VACTERL Association and Feeding

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The Children's Hospital of Philadelphia Hope lives here.

- What are some of the feeding issues specific to VACTERL?
- What is a feeding team and how can it help your child?

- V Vertebral anomalies (~70%)
- A Anal atresia (~55%)
- C Cardiovascular anomalies (~75%)
- T Tracheoesophageal fistula (~70%)
- E Esophageal atresia (~70%)
- R Renal (Kidney) anomalies (~50%)
- L Limb anomalies (~70%)
- S Single umbilical artery (~35%)

- V Vertebral anomalies
 - Does not generally impact feeding
 - Tethered cord can lead to constipation
- A Anal atresia
 - Constipation after repair of imperforate anus
 - Nobody wants to eat if their abdomen is full of stool

- C Cardiovascular anomalies
 - Feeding is exercise for infants
 - Some cardiac anomalies can lead to fatigue during feeding
 - Cardiac surgery can result in damage to the nerve (recurrent laryngeal) that controls the vocal folds
 - This can lead to increased risk for aspiration
 - Prolonged intubation after cardiac surgery can lead to oral aversion

- T Tracheoesophageal fistula
- E Esophageal atresia
 - Post-operative tracheal stenosis
 - Difficulty breathing can lead to difficulty feeding
 - Esophageal strictures
 - Can lead to difficulty swallowing, discomfort with feeding
 - Abnormal esophageal motility
 - Abnormal development and innervation
 - Can lead to difficulty swallowing, discomfort with feeding, and GE reflux

- T Tracheoesophageal fistula
- E Esophageal atresia
 - Gastroesophageal reflux (heartburn)
 - Refluxing of stomach materials into the esophagus can cause discomfort from the stomach acid
 - Children who have reflux +/- vomiting may learn that eating leads to pain
 - Reflux in any child can lead to a feeding aversion

- T Tracheoesophageal fistula
- E Esophageal atresia
 - Gastroesophageal reflux (heartburn)
 - Refuse to eat because they would rather have the pain of hunger than the pain from reflux
 - Learn they are more comfortable with small, frequent feedings
 - Prefer to drink instead of eat to wash down the acid
 - Have inconsistent oral acceptance
 - Feed better when sleepy
 - Have difficulty progressing textures

- R Renal (Kidney) anomalies
 - Most do not impact feeding
- L Limb anomalies
 - Difficulty self-feeding
 - Trouble with positioning for feeding
- Slow growth
 - May start intrauterine, especially if there is a single umbilical artery
 - Nutritional support

What is a Feeding Team, and how can one help you and your child?

Team Members

- Medical Physicians and Nurse Practitioners
- Medical Assistant
- Nutritionists
- Speech and Language Pathologists
- Occupational Therapists
- Behavioral Health Pediatric Psychologists
- Social Worker
- Clinical Feeding Specialists
- Manager
- Administrative assistants

- Medical
 - Complete history and physical looking for medical factors contributing to feeding disorders
 - GI Disorders
 - GE reflux
 - Constipation
 - Food allergies
 - Eosinophilic Esophagitis
 - Neurologic, Genetic, Metabolic disorders
 - Autistic spectrum

- Dietitian
 - Full dietary history
 - Evaluate growth parameters
 - Suggest micro and macro nutrient supplements
 - Nutritious beverages
 - Calorie boosting
 - Vitamins/minerals
 - Supplemental tube feeds

- Speech Pathology
 - Co-presenter, Susan McCormack, M.A.,
 CCC-S
- Occupational Therapy
 - Fine motor/Self-feeding
 - Positioning
 - Sensory processing

- Behavioral health (psychology)
 - Mealtime structure
 - Refusal behaviors
 - Intensive Day Hospital Feeding Program

Day Hospital Feeding Program

- Medical/nutritional issues (i.e. reflux, eosinophilic esophagitis, failure to thrive) must be under control before patient is admitted
- 6 patient capacity
- Typically 4 week admission
 - Monday Friday, 8:30 am 4:30 pm
- 3 meals per day by Feeding Therapists using Applied Behavior Analysis (ABA)
 - Desired behaviors rewarded
 - Undesired behaviors ignored
- Parents watch through one-way mirror, meals recorded on DVDs
- Parents are trained during second part of admission
- All patients followed by Nutrition and Medical
- All families assessed at admission by Social Work
- Patients may receive OT and/or ST depending on their needs
- Patients seen for follow-up two weeks after discharge, then monthly
- If doing well, ABA protocol gradually phased out

Contact information

- To do an intake: 215-590-7500
- General questions:
 - Sherri Cohen, MD, MPH, Medical Director
 - 267-426-0073, <u>cohens@email.chop.edu</u>
 - Andrea Mattie, MSW, Manager
 - 267-426-5624, <u>mattie@email.chop.edu</u>
- Website
 - www.chop.edu, type "feeding" in the search box, then click on the second option

http://www.chop.edu/consumer/jsp/division/generic.jsp?id=70529