# FEEDING THE MEDICAL COMPLEX PEDIATRIC PATIENT

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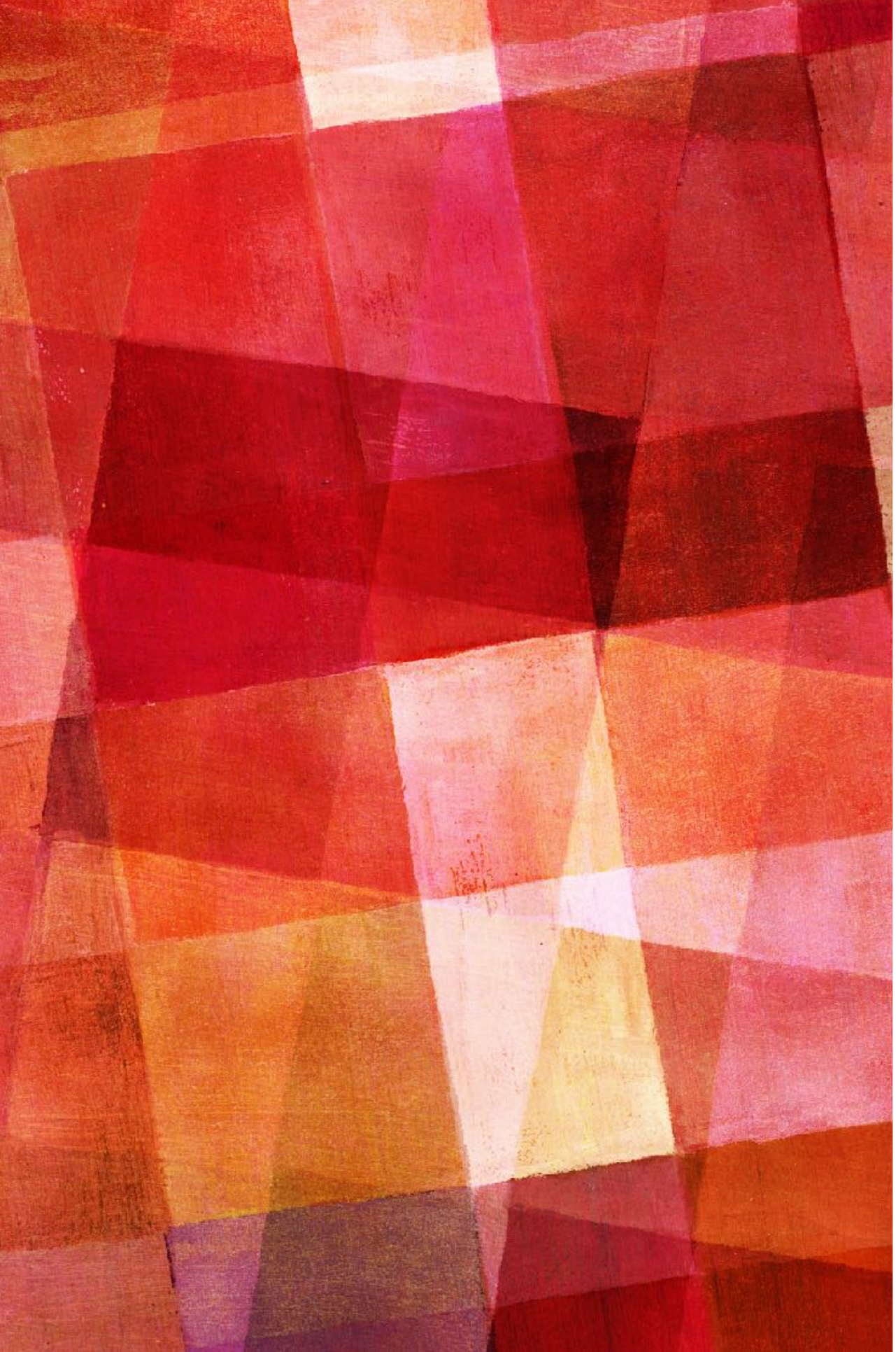
# DISCLOSURES

- Ms. Sitzmann is speech-language pathologist at Children's Mercy for which she receives a salary.
- Ms. Sitzmann is receiving an honorarium for presenting this workshop.
- Ms. Sitzmann has no non-financial relationships to disclose.

# PEDIATRIC FEEDING DISORDER

Goday, et al. 2017

- An impairment (system failure) creates a pediatric feeding disorder (PFD) that results in a dysfunction
- The resulting dysfunction is not considered age- appropriate
- Impacts at least one of these domains:
  - medical
  - nutrition
  - skill and ability
  - psychosocial
- Today's presentation will focus on the impact of the medical domain on skill and ability.



# OVERVIEW

- Non-oral feedings
- Eosinophilic esophagitis
- Laryngomalacia
- Laryngeal cleft

# NON-ORAL FEEDINGS

# NON-ORAL FEEDINGS

- Very useful tools
  - Enables patients to receive adequate nutrition while the team addresses medical, psychosocial, and skill/ability concerns
- Have a plan to work towards removal before the tube is placed however this may not be the goal for all patients

# NON-ORAL FEEDINGS

Studies have shown that g-tubes:

- Improve weight gain and mid-arm circumference
- Reduce feeding time
- Improve quality of life for caregivers and patients

(Gottrand et al. 2010)

# NON-ORAL FEEDINGS

Today we are going to explore the following types of non-oral feedings:

- Nasogastric (NG) tube
- Nasojejunal (NJ) tube
- Gastrostomy (G) tube
- Gastro-jejunal (G/J) tube

# NASOGASTRIC (NG) TUBE

- A long feeding tube is inserted through the nose and passed into the stomach
- In GI Multidisciplinary Feeding Clinic, we often use NG tubes to trial non-oral feedings
  - Will the patient…
    - tolerate feedings
    - gain weight appropriately

# NASOGASTRIC (NG) TUBE

- Pros:
  - Temporary
  - Non-surgical placement
  - Bolus or continuous feedings into the stomach
- Cons:
  - Temporary (easily pulled out, vomiting)
  - Needs to be replaced more frequently than a g-tube
  - Concerns that it may interfere with swallow function (unable to find research indicating that this is true)
  - May increase oral aversion

# NASOJEJUNAL (NJ) TUBE

- Tube is inserted through the nose, passed through the stomach and placed in the jejunum (second part of the intestines)
- Continuous feedings (no bolus feedings) into the jejunum
  - Limited options for formula
- Often used if the patient is not tolerating NG tube feedings
  - Frequent vomiting
  - Significant reflux concerns

# NASOJEJUNAL (NJ) TUBE

- Pros:
  - Temporary
  - Non-surgical placement
  - Can eliminate vomiting associated with NG feedings
- Cons:
  - Temporary (easily pulled out; vomiting)
  - Needs to be replaced more frequently than a g-tube
  - Placement confirmed with x-ray
  - Concerns that it may interfere with swallow function (unable to find research indicating that this is a valid concern)
  - May increase oral aversion
  - Difficult to wean to oral feedings if patient is only tolerating NJ tube feedings

# GASTROSTOMY (G) TUBE

- Tube is inserted through the abdomen and delivers nutrition directly to the stomach
- Typically considered a good option if it is expected that the need for non-oral feedings will be greater than 3 months
- Can be used for bolus and continuous feedings
  - gravity feedings
  - feeding pumps
- Initial replacement of the tube occurs ~3 months post surgery and typically requires a visit to the surgeon
- Replaced every 3 months or sooner if concerns arise
  - caregivers may be trained to replace the tube at home

# GASTROSTOMY (G) TUBE

# GASTROSTOMY (G) TUBE

# GASTROSTOMY (G) TUBE

- Pros:
  - Semi-permanent (can be removed)
  - Decreased risk of oral aversion
    - Not taped to the child's face
    - Does not irritate the nose, pharynx, or esophagus
- Cons
  - Surgical placement
  - Complications with stoma site
    - Granulation tissue
    - Leaking

# GASTRO-JEJUNAL (G/J) TUBE

- Tube is inserted through the abdomen and delivers nutrition directly to the stomach (g-tube) and also contains another tube that is passed into the jejunum (j-tube)
- Often start with a g-tube then progress to a g/j tube if the patient is having difficulty tolerating g-tube feedings
- Provide continuous feedings into the jejunum
- Replaced using x-ray guidance

# GASTRO-JEJUNAL (G/J) TUBE

- Pros:
  - Semi-permanent (can be removed)
  - Decreased risk of oral aversion
    - Not taped to the child's face
    - Does not irritate the nose, pharynx, or esophagus
  - J-tube is helpful when the patient is unable to tolerate g-tube feedings
- Cons:
  - Surgical placement
  - Cannot be replaced at home
  - Continuous feedings make weaning difficult
  - Complications with stoma site
    - Granulation tissue
    - Leaking

# WEANING NON-ORAL FEEDINGS

- Criteria typically includes:
  - Within 90% of ideal body weight with steady weight gain
  - Strong oral motor feeding skills
  - Medically stable
    - Ideally this includes being able to tolerate bolus feedings into the stomach
    - Continuous feedings are often a sign of ongoing GI concerns and interfere with hunger signals
- Supportive caregivers
  - Strong child-caregiver interactions

# WEANING NON-ORAL FEEDINGS

- Multiple approaches
  - The typical approach used by the GI Multidisciplinary Feeding Clinic at CMH is outlined in the following slides
- Highly individualized process
- Must be completed under the guidance of the patient's medical team
  - It takes a village
  - Feeding teams are very helpful

# WEANING NON-ORAL FEEDINGS

STEP 1:

- Address medical concerns
  - Reflux
  - Aspiration
  - EoE
  - Constipation
  - Slow gastric emptying
- Establish successful non-oral feedings
- Ensure adequate weight gain
- Continue oral stim program and oral feedings as tolerated
  - expect a decrease in oral feeding initially

# WEANING NON-ORAL FEEDINGS

STEP 2:

- Work towards bolus feedings into the stomach
  - Pump or gravity feeds
  - Ideally, age-appropriate volume given over 30 minutes or less
- Build oral motor feeding skills and normalize oral sensation if aversion is a concern

# WEANING NON-ORAL FEEDINGS

STEP 3:

At this point, the patient is interested in eating and taking a variety of foods orally but oral intake is limited

- Safe plan for liquids and intake is steadily increasing
- Offer oral feedings 2-3 times per day prior to non-oral feedings
  - goal = 30 minutes or less of time in the highchair/oral feeding
  - Provide 15 minutes to eat orally then start the non-oral feeding while the child continues to eat (if interested)
  - work on adding variety
    - Protein, vegetables, fruits
    - Hydration

# WEANING NON-ORAL FEEDINGS

STEP 3 (continued):

- Rearrange non-oral feedings to encourage hunger - "Hunger provocation"
  - Work with a dietician and physician
  - More time between feedings
  - Provide individual feedings over a shorter period of time
    - Decrease pump feedings from 45 minutes to 30 minutes
    - Transition from pump feedings to a gravity feeding
- Condense feedings
  - If child is receiving five 4 oz. formula boluses during the day (every three hours, example 6 am, 9 am, 12 pm, 3 pm & 6 pm), transition to four 5 oz boluses given every 4 hours (6 am, 10 am, 2 pm, 6 pm)
  - Ideally non-oral feeding schedule will match a typical meal schedule

# WEANING NON-ORAL FEEDINGS

STEP 4:

- As intake increases, may start "counting calories" and adjusting non-oral feedings based on oral intake
  - If the child typically receives a 4 oz PediaSure bolus but drinks 2 oz orally, only 2 oz. are provided non-orally after the oral feeding
- More complicated when calculating intake of solids

# WEANING NON-ORAL FEEDINGS

STEP 4 (continued):

- Another option is to reduce all feedings by a set amount (determined by dietician based on current oral intake) then provide a "catch-up feeding" at the end of the day
  - Volume of "catch-up feeding" depends on oral intake
  - If the child typically receives five 6 oz. boluses, each bolus is reduced to 4 oz. If the child drinks 10 oz. of formula during that day there is no need for a supplemental feeding however if only 4 oz. are consumed orally, an additional 6 oz. feeding is provided

# WEANING NON-ORAL FEEDINGS

STEP 5:

- Start eliminating non-oral bolus feedings and/or significantly reduce calories provided via non-oral feedings until the child is meeting nutritional needs via oral feedings only
  - typically start with the meal with the best oral intake
    - may provide a supplemental non-oral feeding at the end of the day
- May take a little while (few days) for the child to adjust oral intake to compensate for fewer non-oral feedings
  - do not expect weight gain during this transition
- Ensure patient is drinking enough fluids (not just formula/milk)
- Plan for administering medication

# WEANING NON-ORAL FEEDINGS

## General guidelines:

- Remember the big picture
  - Weaning may not be appropriate for all patients
  - Quality of life
    - Develop an appropriate long-term plan with the family
      - ongoing discussion
- Typically try to avoid nighttime/overnight feedings
  - Want to mirror an age-appropriate schedule
  - Overnight feedings tend to interfere with oral intake in the morning

# WEANING NON-ORAL FEEDINGS

## General guidelines (continued):

- If the child does not seem to be recognizing hunger, medical team may consider medication
  - Cyproheptadine/Periactin
  - Ensure oral motor skills are appropriate before using medication
- Demonstrate adequate growth and weight gain for 6 months before the g-tube is removed
  - "make it through a respiratory season without using the tube"
- Monitor weight gain closely
  - but not too closely (no daily weight checks)
- Puree by g-tube/blenderized diets
- Intensive feeding therapy programs

# EOSINOPHILIC ESOPHAGITIS

# EOSINOPHILIC ESOPHAGITIS (EOE)

"A chronic disease of the esophagus that is often confused with gastroesophageal reflux disease but is unresponsive to treatment with proton pump inhibitors." (Chadha et al. 2014)

- Increasing reports of EoE most likely due to increased awareness
- Estimated US & European incidence = 1.3 to 12.8/100,000 children and adults (Dellon 2014)

# EOSINOPHILIC ESOPHAGITIS (EOE)

**Common symptoms:**

- Young children
  - Vomiting
  - Poor appetite
  - Poor growth
- Older children
  - Abdominal pain

**Long-term complications:**

- Fibrosis
- Stricture formation
- Food impaction

(Chawla et al, 2016)

# EOSINOPHILIC ESOPHAGITIS (EOE)

- Diagnosed via an EDG (esophagogastricduodenoscopy)
  - Endoscopy that examines the esophagus, stomach, and first portion of the duodenum (small intestine)
    - completed under anesthesia
  - Obtain biopsies that are examined for the presence of eosinophils
    - Must see a minimum density of a predetermined number of eosinophils per biopsy to diagnosis EoE

# EOSINOPHILIC ESOPHAGITIS (EOE)

- **Common course of treatment at CMH:**
  - High-dose PPI
  - Re-scope in 8 weeks
  - If EoE is still present, options include:
    - Dietary therapy
    - Topical steroids
- Therapy plan
  - Skill building
  - Address oral aversion
  - When the EoE is well managed, begin feeding therapy to add foods and increase volume of oral intake

# EOSINOPHILIC ESOPHAGITIS (EOE)

## Dietary therapy:

- Empiric six-food elimination diet
  - Dairy, egg, wheat, soy, peanut/tree nuts, seafood
- Targeted elimination diet
  - foods are eliminated based on allergy testing (skin-prick)
- Elemental diet
  - amino acid based with fats, sugars, vitamins and minerals
  - EO28 Splash, Neocate, Elecare, Nutramigen AA
- Very challenging to implement dietary changes when intake is restricted and/or variety is very limited

# EOSINOPHILIC ESOPHAGITIS (EOE)

## Topical Steroids:

- Swallowed budesonide
- Swallowed fluticasone

- Stopping the topical steroid will result in elevated eosinophils because the foods that are causing the issue have not been eliminated
- Commonly used in our GI MDFC population
  - As oral intake improves, may transition to an elimination diet

# LARYNGOMALACIA

# LARYNGOMALACIA

**"A congenital anomaly of the larynx leading to inward collapse of the supraglottic airway with inspiration."**

- Diagnosed via flexible endoscopy
- Characteristics include:
  - Inspiratory prolapse of the arytenoids
  - Redundant arytenoid mucosa
  - Shortened aryepiglottic folds
  - Omega-shaped or tubular epiglottis

(Bedwell et al. 2016; Simons et al. 2015)

# LARYNGOMALACIA

- Most common congenital laryngeal anomaly
- Most frequent cause of stridor in infants
  - starts in the first few weeks of life
  - Peaks at ~6 months of age
  - Most symptoms resolve by 18-24 months
- Commonly associated with:
  - GERD
  - Feeding difficulties
  - Dysphagia including aspiration
  - Obstructive sleep apnea

(Bedwell et al. 2016; Simons et al. 2015)

# LARYNGOMALACIA

- Possible causes
  - Anatomic
    - tissue redundancy that leads to supraglottic obstruction
    - Immature or weak laryngeal cartilage contributes to obstruction
  - Inflammatory
    - GERD (associated but unclear if it is a cause)
  - Neurological
    - Hypotonia
    - Impaired neuromuscular control

(Bedwell et al. 2016; Simons et al. 2015)

# Dysphagia & Feeding Difficulties

- Incidence of dysphagia and aspiration in patients with laryngomalacia is unknown (Simons et al. 2015)
- Impacts coordination of the suck-swallow-breathe pattern

# LARYNGOMALACIA

**Laryngomalacia and Swallowing Function in Children (Simons et al. 2015)**

- 324 patients
  - Mild laryngomalacia = 62.7%
  - Moderate = 28.7%
  - Severe = 8.6%
- Severity was not impacted by gender, age of onset or medical comorbidities
  - Severe laryngomalacia tended to lead to earlier diagnosis and greater prevalence of symptoms such as apnea, cyanosis, failure to thrive and retractions

## Simons et al. 2015 (continued)

- Medical comorbidities included:
  - GERD (226, 69.8%)
    - patients with moderate to severe laryngomalacia were more likely to have GERD compared to mild cases
  - Down syndrome (3.1%)
  - Neurological impairment (6.5%)
  - Congenital heart disease (0.9%)

# LARYNGOMALACIA

**Simons et al. 2015 (continued)**

**Results:**

- Dysphagia or feeding difficulties =163 of 324 patients (50.3%)
  - Severity of laryngomalacia did not have a significant effect on swallowing dysfunction
- Failure to thrive/poor weight gain = 31 patients (9.6%)
- Comorbidities were not associated with increased severity of laryngomalacia
- "Swallow studies are frequently abnormal in laryngomalacia patients presenting both with and without subjective symptoms of dysphagia or feeding difficulty."

# LARYNGOMALACIA

**How to help:**

- Researchers from the Simons et al. 2015 study planned to implement the following clinical care pathway in ADT Clinic:
  - Caregiver report (guided questioning) re: swallowing symptoms
  - Clinical swallowing evaluation with speech pathology
  - At least one baseline instrumental swallowing assessment
    - "The sensitivity of clinical evaluation to detect laryngeal penetration and tracheal aspiration was low, as the majority of aspiration events were silent" (Gasparin et al. 2017)
      - 10 Patients with laryngomalacia and 19 with glossoptosis

# LARYNGOMALACIA

**How to help (continued):**

- External respiratory pacing to improve suck-swallow-breathe coordination
  - After the baby takes 2-3 sucks, tip the bottle down to remove the milk from the nipple (do not remove the nipple from the baby's mouth). After the baby swallows and takes a breath, tip the bottle up to fill the nipple with milk.
  - Repeat this cycle as needed throughout the feeding. If the baby swallows and takes a breathe after 2-3 sucks, you do not need to tip the bottle down.
  - As the baby's feeding skills improve, the need for pacing should decrease
  - Typically "teach" this skill with bottle feedings then improved pacing transfers to breastfeeding

# LARYNGOMALACIA

**How to help (continued):**

- Positioning
  - Elevated side-lying
- Adjusting flow rate for bottle feedings
  - "Just right" balance
- Thickened liquids may be helpful based on VFSS or FEES
  - Do not recommend thickening without an instrumental swallow study

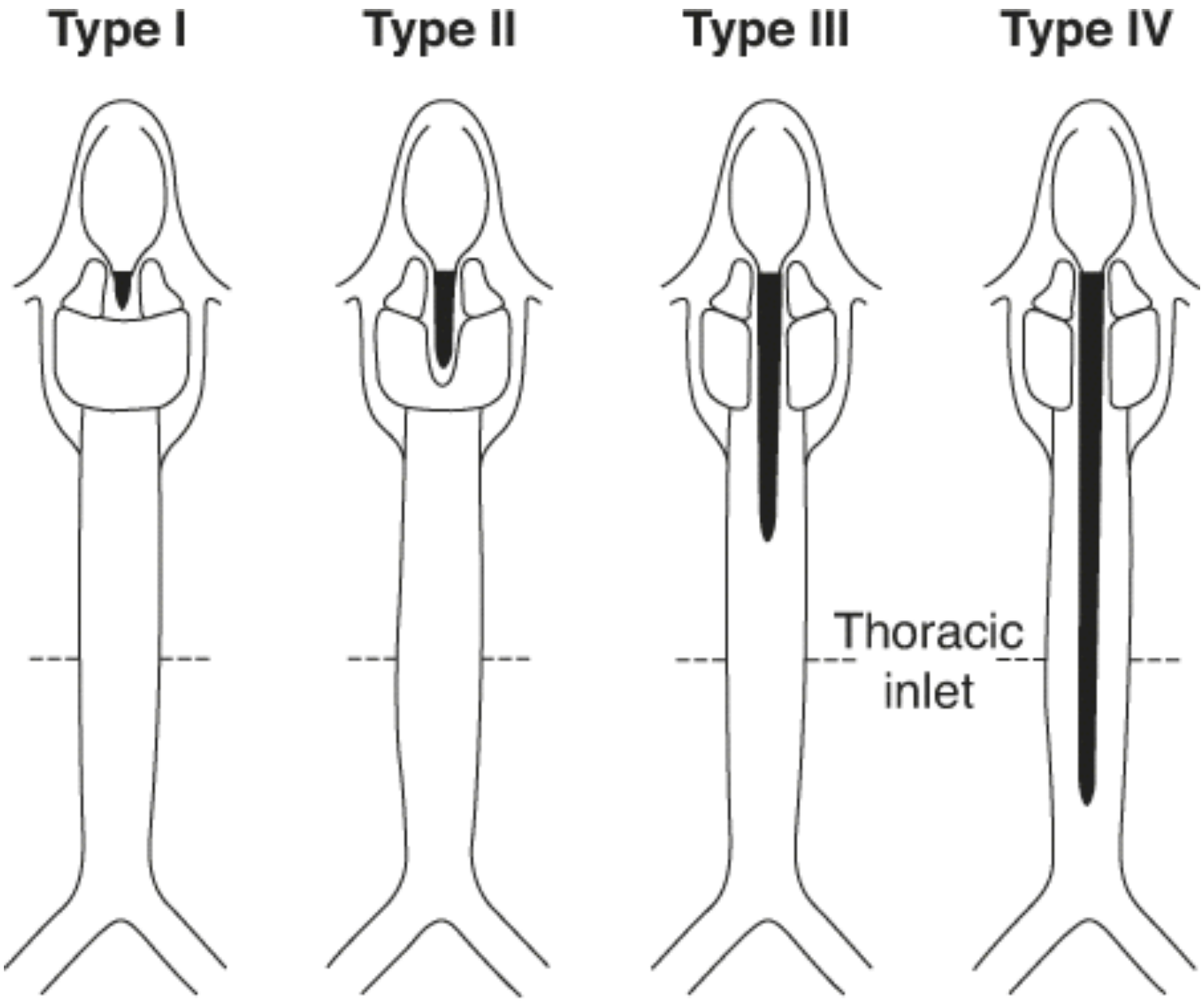
# LARYNGEAL CLEFT

# LARYNGEAL CLEFT

"A rare congenital anomaly in which there is incomplete separation of the aerodigestive tract due to a midline defect in the common wall between the laryngotracheal and esophageal lumens."

(Osborn et al. 2014)

- Grade I to IV
  - I = gap located above the vocal folds
    - is this a variant of normal?
  - II = below the vocal folds
  - III = extends below the larynx into the trachea
  - IV = may go all the way to the bottom of the trachea




Source: Lalwani AK: *CURRENT Diagnosis & Treatment in Otolaryngology – Head & Neck Surgery, 3rd Edition:* www.accesssurgery.com

# LARYNGEAL CLEFT

- Causes dysphagia because the patient may not be able to adequately close the airway and boluses enter the trachea through the cleft

- Commonly associated with other airway anomalies or syndromes with craniofacial, aerodigestive or neurological effects (Osborn et al. 2014)
  - Also see the need for long-term non-oral feedings in some patients

- Diagnosed via microlarygoscopy and bronchoscopy
  - Unable to identify on a VFSS or FEES
  - May be able to see signs that would warrant a referral to ENT
    - Where is the barium entering the sub glottal space?

# LARYNGEAL CLEFT

- Treatment options
  - Small clefts (type I and II)
    - May not cause symptoms
    - If symptomatic, manage with medical and feeding modifications
  - Some small clefts and all type III and IV
    - surgical intervention
      - goal = prevent aspiration and pulmonary compromise
  - At Children's Mercy, typical options include
    - Gel foam injection
    - Supraglottoplasty

(Osborn et al. 2014)

# LARYNGEAL CLEFT

**Swallowing Function After Laryngeal Cleft Repair: More than Just Fixing the Cleft (Osborn et al. 2014)**

- 60 patients
  - Grade I = 21
  - Grade II = 21
  - Grade III = 17
  - Grade IV = 1
- After repair (and possible revision)
  - 34 children has a normal swallow
  - 12 = some degree of penetration
  - 14 = some degree of aspiration

# LARYNGEAL CLEFT

**Swallowing Function After Laryngeal Cleft Repair: More than Just Fixing the Cleft** (Osborn et al. 2014; continued)

- Feeding recommendations
  - 43 were able to take all consistencies by mouth with no-minimal modifications
  - 11 = modified consistencies
  - 6 = unsafe for oral intake

# LARYNGEAL CLEFT

**Swallowing Function After Laryngeal Cleft Repair: More than Just Fixing the Cleft (Osborn et al. 2014; continued)**

- No association between cleft type and final feeding recommendations
- Neurological comorbidities (CHARGE, Opitz, cerebral palsy, trisomy 21, global developmental delays) and g-tube use were associated with feeding modifications
  - 6 times greater risk for neurological concerns
  - 3.6 times greater need for diet modification
- 32 patients were cleared for oral intake of all consistencies within 1 year
  - 11 took more than 1 year

# LARYNGEAL CLEFT

**Swallowing Function After Laryngeal Cleft Repair: More than Just Fixing the Cleft** (Osborn et al. 2014; continued)

- Results:
- 28% of children remained NPO or required the use of thickeners to achieve adequate airway protection after surgery
    - Neurodevelopmental delay = most likely to fall in this category
- Recommendations:
    - swallow evaluations at 3, 6, 12 and 24 months post repair
    - chance of recovering normal swallow function greater than 2 years post-repair is small

# LARYNGEAL CLEFT

How to help:

- Clinical feeding evaluation and an instrumental swallow study prior to repair
- Follow-up swallow assessments following repair
  - Revisions
  - May still be at risk for aspiration even with a successful repair
  - Type of instrumental assessment and timing is important
    - Hersh et al. 2016 found that each child participated in 3.24 VFSS which was the equivalent of 30.6 chest x-rays
- Modifications may be helpful:
  - Thickened liquids
  - Positioning
  - Pacing
- Referral to ENT

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# QUESTIONS?

# THANK YOU!

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