

A Novel Approach in the Management of Failure to Thrive within the Cleft Lip & Palate Patient Population

Presenters:

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Learning Objectives:

- Discuss the challenges and hurdles associated with the nutrition management of cleft lip and palate patients
- Review literature and research related to nutritionally managing infants who struggle with failure to thrive
- Review case studies of CLP infants experiencing failure to thrive

Notes:

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Disclosures

Natalie Seabolt honorarium provided by Nutricia

None pose any conflict of interest for this presentation

Hillary Hart MS, RD, CNSC is employed by Nutricia North America
The opinions reflected in this presentation are those of the speaker and independent of Nutricia North America

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SUPPORTS THE USE OF
HUMAN MILK WHEREVER
POSSIBLE**

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Learning Objectives

01 Discuss the challenges and hurdles associated with the nutrition management of cleft lip and palate patients	02 Review literature and research related to nutritionally managing infants who struggle with failure to thrive	03 Review case studies of CLP infants experiencing failure to thrive	04 Q&A ask the expert, Natalie Seabolt DNP, RD, PNP
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How often do you manage the nutrition of infants with a Cleft Lip or Cleft Palate?

- A. Never**
- B. Rarely (a few times annually)**
- C. Periodically (a few times a month)**
- D. Frequently (on a weekly basis)**

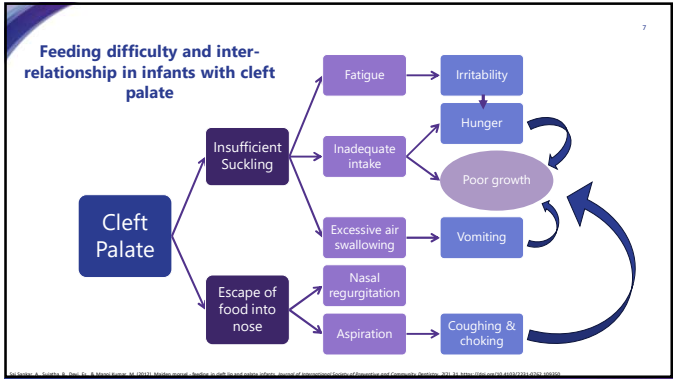
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Prevalence of Cleft Lip and Palate

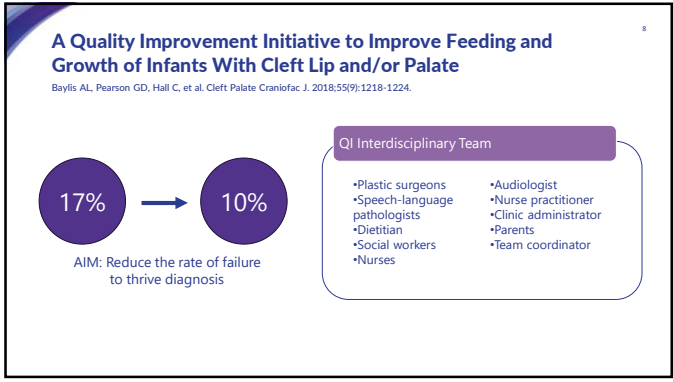
- Affecting 1/700 infants globally
- Most common craniofacial congenital anomaly globally
- 15% are related to syndromes
- Genetic and environmental factors
- Higher incidence in Asian, Native American and Hispanic decent
- More common in males



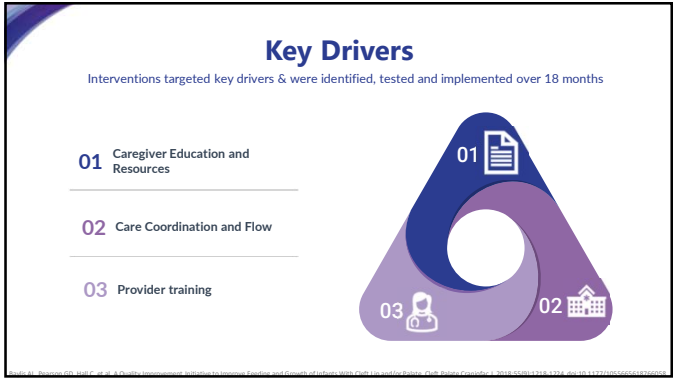
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Outcomes

Primary: percentage of new CLP patients with failure to thrive

- Rate for FTT decreased from 17% to 7% (p<0.003)

Secondary: Frequency of hospitalization for infants with CLP with primary reason for diagnosis of feeding difficulties or FTT

- Frequency improved from 1/30 days to 1/118 days

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Surgery and CLP patients – Why is nutrition important?

Promotion of Wound Healing

CLP children can undergo many surgical interventions throughout their lifetime

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Surgery and CLP patients – Why is nutrition important?

Promotion of Wound Healing

Decreased Time Spent on Mechanical Ventilation

CLP children can undergo many surgical interventions throughout their lifetime

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Surgery and CLP patients –
Why is nutrition important?

- Promotion of Wound Healing
- Decreased Time Spent on Mechanical Ventilation
- Reduced Time Spent in ICU

CLP children can undergo many surgical interventions throughout their lifetime

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Surgery and CLP patients –
Why is nutrition important?

- Promotion of Wound Healing
- Decreased Time Spent on Mechanical Ventilation
- Reduced Time Spent in ICU
- Appropriate Immune System Function

CLP children can undergo many surgical interventions throughout their lifetime

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6 ways the US Standard of Care of Concentrating Infant Formula Fails to Meet Your Standards

- Troubling Tolerability
- The step-up slowdown
- Insufficient Protein
- Inadequate Hydration
- Mix-Ups and Contamination
- Unbalanced Nutrition

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A novel approach: energy- and nutrient-dense formula



- Higher nutrient intake^{1,2,3,6}
- Helps meet nutrient goals sooner^{13,6}
- Supports weight gain / catch-up growth^{2,7,8}
- Supports positive nitrogen balance & anabolism⁴⁻⁶
- Studied in infants with CHD^{7,6-8}

*Prepared as well as 20 kcal/oz or standard infant formula. Infants <12 weeks of age may benefit from a graded introduction to ENDF. 1. Food & Nutrition Research 2023; 29: 1-10. 2. Pediatrics 2023; 151: e20222502. 3. Pediatrics 2023; 151: e20222502. 4. Pediatrics 2023; 151: e20222502. 5. Pediatrics 2023; 151: e20222502. 6. Pediatrics 2023; 151: e20222502. 7. Pediatrics 2023; 151: e20222502. 8. Pediatrics 2023; 151: e20222502. 9. Pediatrics 2023; 151: e20222502. 10. Pediatrics 2023; 151: e20222502. 11. Pediatrics 2023; 151: e20222502. 12. Pediatrics 2023; 151: e20222502. 13. Pediatrics 2023; 151: e20222502.

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Definition of ENDF:

- 30 kcal/ounce term infant formula
- 2.6g of protein / 100 kcal
- Lower osmolality (AAP suggests <400 mOsm/L)
- Well tolerated and supports growth
- Ready-to-feed sterile liquid
- Nutritionally complete
- Can be used to supplement infants consuming breastmilk

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ENDF Indications

For the dietary management of

term infants and young children	0-18 months up to 19 lbs 13 oz (9 kg)
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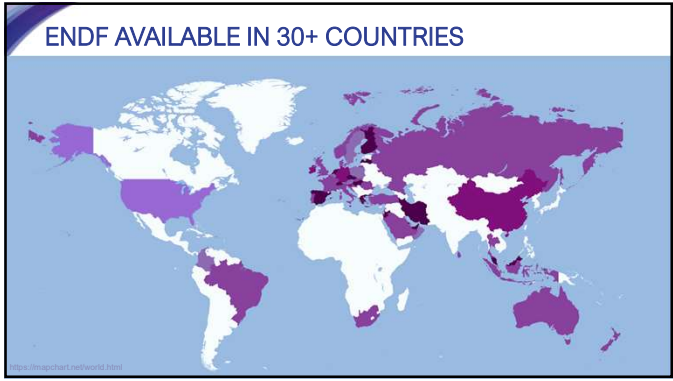
with or at risk of

growth failure	increased energy requirements	fluid restrictions
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due to conditions such as:

congenital heart disease	chronic lung disease	respiratory syncytial virus
neurological syndrome or neuro-disabilities	cystic fibrosis	non-disease-related failure to thrive

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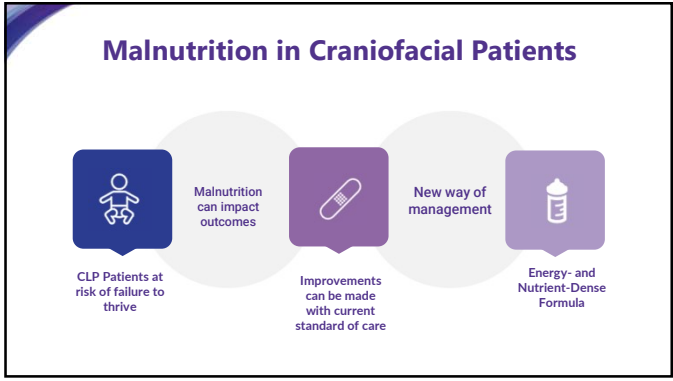


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Which practice do you utilize when feeding FTT infants with Cleft Lip and Palate?

- A. Increase the volume or frequency of feedings
- B. Concentrate powdered formula
- C. Use a higher-calorie formula at a standard concentration
- D. Start with a base and then supplement or fortify with modulators
- E. All of the above
- F. None of the above

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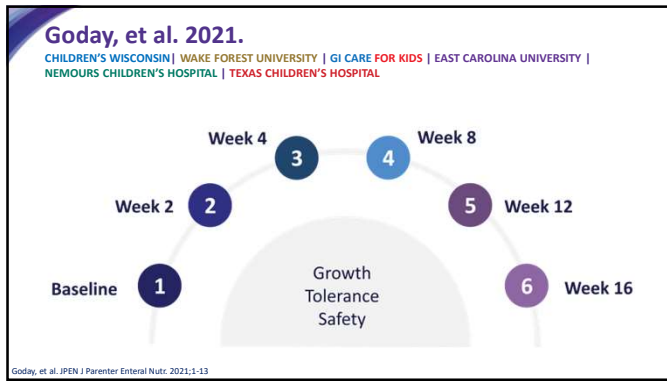
Goday, et al. 2021.
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 NEMOURS CHILDREN'S HOSPITAL | TEXAS CHILDREN'S HOSPITAL

Study Population: n=26

- Route of nutrition: PO or enteral
- Age: 1-8 months
- Diagnosis: malnutrition
 - Weight-for-length z-score \leq -1.0
 - Weight gain velocity z-score \leq -2.0 over 4-8 weeks
- Expected Intake: \geq 80% from ENDF for 16 weeks

Goday, et al. JPEN J Parenter Enteral Nutr. 2021;1-13
 PO = per os; ENDF = energy and nutrient dense formula; CHD = congenital heart defects

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Goday, et al. 2021.
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Outcomes: Nutrient Intake

	kcal/kg/d
Total energy intake	123±32
ENDF intake	116±32

94%

Goday, et al. JPEN J Parenter Enteral Nutr.

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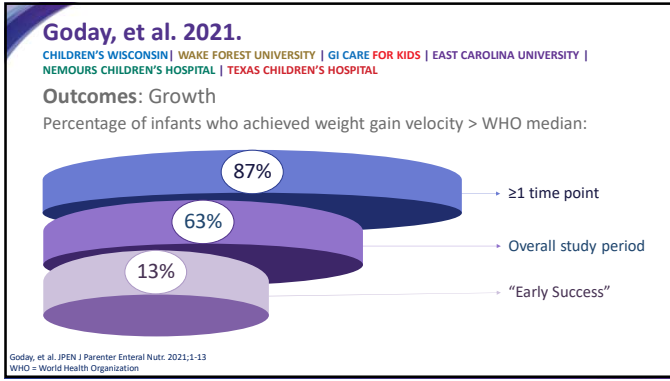
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Outcomes: Growth

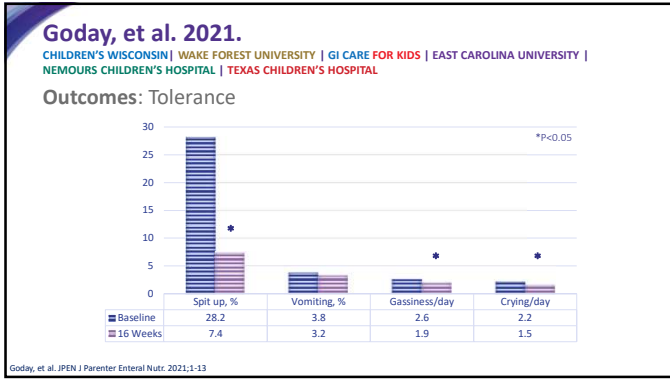
Weight-for-Age	Length-for-Age	Weight-for-Length	Head Circumference
+0.86 ± 0.74 mean WAZ from baseline (p=0.0001)	+0.25 ± 0.61 mean LAZ from baseline (p=0.003)	+0.77 ± 0.81 mean WLZ from baseline (p=0.0001)	+0.54 ± 0.68 mean HCZ from baseline (p=0.001)

Goday, et al. JPEN J Parenter Enteral Nutr.
WAZ = weight-for-age z-score; LAZ = length-for-age z-score; WLZ = weight-for-length z-score; HCZ = head circumference z-score

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We are honored to introduce...

Natalie Seabolt, DNP, RD, PNP
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Le Bonheur Children's Hospital

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Cleft Lip/Palate Statistics

- Prevalence per 10,000 live births
- Cleft Lip (CL) more common in Males & Left side vs Right side
- Cleft palate (CP) twice as likely to be associated with syndrome than CL

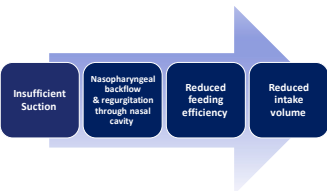
Cleft Lip with or without Cleft Palate	10.00	3,979	1 in 1,000
Cleft Lip with Cleft Palate	6.40	2,518	1 in 1,563
Cleft Lip Only	3.56	1,402	1 in 2,807
Cleft Palate Only	5.93	2,333	1 in 1,687

Prevalence of Cleft Lip & Cleft Palate | Data & Statistics | National Institute of Dental and Craniofacial Research. (n.d.). www.nidcr.nih.gov/health-topics/cleft-lip-palate

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Feeding Concerns with Cleft Lip/Palate

Open structures reduces seal and suction pressures and lead to:



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graph LR; A[Insufficient Suction] --> B[Nasopharyngeal backflow & regurgitation through nasal cavity]; B --> C[Reduced feeding efficiency]; C --> D[Reduced intake volume];
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Interventions

- Feeding equipment/Biomedical assists
- Patient-led compression system vs. assisted delivery
- Feeding obturators vs. NAM vs. nasal elevators
- Lip approximation

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Case Study #1

Nutrition Problem(s)

- 1) Z-score -1.80
- 2) Ineffective feeding efforts
- 3) Goal to gain weight at or above average velocity

Feeding History

- 1) DOS #1
 - Breastfeeding poorly
 - EBM 1.5-2 oz Q2-3 hours
 - 25 minutes on average to complete feedings

Factors that may impact growth

- 1) High metabolic needs r/t genetic syndrome
- 2) Inability to maintain latch
- 3) Prolonged feeding times
- 4) Abnormal anatomy

Two-week-old female with Saerthe-Chotzen syndrome cleft palate, craniosynostosis & tongue tie

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Case Study #1 Cont'd

Feeding Changes

1. DOS 1: Lactation Consult
2. DOS 2: 1ml canula @10oz EBM + food diary
3. DOS 3: Use 1/2 ENDF and 1/2 EBM & Canula for all feeds
4. DOS 4/5 Regimen continued

Growth Recovery Notes

DOS1: Z-score -1.80
 DOS2: Z-score -2.98
 DOS 3: Z-score -3.28
 DOS4: Z-score -2.81
 DOS5: Z-score -2.71

Success: 10lbs by Surgery Date

Caregiver Impact

1. Parents equipped to help infant grow
2. WIC provided formula
3. Craniosynostosis surgery with optimal nutritional status

Two-week-old female with Saerthe-Chotzen syndrome cleft palate, craniosynostosis & tongue tie

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Case Study #1 Cont'd

Two-week-old female with Saerthe-Chotzen syndrome cleft palate, craniosynostosis & tongue tie

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Case Study #2

Nutrition Problem(s)

- 1) 25th percentile for weight
- 2) Increasing nutritional needs for growth
- 3) Dysphagia contributing to increased nutritional needs

Feeding History

- 1) DOS 1: Standard infant formula (4oz at unknown intervals)
- 2) >25 minutes to feed
- 3) Coughing and choking

Factors that may Impact growth

- 1) Cleft Palate
- 2) Suspected Aspiration/Dysphagia
- 3) Premature Weaning
- 4) Parental intellectual deficit

Five-month-old female with Cleft Lip and Palate

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Case Study #2 Cont'd

Feeding Changes

- 1) DOS 1: Change all feeds to ENDF Infant Formula
- 2) Order MBS
- 3) Slower nipple

Growth Recovery

- 1) DOS 1: 25th percentile
- 2) DOS 2/3: Process of obtaining ENDF from WIC
- 3) DOS 4: Weight increased +27g/d X 11 days
Success! 18.5 lbs. by Surgery Date

Caregiver Impact

- 1) Caregiver felt equipped to help baby grow
- 2) WIC provided formula
- 3) Parents and surgeon comfortable with nutritional status prior to surgery

Five-month-old female with Cleft Lip and Palate

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Case Study #2 Cont'd

Five-month-old female with Cleft Lip and Palate

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IN SUMMARY

Infants with CLP have multiple nutritional challenges:

- Insufficient sucking
- Fatigue
- Inadequate milk intake
- Poor weight gain
- Excessive air swallowing
- Multiple surgeries throughout lifetime
- Vomiting/aspiration



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IN SUMMARY

Infants with CLP have multiple nutritional challenges:

- Insufficient sucking
- Fatigue
- Inadequate milk intake
- Poor weight gain
- Excessive air swallowing
- Multiple surgeries throughout lifetime
- Vomiting/aspiration

Assessment:

- Assessment based on severity of malformation
- DR's for the typically developing child
- Feeding devices to maximize nutrition
- Rule of 10's for surgery
- Adapt feeding techniques as necessary
- Monitor micronutrients (Vitamin D)
- Supplement as needed



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IN SUMMARY

Infants with CLP have multiple nutritional challenges:


- Micronutrient deficiencies
- Volume restrictions
- Bone mineral density loss
- GI complications
- Muscle wasting
- Multiple surgeries throughout one's lifetime

Assessment:

- Assessment based on severity of malformation
- DR's for the typically developing child
- Feeding devices to maximize nutrition
- Rule of 10's for surgery
- Adapt feeding techniques as necessary
- Monitor micronutrients (Vitamin D)
- Supplement as needed

Multiple options for feeding infants with CLP and malnutrition:

- Specialty feeding bottles
- ENDF
- NAM feeding plate
- Canola oil
- Modular products
- Encourage breastfeeding when appropriate
- Concentrating infant formula



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Q&A
ASK THE EXPERT: NATALIE SEABOLT DNP, RD, PNP

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