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Tracheostomy Dependence Patterns in Children with 22q11 Deletion Syndrome

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Research Abstract Title

Title: Tracheostomy Dependence Patterns in Children with 22q11 Deletion Syndrome

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IRB Number: Study00002406

Describe role of Submitting/Presenting Trainee in this project (limit 150 words): Data collection, statistics, and manuscript preparation

Background, Objectives/Goal, Methods/Design, Results, Conclusions limited to 500 words

Background: 22q11.2 deletion syndrome (22q11DS) is the most common chromosomal microdeletion syndrome and presentation often includes congenital heart disease (CHD), palate anomalies, and developmental delay. Due to the medical complexity of this syndrome, some patients require tracheostomy. To date, there is little in the literature regarding tracheostomy for these patients.

Objectives/Goal: our aim is to better delineate patients with 22q11DS who require tracheostomy, assess outcomes including decannulation and complications.

Methods/Design: This is a retrospective chart review of patients in our 22q Center's repository. Inclusion criteria were a diagnosis of 22q11DS with a current or previous history of tracheostomy. Data collected includes current age, age at tracheostomy, and past medical history including history of CHD and cleft palate, indication for tracheostomy, complications, successful decannulation, duration of tracheostomy, length of follow-up, history of laryngotracheal reconstruction, G-tube dependence, and mortality.

Results: 170 charts were reviewed and 10 patients met inclusion criteria, with a mean current age of 13.56 years (range 6years-23years). All patients had CHD and 3 had history of cleft palate. Mean age at

tracheostomy was 6.22 months (range 2months-15months). The most common indication was cardiac/respiratory failure (n=7). Flexible laryngoscopy revealed bilateral vocal cord paralysis (VCP) in 2 patients and unilateral VCP in 2 patients. Nine patients were decannulated with a mean tracheostomy duration of 3.94 years (range 1year-8years); 1 patient passed away at 5 years of age prior to decannulation. Decannulation required laryngotracheal reconstruction in 3 patients and 7 patients remain G-tube dependent.

Conclusions: The present study describes patterns of tracheostomy in children with 22q11DS. Interestingly, all patients requiring tracheotomy had a history of CHD. Most patients were successfully decannulated, although it often took many years and additional procedures to facilitate decannulation. This information may aid preoperative counseling for families of patients with 22q11.2 deletion syndrome requiring tracheostomy.