



NEONATOLOGY TAKES THE LEAD IN INFANT TRACHEOSTOMY AND HOME VENTILATOR PROGRAM

NEONATOLOGY CREATES A MEDICAL HOME FOR BABIES ON LONG-TERM BREATHING SUPPORT

Babies born with significant prematurity typically require long-term breathing support, even after they are discharged to home. To improve the level of care provided to this patient population, Children's Mercy Kansas City developed the Infant Tracheostomy and Home Ventilator Program in 2005. Led by Winston Manimtim, MD, neonatologist and Medical Director for the program, it offers babies the opportunity to be sent home earlier than ever before.

THE ONLY PROGRAM OF ITS KIND

This program is the only one in the U.S. where neonatologists serve as both primary care provider and intensivist for each tracheostomy and home ventilator patient. The neonatology-led model simplifies the experience for families because all care is managed by the neonatologists who have cared for their child since birth.

Serving as the medical home, the neonatologists look at the whole health of the child, considering every factor that could affect a child's outcomes. They collaborate with other subspecialists, such as pulmonologists, gastroenterologists and otolaryngologists, and the team makes decisions together as necessary. In addition, a dedicated nutritionist is part of the team, with a strong focus on patients' growth.

Most babies at Children's Mercy who require a ventilator are discharged from the hospital at 6 to 7 months old. Being at home offers patients and their families a stronger

sense of normalcy. These babies tend to thrive in their home environment while still receiving complex medical care from Children's Mercy. They receive support from an on-call neonatologist 24/7, the multidisciplinary care team, and a private nurse in the home.

In 2017 alone, the Infant Tracheostomy and Home Ventilator Program at Children's Mercy added 25 new patients who required long-term ventilation at home, making it one of the largest programs in the U.S. As of today, the program has cared for more than 250 patients, the majority of whom have graduated from the program after being weaned off the ventilator and having their tracheostomy removed.

LOCAL OUTCOMES EXCEED NATIONAL AVERAGE

Currently, 90 percent of Children's Mercy patients who are born prematurely and require tracheostomy and ventilator support while in the hospital survive to the time of hospital discharge, equal to the national survival rate of a similar cohort. After these patients are discharged to home, however, the Children's Mercy cohort survival rate is approximately 95 percent, which is slightly higher than the 90 percent national average.

Dr. Manimtim attributes this success to his team's constant availability to their patients. For any issue, large or small, the neonatology team is involved. When early signs of illness are present, the team can quickly decide on next steps, even troubleshooting many issues over the phone. In most cases, hospital readmissions can be avoided.

STUDY UNCOVERS RISKS FOR HOSPITAL READMISSIONS

To identify the factors that lead to readmission to the hospital of tracheostomized, ventilator-dependent babies in the NICU through their first two years of life, Dr. Manimtim designed a retrospective cohort study. The study identified these key risk factors:

- Prolonged oxygen use
- Certain medications, such as inhaled steroids
- Respiratory infections such as rhinovirus and enterovirus
- Multiple diagnoses

In addition, the study¹ revealed that a number of babies were readmitted to the hospital due to equipment malfunctions, such as a dislodged or blocked tracheostomy. The team addressed this issue by offering more targeted training to care providers in the home.

The results of the study will help doctors and their teams design effective protocols for long-term care management at the time of NICU discharge, anticipating home nursing needs and guiding parental discharge education to improve each patient's short-term and long-term outcomes. Ultimately, when care teams are better at identifying at-risk infants, they can decrease mortality and morbidity in this population, and minimize the health care burden.

IMPACT OF BREATHING SUPPORT ON LANGUAGE DEVELOPMENT

Another question of interest to Dr. Manimtim was the effect of tracheostomy on a child's language development. That's why his team also conducted a retrospective review of patient experience since the inception of the program. The study compared patients diagnosed with bronchopulmonary dysplasia (BPD) with tracheostomy to patients with a diagnosis of BPD who had no tracheostomy. The data revealed that at about 2 years of age, language development and cognitive development were the same in both groups. This insight has been shared at three major national conferences to date, and a manuscript is in development.



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SOURCES

¹ Factors leading to rehospitalization for tracheostomized and ventilator-dependent infants through 2 years of age. Akangire G, Manimtim W, Nyp M, Townley N, Dai H, Norberg M, Taylor JB. *Journal of Perinatology*. 2017 Jul; 37(7): 857-863. doi: 10.1038/jp.2017.54. Epub 2017 Apr 20.



LEARN MORE ABOUT TRACHEOSTOMY AND HOME VENTILATOR CARE.

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