracheostomy is commonly seen by the providers as a poor outcome (Murthy, 2014).

Moreover, acceptance of the need for chronic ventilation is frequently rejected by providers and families. Currently, there are no consensus recommendations in the literature or among neonatologists for the optimal timing of tracheostomy placement in infants with severe BPD (Akangire, 2021; Murthy, 2017; Yallapragada, 2021). Most single-center studies have reported tracheostomy placement at a median postmenstrual age (PMA) of 45-51 weeks (Cristea, 2013; Gien, 2017; Mandy, 2013; Upadhyay, 2020). Neonates with severe BPD may benefit from early tracheostomy for improved growth, decreased sedative exposure, and increased participation in developmentally appropriate activities (Akangire, 2021; Luo, 2018; Taha, 2024; Upadhyay, 2020).

b. For patients with BPD, the overall goal of chronic mechanical ventilator support is to reduce the severity of respiratory distress, including retractions, head-

bobbing, dyspnea, and “spells,” providing clinical stability that will enhance survival and optimize long-term developmental, neurocognitive, and growth-related outcomes (Yallapragada, 2021). A more advanced PMA at referral for tracheostomy placement has been associated with a worse respiratory and neurodevelopment outcome at 2 years of age in patients with tracheostomy secondary to BPD (Upadhyay, 2020). Considering the procedure earlier for selected patients without respiratory improvement, as suggested by Mandy and colleagues (2013), represents an opportunity to improve survival and clinical outcomes by enabling earlier hospital discharge. At our center, the median age for tracheostomy placement for patients with BPD ranged from 50 to 55 weeks PMA over the last several years (Machry, 2024). Nonetheless, the optimal timing of tracheostomy for infants with moderate and severe BPD remains to be determined (Upadhyay, 2020).

c. Beyond tracheostomy placement, the emphasis should be directed toward the role of sustained mechanical ventilation to promote growth and development, as supported by an interdisciplinary care team with a shared decision-making involving the family, and not simply the placement of a tracheostomy (Edwards, 2020).

d. A multicenter study is currently being conducted at our institution, “HomeVENT: Home Values and Experiences Navigation Track” (IRB00395948; Principal Investigator Renee Boss Funded by NIH - R01 HD110414-01A1). Providers are welcome to refer patients for enrollment.

III. Patient qualifications for multiple procedures under the same anesthesia:

a. There is strong evidence from preclinical studies that most general anesthetics modulate brain development. The evaluation of anesthesia exposure in developing humans under 3 years of age suggests an association with changes in neurodevelopment outcomes, and the association may be stronger after multiple or prolonged exposures. In 2016, the Federal Drug Administration (FDA) issued a “Drug Safety Communication (www.fda.gov/Drugs/DrugSafety/ucm532356.htm) warning that anesthesia for more than 3 hours or repeated use of anesthetics may affect the development of children’s brains (Andropoulous, 2017).

b. In a matched cohort study of patients exposed to single, multiple, or no anesthesia before 3 years of age, there were no differences in intelligence; however, multiple exposures were found to be associated with modest decreases in processing speed and fine motor coordination. Parents also reported that multiply exposed children have more difficulties with behavior and reading (Warner, 2018).

c. In a multi-center, randomized, controlled trial of children under 60 weeks' PMA who were born at more than 26 weeks' gestation, it was demonstrated that less than one hour of general anesthesia in early infancy does not alter

neurodevelopmental outcome at the age of 2 and 5 years compared with awake-regional anesthesia (Davidson, 2016; McCann, 2019).

d. A study comparing previously healthy sibling pairs (anesthesia-exposed and not) undergoing inguinal hernia repair before 36 months of age showed there were no statistically significant differences in intelligence quotient (IQ) scores in later childhood (8-12 years) (Sun, 2016).

e. These results are difficult to extrapolate to the long-term adverse neurodevelopment effects after prolonged or repeated anesthesia administration in a population of sick premature infants who often have already been brain injured by inflammation or chronic hypoxia prior to the anesthesia exposure (Andropoulos, 2017).

f. On average, a routine tracheostomy procedure takes 30 minutes, a routine GT takes 60 minutes, Nissen fundoplication takes 60-120 minutes, hernia repair takes 20 minutes, and line placement and muscle biopsy take about 20 minutes each. Tracheostomy is usually the last procedure performed because airway stability is required during prior surgical interventions.

g. There are no guidelines on criteria to perform all procedures at one anesthesia event; however, preferably, anesthesia time should be kept under 3 hours. Certain patients will not tolerate multiple procedures due to cardiorespiratory instability.

IV. Clinical stability for the tracheostomy procedure:

a. A highly unstable PHTN cardiopulmonary disease can be a relative contraindication. There are no universally agreed contraindications for maximum fraction of inspired oxygen (FiO_2) levels or peak airway pressure (PAP) levels (Walsh, 2018). A survey of 150 practicing pediatric otolaryngologists found that FiO_2 and PAP were not influential in the decision to perform a tracheostomy (Schroeder, 2012). If the neonate is unable to safely be transported to the operating room, be manipulated and positioned for surgery, tolerate exchange of the endotracheal tube to a tracheostomy tube, or if short-term survival is in question, then surgery should be deferred (Schroeder, 2012).

b. There is no absolute weight requirement for a tracheostomy procedure. However, a limiting factor is the size of the neonatal airway in relation to the smallest available tracheostomy tube outer diameter (OD). A weight of 2 kilograms (kg) is a typical cutoff for tracheostomy placement; however, safe tracheostomy has been performed in ultralow-birthweight infants weighing less than 2 kg. The internal diameter (ID) of a full-term newborn is approximately 3.5 to 4 millimeters (mm). Ultralow-birthweight premature infants may have an ID of 2 mm. The smallest OD tracheostomy tubes are the NEO Bivona 2.5 TTS (Dublin, OH), with an OD of 4.0 mm, and the NEO Shiley Cuffless 2.5 (Medtronic, Minneapolis, MN), with an OD of 4.2 mm. Tracheal length may also

be a factor in accommodating standard-length tracheostomy tubes. Custom tracheostomy tubes can be made to accommodate nonstandard anatomy requirements (Schroeder, 2012).

c. It is suggested that patients undergoing tracheostomy have secured intravenous (IV) access in the form of a central venous catheter for management of postoperative sedation and pain, as well as possible emergencies (Schroeder, 2012).

V. Tracheostomy tube sizes:

a. It is ultimately the decision of the surgeon performing the tracheostomy to determine the adequate size for each patient at the time of placement. Multidisciplinary teams are encouraged to assess and discuss what the ideal size is based on clinical status, chest X-ray findings, blood gases, and oxygenation.

Table 1: Neonatal Tracheostomy Tube Choices - Size and Length:

Tracheostomy tube		ID (mm)	OD (mm)	Distal Length (mm)	Cuff Option	Material
Bivona (Neo)	2.5	2.5	4	30	Y	Silicone
	3	3	4.7	32	Y	Silicone
	3.5	3.5	5.3	34	Y	Silicone
	4	4	6	36	Y	Silicone
Bivona (PED)	2.5	2.5	4	38	Y	Silicone
	3	3	4.7	39	Y	Silicone
	3.5	3.5	5.3	40	Y	Silicone
	4	4	6	41	Y	Silicone
Shiley (Neo)	2.5	2.5	4.2	30	Y	PVC
	3	3	4.8	30	Y	PVC
	3.5	3.5	5.4	32	Y	PVC
	4	4	6	34	Y	PVC
	4.5	4.5	6.7	36	Y	PVC
Shiley (Ped)	2.5	2.5	4.2	39	Y	PVC
	3	3	4.8	39	Y	PVC
	3.5	3.5	5.4	40	Y	PVC
	4	4	6	41	Y	PVC
	4.5	4.5	6.5	42	Y	PVC

Abbreviations: Neo: neonate; PED: pediatric; PVC: polyvinyl chloride (synthetic polymer of plastic); Y: yes

VI. Tracheostomy care:

a. Consensus recommendations, including pre-operative, intra-operative, and post-operative considerations, as well as sedation and nutrition management, were published by the International Pediatric Otolaryngology Group (IPOG). The recommendations were based on the collective opinion of the IPOG members and are intended for otolaryngologists who perform tracheostomies in pediatric patients and intensivists involved in their care (Strychowsky, 2016).

VII. Post-operative pain and sedation:

a. The American Academy of Pediatrics (AAP) recommends the implementation of center-specific guidelines and the use of both non-pharmacological and pharmacological measures in treating pain associated with surgery and major procedures in neonates (AAP, 2006). Evidence-based guidelines are shown to significantly reduce the exposure of neonates to opioids and iatrogenic narcotic dependence (Rana, 2017).

b. For patients with newly placed tracheostomy tubes, the goal is to limit post-procedure pain, agitation, or excessive movement that jeopardizes adequate wound healing or leads to accidental decannulation, a potentially devastating complication occurring in 8-15% of patients and 0-3.5% mortality (de Trey, Perez-Ruiz, 2013).

c. With the “Bjork” technique (Kinley, 1965), there is minimal risk of immediate postoperative false tract in case of tracheostomy dislodgement, and the tube can be changed as often as necessary by nursing staff as soon as the operation is completed. Therefore, neck movement in the immediate postoperative period is not a risk factor, and neuromuscular blockade is not necessary.

d. The literature suggests that the use of neuromuscular blockade in neonates increases morbidity and mortality. Potential complications include delayed feeding, prolonged indwelling urinary catheter use, and worsening respiratory function. Sustained use of neuromuscular blockade is associated with prolonged mechanical ventilation, longer pediatric intensive care unit stay, and higher incidence of ventilator-associated pneumonia when compared with controls (Da Silva, 2010). In a retrospective review of outcomes following neuromuscular blockade in pediatric patients receiving tracheostomies, patients had prolonged postoperative hospital courses; however, the rate of postoperative complications was the same as in patients who did not receive neuromuscular blockade (Baeur, 2016).

e. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) recommends the use of validated scales for the assessment of pain and agitation. The State Behavioral Scale (SBS) is a sedation assessment instrument for infants and young children supported on mechanical ventilation (Curley, 2006). The Face, Legs, Activity, Cry, Consolability (FLACC) scale is used to assess pain in infants from 2 months to 7 years (Merkel, 1997). The Neonatal Pain, Agitation and Sedation (N-PASS) scale is used to assess pain and sedation in neonates (Hummel, 2008).

f. The JHACH NICU utilizes clinical pathways to address postoperative pain and sedation practices among critically ill neonates. Clinicians should refer to Neonatal Pain Management - Pediatric Clinical Pathway | Johns Hopkins All Children's for more details.

VIII. Discharge planning:

a. The American Thoracic Society (ATS) released a Clinical Practice Guideline for pediatric patients undergoing chronic invasive home ventilation in 2016 and updated it in 2025. The guideline is based mainly on expert opinion, as there is limited scientific evidence to support it. It addresses decision making for tracheostomy placement, a multidisciplinary approach, standardization of the discharge process, and many other aspects of outpatient care and rehospitalization. For the current pathways, the published guideline will serve as a reference to hospital discharge criteria, caregiver training, equipment for monitoring, emergency preparedness, and airway clearance (Amin, 2025; Sterni, 2016).

b. A national U.S. survey highlights heterogeneity in the practice realities of discharging pediatric patients with home ventilation needs. Although no consensus exists, defining medical stability as no ventilator changes 1-2 weeks before discharge was common, as was having an institutional requirement for training two caregivers. Identification of factors driving heterogeneity, data to inform standards, and barriers to implementation are needed to improve outcomes (Sobotka, 2020).

c. Qualitative research has identified a gap between family members' expectations and what the community healthcare services can provide. It is important to prepare families and adjust their expectations for services provided in the outpatient setting (Dybwik, 2011).

IX. Parent/Caretaker education:

a. According to the ATT Clinical Practice Guideline for pediatric patients undergoing tracheostomy and chronic home invasive ventilation, improved caregiver training may help reduce morbidity and mortality in this population. The guidelines recommend that caregivers demonstrate competency in caring for and replacing their child’s tracheostomy. That education includes recognizing and responding to urgent issues such as tube obstruction, decannulation, and bleeding from the tracheostomy. Caregivers must be able to safely transport the child and be trained in the use of a “Go Bag” containing all necessary travel items, including extra tracheotomy tubes and obturators, suction catheters, tracheostomy tube ties, and other necessary items that must remain with the child at all times. Caregivers must demonstrate the delivery of all prescribed therapies, including medication administration, feeding, respiratory care, suctioning, use of a self-inflating bag, home ventilator use, responding to monitors, and cardiopulmonary resuscitation (CPR). Caregivers should receive training with simulated emergencies and complete an independent stay before hospital discharge, during which they are responsible for all aspects of the child’s care (Amin, 2025; Sterni, 2016).

b. Data examining the impact of caregiver training on patient outcomes is minimal. A single-center quality improvement project found that a standardized, comprehensive approach to caregiver training decreased the length of stay and readmission rate among tracheostomy patients (Wells, 2018).

c. Single centers also have reported success of simulation-based education for caregivers in improving knowledge, confidence, and emergency management skills for tracheostomy patients (Agarwal, 2016; Wooldridge, 2021; Thrasher, 2018; Prickett, 2019). A qualitative study of survey results from caregivers undergoing simulation training for tracheostomy emergency preparedness reported that caregivers reported greater preparedness, confidence, and knowledge of emergency management (Arnold, 2016).

X. Patient handoff to PICU providers at discharge:

a. Limited data is evaluating the impact of intra-facility standardized handoff intervention(s) compared with no standardized handoff intervention and measured patient-related outcomes. A recent review of the literature (any age of patients) found only one study examining inter-facility transfers, which demonstrated that it improves processes but has mixed, inconsistent outcomes and no effect on mortality. Inconsistent results and limited data limit the ability to draw definitive conclusions about best practices for standardized handoffs (Rosenthal, 2018).

b. No published data addresses the transition of neonatal to pediatric care for patients requiring chronic mechanical ventilation and/or with complex medical needs. This is an identified knowledge gap that needs to be addressed.

Clinical Management:

I. Overall goals:

a. To provide multidisciplinary, comprehensive, timely, and safe care with a high level of excellence to infants with or being considered for tracheostomy placement
b. Transition highly complex patients with a tracheostomy and/or long-term ventilation needs to go home in a safe and timely fashion

II. Multidisciplinary approach:

a. Every patient with a tracheostomy or those under consideration for tracheostomy placement should be evaluated and discussed by a multidisciplinary team.
b. At JHACH NICU, the multidisciplinary team formerly called “NICU Tracheostomy Team” was renamed to “BREATHE team,” which stands for **B**PD **RE**spiratory support **A**irway and **T**rac**H**eostomy **E**xcellence, and is designed to expand multidisciplinary discussions for patients in need of chronic respiratory support.
c. Patient enrollment criteria:
    i. Tracheostomy already in place

ii. Medical conditions that often require tracheostomy placement (craniofacial malformation, airway obstruction syndrome, chest wall abnormality syndrome, neuromuscular disorder, etc.)
iii. Born at <32 weeks and on invasive positive pressure or non-invasive positive pressure ventilation (NIPPV) or continuous positive airway pressure (CPAP) peak end expiratory pressure (PEEP) >10 cmH2O at 36–40-weeks PMA
iv. Patient born ≥ 32 weeks gestational age (GA) and ventilator dependent at 56 days of life

d. Consults
    i. "BREATHE"- place Epic order and contact any of the team leads (Neonatologist lead, NICU respiratory therapy clinical supervisor, respiratory therapist tracheostomy/ventilator coordinator, NICU complex discharge coordinator)
    ii. The following are recommended to be consulted or re-engaged if previously consulted. The reason for consultation should be specifically directed at the discussion of tracheostomy:
        1. Anesthesia/Pain Team
        2. Case Management
        3. Esophageal and Airway Treatment (EAT) Team
        4. Palliative Care Team
        5. Pediatric Otolaryngology (ENT) - All Children's Hospital (ACH) group
        6. Pulmonology
        7. Social Work
        8. Speech-Language Pathology

e. BREATHE Team multidisciplinary rounds
    i. Patients will be discussed at bedside by the multidisciplinary team rounds bimonthly until disqualified for a tracheostomy or hospital discharge, whichever occurs first.
    ii. Recommendations suggested by the BREATHE Team will be documented on the electronic medical record (EMR) and verbally communicated to the primary team.
    iii. The health care providers invited to participate on rounds include ENT physician and/or advanced practice provider (APP), EAT physician/APP neonatologists, pulmonologists, tracheostomy champion registered nurses (RNs), NICU and/or pediatric intensive care unit (PICU) respiratory therapists (RTs), Palliative Care, Pain Team, Psychology, Anesthesiology, Critical Care providers for transition of care, Nutritionist, Case Management, Wound Team, Child Life Specialist, Social Work, SLP and the patient's family.

III. Pre-operative preparation:

a. Assess if the patient qualifies for multiple procedures under the same anesthesia. A multidisciplinary team should make the decision and consider the estimated

total anesthesia time, comorbidities (e.g., PHTN, cardiac disease), respiratory stability, and the urgency of the procedures. The order of procedures should also be discussed on an individual basis.

IV. Clinical stability for tracheostomy – Key considerations:

a. Clinical stability should be assessed prior to tracheostomy placement (at least 48 hours in advance) by evaluating the following:

   i. Confirm central IV access is present or will be placed
   ii. Determine plan for route and/or dose conversion of critical medications to IV while NPO
   iii. Confirm need for cardiac anesthesia
   iv. Identify any active infections
   v. Confirm plan for NPO status
   vi. Determine if stress-dose steroids are required
   vii. Review if nutritional status is adequate to support optimal wound healing
   viii. Confirm ability to maintain adequate oxygenation during movement, handling, and transport
   ix. Consider the need to coordinate multiple procedures under the same anesthesia
   x. Develop a post-operative sedation plan, including whether neuromuscular blockade is needed

V. Tracheostomy post-operative care:

a. Formal bedside handoff will occur from the OR team to the NICU following surgery.
b. Obtain information on the surgical technique used to determine the need for post-operative muscle paralysis.
c. Refer to **"JHH-BMC-ACH Pediatric Tracheostomy Focused"** order set for immediate post-operative tracheostomy care. Orders will be placed by the surgical team performing the tracheostomy. The orders should be followed until the first tracheostomy change is performed, typically between 5 and 7 days after tracheostomy placement.
d. Place the emergency tracheostomy card at the bedside as soon as the patient arrives from the OR.

VI. Immediate post-operative pain and sedation plan:

a. The goal of pharmacological therapy is to maintain patients with limited movement, allowing for proper healing of the tracheostomy surgical site, preserving skin integrity, and avoiding accidental decannulation or wound bleeding.
b. Postoperative pain and sedation should be addressed following the existing clinical pathway: Neonatal Pain Management - Pediatric Clinical Pathway | Johns Hopkins All Children's (Note: refer to tracheostomy under the major surgery category)
c. Muscle paralysis

i. Neuromuscular blockade should be avoided but can be used with proper indication and documentation.
ii. For patients undergoing a tracheostomy procedure under the Björk technique, head and neck movement in the immediate postoperative course is not a risk, and sedation can be minimized according to each patient's preoperative needs. There is no need for neuromuscular blockade.
iii. Consider patients with high risk of tolerance to sedatives and analgesics, history of clinical instability associated with agitation, patients with PHTN, and patients with neck movement despite escalation of sedation. Paralysis discontinuation should be assessed daily and lifted as soon as able.

VII. Weaning analgesia and sedation:

a. The weaning phase should be instituted within 3-7 days of adequate control and only after the first tracheostomy change if ENT performs the tracheostomy procedure. If the Björk technique is performed, then weaning is independent of the first tracheostomy change and should be initiated based on pain and sedation scales.
b. The initial step is to down-titrate the continuous infusion rate of sedative medication by 25-50%. Infants should then be carefully monitored for 24 hours.
c. Weaning of analgesia/sedation should be based on appropriate pain/sedation scales currently adopted by the NICU.

VIII. Addressing Iatrogenic Withdrawal Syndrome:

a. Obtain baseline Withdrawal Assessment Tool (WAT-1) score BEFORE transition, with scoring occurring every 4 hr thereafter.
b. Stratify for withdrawal based on the number of days on continuous infusions (see Table 1 below).
c. For more information on medication weaning, please refer to the Iatrogenic Withdrawal Clinical Pathway.
d. When scheduled medication is at 0.05 mg/kg/dose (diazepam/methadone) or 0.5 mcg/kg/dose (clonidine), consider weaning the interval (e.g., Q6h to Q8h).

Table 1: Continuous Infusion Weaning by Duration of Therapy:

Days on continuous infusion	Scheduled medicine conversion (Use dosing guideline table)
<5 days	Scheduled medication NOT warranted
5-9 days	After 2nd dose, decrease by 50% After the 3rd dose, discontinue the drip
10–21 days	After 2nd dose, decrease by 50% After 3rd dose, decrease by 50% After 4th dose, discontinue drip
>21 days (notify Pain Team)	After 3rd dose, decrease by 50% After 6th dose, decrease by 50% After 9th dose, discontinue drip

IX. Discharge planning:

a. Discharge planning starts prior to tracheostomy placement.
b. Meet with family prior to tracheostomy surgery to discuss discharge needs, equipment, and discharge criteria. Take the same multidisciplinary approach, with participation from the complex discharge coordinator, RT, Speech Therapist, and Case Manager. Document discussion in a "multidisciplinary team-family meeting note" (EPIC smart phrase: "**JHM IP AD PEDS Family Meeting**").
c. Discharge home criteria include being medically stable, on stable respiratory support settings for at least 10 days-2 weeks (if on mechanical ventilation) or 5 days (heat and moisture exchanger [HME]/trach collar), when two caregivers have completed full tracheostomy and home equipment training and gone through simulation (see table below).
d. It is recommended that an awake and attentive trained caregiver be in the home of a child requiring chronic invasive ventilation at all times.
e. At least two trained family caregivers should be prepared to care for the child at home.
f. Aim for ongoing education to acquire, reinforce, and augment skills required for patient care for both the family and professional caregivers of children requiring chronic home invasive ventilation.
g. A pulse oximeter should be placed, especially when the child is asleep or unobserved.
h. Equipment includes a ventilator, a back-up ventilator (if provided by home care company), batteries, a self-inflating bag and mask, portable suctioning equipment, a heated humidifier, supplemental oxygen, an oxygen concentrator if on oxygen, a pulse oximeter, and a "Go Bag."
i. Family awareness that regular maintenance of home ventilators and all associated equipment is required, as outlined by the manufacturer, and is the durable medical equipment company's responsibility.

j. Speech Therapist will complete assessment of oral skills and speaking valve evaluation. Refer to the Speaking Valve Procedure policy on Hopkins Policy Online (HPO) Document Library.
k. The ENT or EAT team will be responsible for post-discharge outpatient follow-up and orders pertinent to tracheostomy supplies and management, including recommendations for upsizing tubes, management of complications, and decannulation in collaboration with Pulmonologists.
l. Ensure coordination with the Acute Pain Team and/or Chronic Pain Clinic to support follow-up and weaning of opioid and/or sedative medications.

IV. Parent/Caregiver education:

a. Caregivers will view all tracheostomy videos available on Get Well Network, preferably prior to tracheostomy.
b. Caregivers will be issued the tracheostomy parent handout (available on HPO).
c. Caregivers will be issued a home mechanical ventilation handout if needed (available on HPO).
d. The Tracheostomy Teaching Checklist will be placed at the patient's bedside.
e. All parent/caregiver training is to be validated via return demonstration and/or verbal teach back and documented under "tracheostomy education" in the EMR.
f. Training provided to the caregiver(s) described in the following table:

Table 4: Required Parent/Caregiver Tracheostomy Education:

Required Tracheostomy Training Topics	Parent/Caregiver Competency [1]

• Anatomy and function of airway/trach tube
• Purpose of humidification
• Suctioning
• Trach/skin care
• Tracheostomy tube change
• Tracheostomy tube cleaning
• General safety and use of a "Go Bag."
• Accidental removal of trach tube
• Symptoms of breathing problems
• Respiratory Arrest/CPR
• Care of the speaking valve (if used)
• If ventilator dependent:
  ○ Function and indication for the mechanical ventilator
  ○ Overview of ventilator settings and parameters
  ○ Purpose of humidification
  ○ Assembly of ventilator circuit configuration for home and travel
  ○ Battery life and portability of equipment
  ○ Delivery of oxygen to the ventilator (home and travel)
  ○ Monitoring of ventilation
  ○ Troubleshooting the ventilator
	• Trach tube change x 2
	• Trach care x 2 (stoma cleansing, neck cleansing, dressing, and trach tie change)
	• Trach suction with a single-use catheter
	• Manual ventilation with a self-inflating bag
	• If ventilator dependent:
	  ○ Inline suction
	  ○ Circuit set up
	  ○ Circuit change
	  ○ Transition from home ventilator circuit configuration to travel and back
	• Must attend CPR class or provide proof of current CPR certification prior to simulation training
	• Must attend Parent Emergency Preparedness for Tracheotomy Assisted Living and Care (PEP-TALC) session in Simulation Lab prior to rooming in
	• Caregivers will room in for 24-48 hours per rooming-in guidelines

[1] Each parent/caregiver must independently demonstrate required tasks prior to discharge.

Abbreviations: CPR = cardiopulmonary resuscitation

V. Patient handoff to PICU staff at discharge:

a. It is advisable to conduct a patient handoff from NICU to PICU around the time of discharge. While the **BREATHE** Team continues to design a standardized process and test its efficacy through innovative research, this important part of the guideline remains open to future amendment.

VI. Outside hospital transfer acceptance to JHACH NICU for patients with or undergoing evaluation for tracheostomy:

a. Recommend a care conference with the medical team and family members prior to acceptance/transfer of the patient. The goal is to present the family with a roadmap for discharge and standard procedures to achieve discharge readiness, set realistic expectations for the process, and obtain their commitment to tracheostomy care training.

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Does the NICU patient have ***any*** of the following?

- Tracheostomy in place
- Medical condition(s) that may require future tracheostomy placement, such as:
  - craniofacial malformation
  - airway obstruction syndrome
  - chest wall abnormality
  - neuromuscular disorder
- Born <32 weeks and on invasive positive pressure at 36–40-weeks PMA or NIPPV with PEEP >10 cmH2O
- Patient born ≥ 32 weeks gestational age (GA) and ventilator dependent at 56 days of life.

NO → **Off Pathway**

YES → Consult the following in Epic, if not already involved:

- BREATHE Team
  - Notify any BREATHE Team member
- Case Manager
- EATs Team
- ENT
- Pain Team
- Palliative Care Team
- Psychology
- Social Worker
- Speech Therapy

Does patient already have tracheostomy in place?

NO

Hold multidisciplinary family meeting to discuss:

- Implications of tracheostomy
- Commitment to trach care, education, and training *and/or* discharge to chronic care facility
- Goals of care and decision making

Document in EPIC ("**JHM IP AD PEDS Family Meeting**")

NO

Off Pathway

- Ongoing discussion for trach in the future
- BREATHE Team to round on patient every other week

YES

- Notify ENT, EATs, and Pulmonology of decision to move forward with trach
- Confirm OR date
- Ensure consent has been obtained by surgical team
- BREATHE Team to round on patient every other week

48 hours prior to procedure:

- Review Clinical Stability for Tracheostomy: Key Considerations*
- Discuss with attending physician the elements that need attention
- Order surgical bath for the nurse to complete night prior
- Ensure active type and screen, and recent CBC documented

Upon return from OR, complete handoff with Surgical Team

- Surgical Team will place their post-op orders
- Place NICU postop orders **using *JHH-BMC-ACH Pediatric Tracheostomy Care Focused*** order set
- Order postoperative sedation using the ***JHH-BMC-ACH NICU Sedation, Analgesia, Paralysis*** order set and referencing **Neonatal Pain Management - Pediatric Clinical Pathway | Johns Hopkins All Children's**
- Nursing to place emergency tracheostomy card at the bedside as soon as infant arrives from OR

- When ready, start weaning pain and sedation medications
- Begin process for discharge teaching, parent/caregiver education, and required trach training topics

YES

Tracheostomy in place

YES

Continue supportive care with consulting teams

- BREATHE Team to round on patient every other week.
- Hold multidisciplinary family meeting to discuss discharge process
- Document in EPIC ("**JHM IP AD PEDS Family Meeting**")

***Clinical Stability for Tracheostomy: Key Considerations**

- Confirm central IV access is present
- Determine plan for route and/or dose conversion of critical medications to IV while NPO
- Confirm need for cardiac anesthesia
- Identify any active infections
- Confirm NPO status
- Determine if stress-dose steroids are required
- Review if nutritional status is adequate to support optimal wound healing
- Confirm ability to maintain adequate oxygenation during movement, handling, and transport
- Consider the need to coordinate multiple procedures under the same anesthesia
- Develop post-operative sedation plan, including whether neuromuscular blockade is needed

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Outcome Measures:

1. BREATHE team and individual disciplines consultation when indicated (according to eligibility criteria)
2. Documentation of family communication about the possibility of a tracheostomy prior to consulting the **BREATHE** Team (not necessary to have family agreement for a tracheostomy to consult the team)
3. Compliance with immediate postoperative orders
4. Documentation of multidisciplinary family meetings prior to tracheostomy placement to discuss implications and discharge pathways for patients with tracheostomy. Obtain commitment from family with necessary education for home care or agreement to discharge to a chronic care facility if unable to be trained for home care.
5. Survival
6. Tracheostomy complications documentation (tracheitis/pneumonia, accidental decannulation, bleeding, postoperative infection within first 7 days, granuloma)
7. Length of stay post tracheostomy

Clinical Pathway Team

Tracheostomy-Related Care in the NICU Clinical Pathway

Maternal, Fetal, and Neonatal Institute

Johns Hopkins All Children's Hospital

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Disclaimer:

Clinical Pathways are intended to assist physicians, physician assistants, nurse *practitioners,* and other health care providers in clinical decision-making by describing a range of generally acceptable approaches for diagnosing, managing, or preventing specific diseases or conditions. The physician must make the ultimate judgment regarding the care of a particular patient in light of the patient's individual circumstances.

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