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### Functional outcomes of Infants with Chiari II Malformation with Tracheostomy and Home Ventilator Dependence

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# Functional Outcomes of Infants with Chiari II Malformation with Tracheostomy and Home Ventilator Dependence

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## Children's Mercy Kansas City

### Background

- Chiari II malformation has the incidence of 1 in 1000 live births
- Characteristic features include peaked midbrain, downward displacement of cerebellar tonsils and vermis, and spinal myelomeningocele which can be associated with hydrocephalus
- Mortality is 50-70% if not recognized early
- Survivors have a high morbidity and develop neurologic abnormalities and significant developmental delays
- A subset of infants with Chiari II malformation may develop central and obstructive apneas that may require long-term ventilator support through a tracheostomy

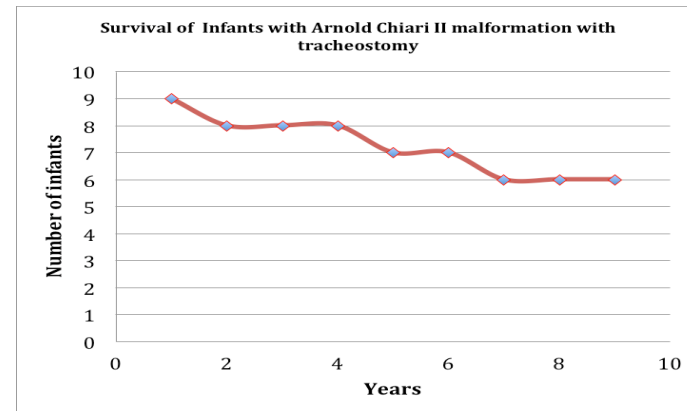
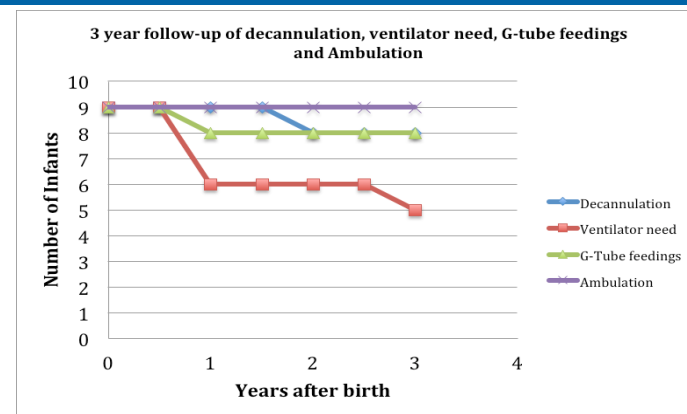
### Objective/Methods

- Objective- To describe the short-term functional outcomes of patients with Chiari II malformation who are ventilator dependent at home through tracheostomy
- IRB approved retrospective study

- Cohort from 2010-2018
- A 3-year analysis of:
  - Survival
  - Decannulation from tracheostomy
  - Length of ventilator dependence
  - G-tube feeds for nutrition
  - Ability to ambulate were assessed.

### Results

- Over the 8-year period (2010-2018), 85 infants were discharged from the hospital with Chiari II malformation
- Of the 85 infants, 9 (10.5%) received tracheostomy for home ventilation due to vocal cord paralysis and central apnea
- Tracheostomy was placed within 3 months (range-1.5-3 months) of life
- Of these 9 infants, 1 (11%) was successfully decannulated at 2 years of age, 3(33%) died, and 5(56%) remained tracheostomy and ventilator dependent
- By the age of 3 years of age, all surviving infants were non-ambulatory without assistive support and had significant speech/language delays
- 8 (89%) of the 9 infants continue to require G-tube feeds for nutrition



### Conclusion

These findings will provide additional data regarding the short-term functional outcomes of a subset of infants with Chiari II malformation who are ventilator-dependent at home. Furthermore, awareness of these findings will help health care providers and parents to make well-informed care decisions for these medically complex children.