

**© 2023 Nutricia North America** – Nurses may claim CE credit for this webinar. RDs may claim CE credit for this webinar through 5/31/2025. To obtain a certificate of attendance: 1) Complete this [survey](https://nlc.pub/CleftPalate) (<https://nlc.pub/CleftPalate>); 2) Note event code at end of survey; and 3) enter event code at [NutriciaLearningCenter.com](https://nlc.pub/CleftPalate) in 'My NLC Dashboard' to add certificate to your profile.



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



**Natalie Seabolt**  
DNP, RD, PNP  
Nurse Practitioner,  
Pediatric  
Otolaryngology  
Le Bonheur  
Children's Hospital



**Janelle Karrell,**  
APRN, RN, PNP  
Nurse Practitioner  
Medical Science  
Liaison  
Nutricia North  
America

1

---

---

---


---

---

---

---

---



## Disclosures

Natalie Seabolt honorarium provided by Nutricia

*None pose any conflict of interest for this presentation*

Janelle Karrell APRN, RN, MSN employed by Nutricia North America  
*The opinions reflected in this presentation are those of the speaker and independent of Nutricia North America*

2

---

---

---

---

---

---

---

---



**Cleft and Craniofacial Awareness Week**  
May 6<sup>th</sup>-14<sup>th</sup> 2023

3

---

---

---

---

---

---

---

---

## NUTRICIA NORTH AMERICA SUPPORTS THE USE OF BREAST MILK WHEREVER POSSIBLE

4

---

---

---

---

---

---

---

---

### 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

5

---

---

---

---

---

---

---

---

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)

6

---

---

---

---

---

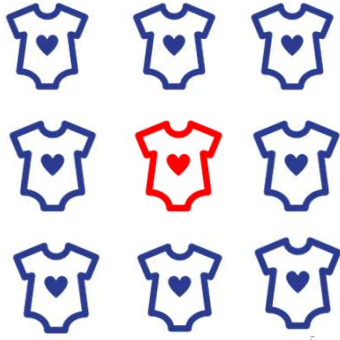
---

---

---

## Prevalence

- 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 descent
- More common in males



About Cleft Lip and Palate (CLP). [www.northeastchildrens.org](http://www.northeastchildrens.org). Retrieved April 23, 2023, from <https://www.northeastchildrens.org/specialties/cleft-lip-and-palate-center/about-cleft-lip-and-palate>

7

---

---

---

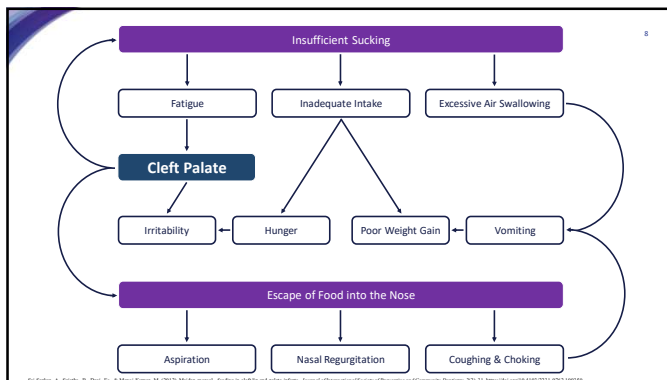
---

---

---

---

---



8

---

---

---

---

---

---

---

---

## 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



9

---

---

---

---

---

---

---

---

## INTRODUCING: A NEW WAY IN FTT MANAGEMENT



- Higher nutrient intake<sup>12,3,6</sup>
- Helps meet nutrient goals sooner<sup>13,6</sup>
- Supports weight gain / catch-up growth<sup>2,7,8</sup>
- Supports positive nitrogen balance & anabolism<sup>4-6</sup>
- Studied in infants with CHD<sup>2,6-8</sup>

\*Tolerated as well as 20 kcal/oz as standard infant formula. Infants <12 weeks of age may benefit from a graded introduction to a higher nutrient formula. CHD = congenital heart disease; FTT = failure to thrive; 1. Evans, et al. J Hum Nutr Diet. 2006;19:559-7. 2. Elkanal, et al. J Pediatr. 2007;152:1001-1004. 3. Elkanal, et al. J Clin Nutr. 2009;28:249-55. 4. Cui, et al. J Pediatr. 2018;192:196-204. 5. de Bont, et al. Arch Dis Child. 2014;99:1014-1018. 6. Elkanal, et al. J Clin Nutr. 2009;28:249-55. 7. Doolittle, et al. J Hum Nutr Diet. 2019;32:3-10. 8. Scheffer, et al. J Pediatr. 2019;192:196-204.

10

---

---

---

---


---

---


---

---

## 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



Endocrine and Clinical Research™ (ENCR)™. Endocrine and Clinical Research. <https://www.endocrine.org/publications-and-clinical-research>

11

---

---

---

---

---

---

---

---

## ENDF Implications







**For the dietary management of**

<b>term infants and young children</b>	0-18 months up to 19 lbs 13 oz (9 kg)
--	--

with or at risk of

<b>growth failure</b>	<b>increased energy requirements</b>	<b>fluid restrictions</b>
-----------------------	--------------------------------------	---------------------------

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

12

---

---

---

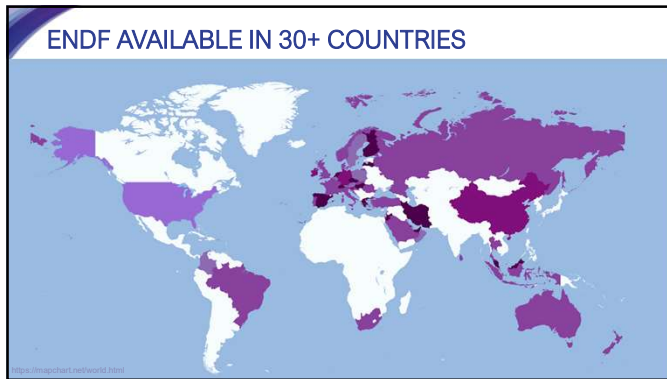
---

---

---

---

---



13

---

---

---

---

---

---

---

---

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

<input type="checkbox"/> A. Increase the volume or frequency of feedings	<input type="text"/>
<input type="checkbox"/> B. Concentrate powdered formula	<input type="text"/>
<input type="checkbox"/> C. Use a higher-calorie formula at a standard concentration	<input type="text"/>
<input type="checkbox"/> D. Start with a base and then supplement or fortify with modulars	<input type="text"/>
<input type="checkbox"/> E. All of the above	<input type="text"/>
<input type="checkbox"/> F. None of the above	<input type="text"/>

14

---

---

---

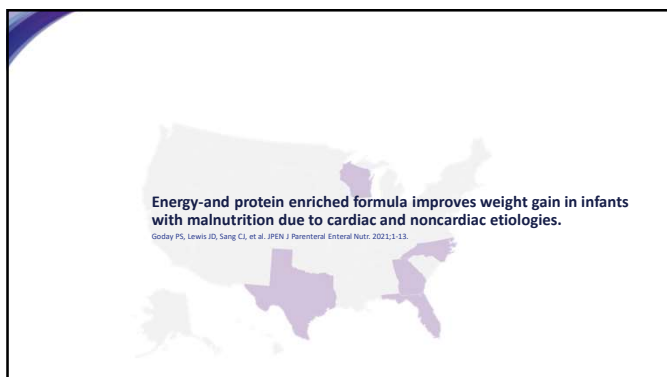
---

---

---

---

---



15

---

---

---

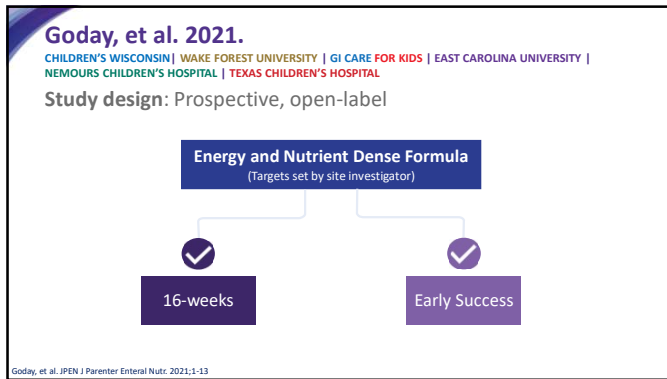
---

---

---

---

---



16

---

---

---

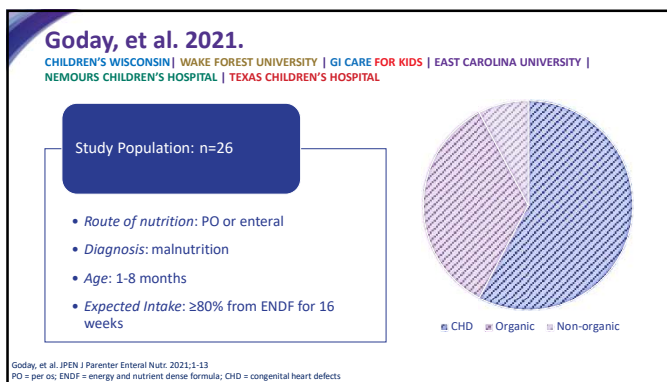
---

---

---

---

---



17

---

---

---

---

---

---

---

---

**Goday, et al. 2021.**  
 CHILDREN'S WISCONSIN | WAKE FOREST UNIVERSITY | GI CARE FOR KIDS | EAST CAROLINA UNIVERSITY |  
 NEMOURS CHILDREN'S HOSPITAL | TEXAS CHILDREN'S HOSPITAL

**Intervention:**

**Infant <12 weeks and orally fed – FADE BY REPLACING FEEDINGS**

- Day 1: Give 3 feeds of original formula & remainder of feedings as ENDF
- Day 2: Give 2 feeds of original formula & remainder of feedings as ENDF
- Day 3: Give 1 feedings of original formula & remainder of feedings as ENDF
- Day 4: All feedings – ENDF

**Child  $\geq 12$  weeks and requiring transition or any drip-fed child – FADE BY BLENDING**

- Day 1: 50% ENDF, 50% old formula
- Day 2: 70% ENDF, 30% old formula
- Day 3: 90% ENDF, 10% old formula
- Day 4: 100% ENDF

Goday, et al. JPN J Parenter Enteral Nutr. 2021;1-13

18

---

---

---

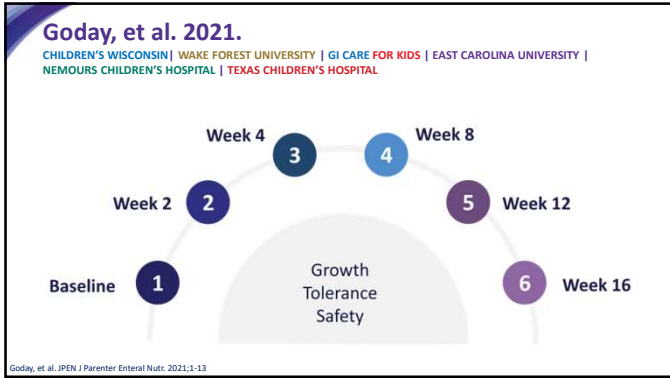
---

---

---

---

---



19

---

---

---

---

---

---

---

---

**Goday, et al. 2021.**  
CHILDREN'S WISCONSIN | WAKE FOREST UNIVERSITY | GI CARE FOR KIDS | EAST CAROLINA UNIVERSITY |  
NEMOURS CHILDREN'S HOSPITAL | TEXAS CHILDREN'S HOSPITAL

**Outcomes: Nutrient Intake**

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

Goday, et al. JPEN J Parenter Enteral Nutr. 2021;1-13

20

---

---

---

---

---

---

---

---

**Goday, et al. 2021.**  
CHILDREN'S WISCONSIN | WAKE FOREST UNIVERSITY | GI CARE FOR KIDS | EAST CAROLINA UNIVERSITY |  
NEMOURS CHILDREN'S HOSPITAL | TEXAS CHILDREN'S HOSPITAL

**Outcomes: Nutrient Intake**

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

94%

Goday, et al. JPEN J Parenter Enteral Nutr.

21

---

---

---

---

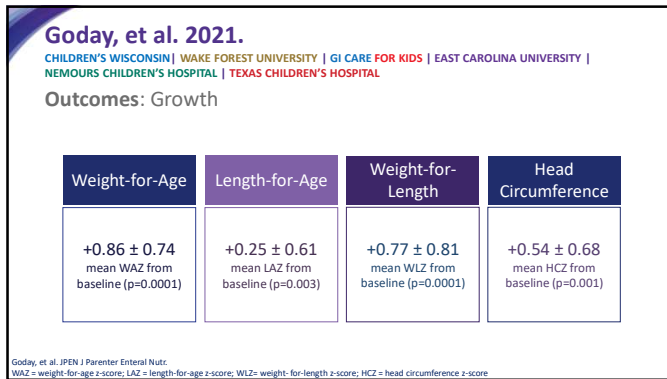
---

---

---

---





22

---

---

---

---

---

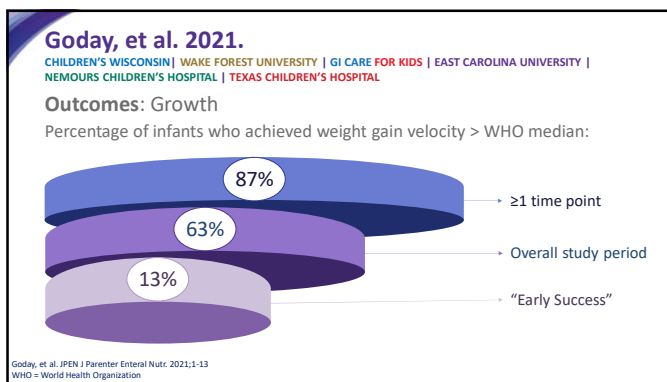
---

---

---

---

---



23

---

---

---

---

---

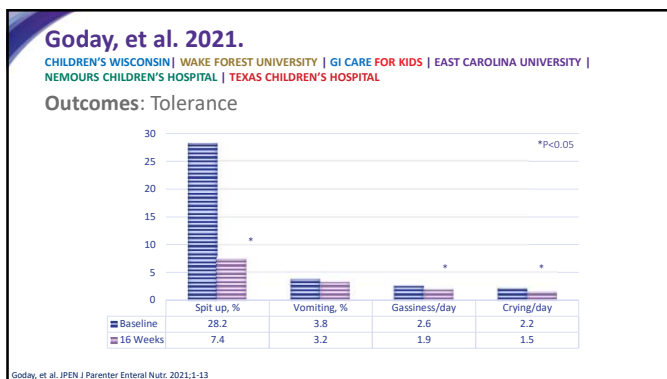
---

---

---

---

---



24

---

---

---

---

---

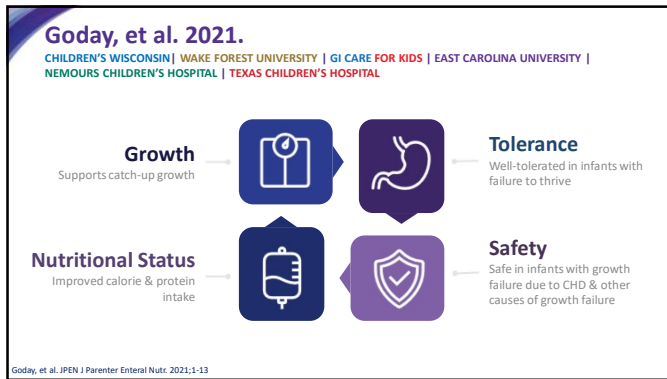
---

---

---

---

---



25

---

---

---

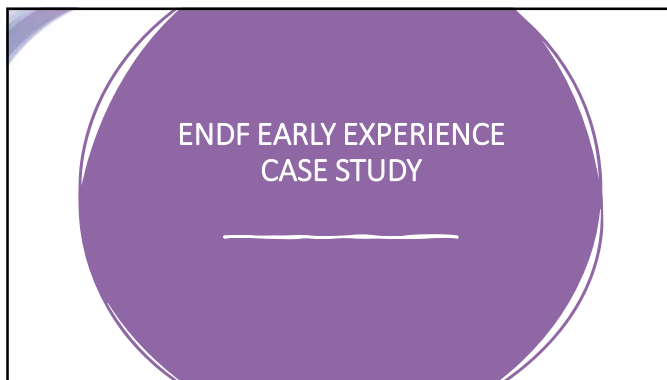
---

---

---

---

---



26

---

---

---

---

---

---

---

---



27

---

---

---

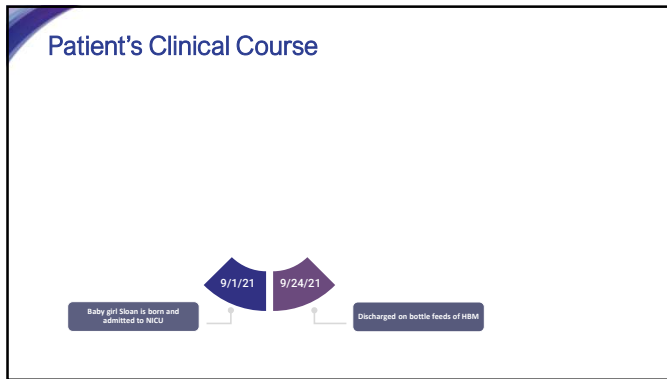
---

---

---

---

---



28

---

---

---

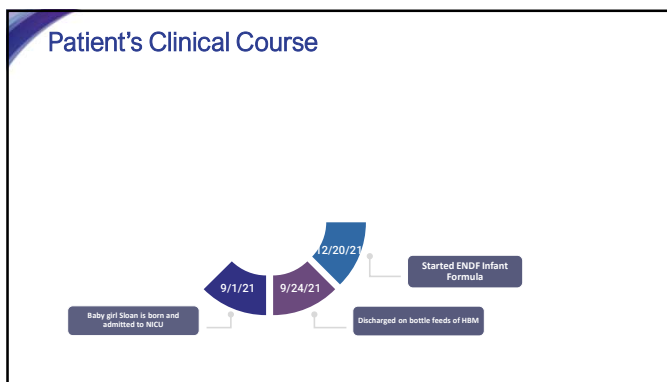
---

---

---

---

---



29

---

---

---

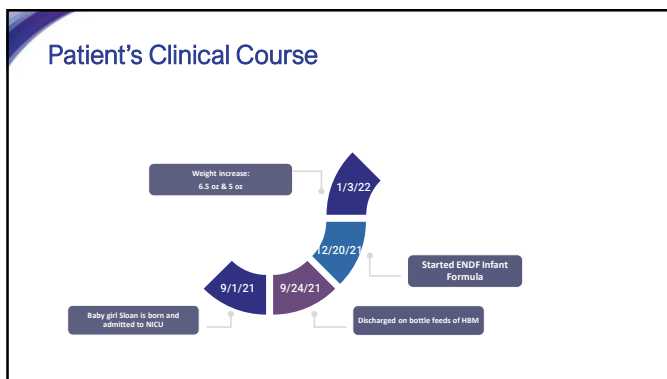
---

---

---

---

---



30

---

---

---

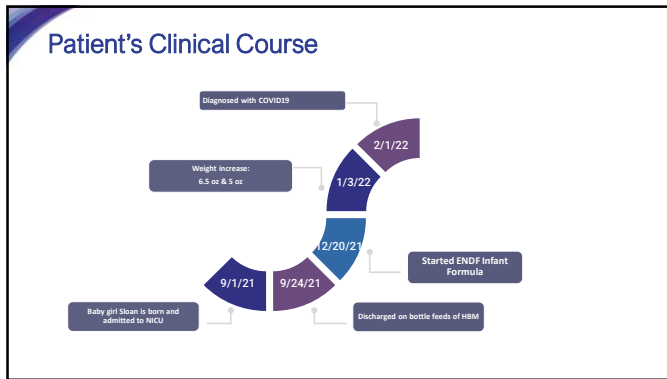
---

---

---

---

---



31

---

---

---

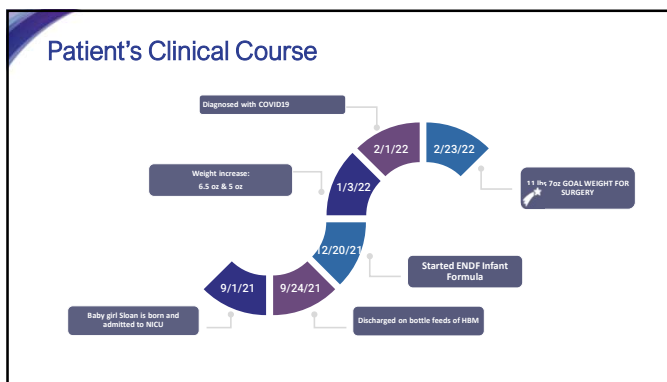
---

---

---

---

---



32

---

---

---

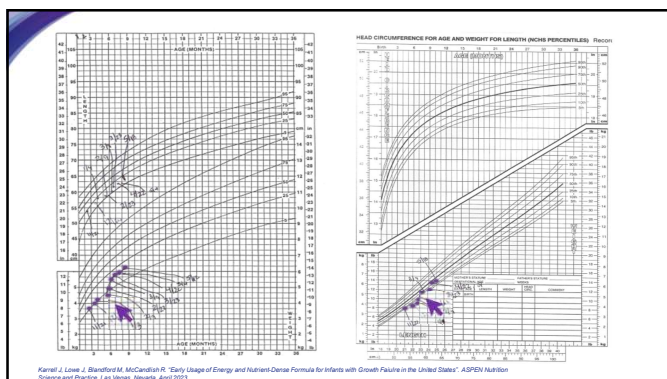
---

---

---

---

---



33

---

---

---

---

---

---

---

---

**Surgery and CLP patients –  
Why is nutrition important?**

Promotion of Wound Healing

CLP children can undergo many surgical interventions throughout their lifetime



Wells, C., & Wicksman, P. E. (2016). Preoperative nutrition and the Pediatric Surgical Patient: Why, how and what? *Anesthesiology*, 124, 17-33. <https://doi.org/10.1016/j.anes.2016.02.006>

34

---

---

---

---

---

---

---

---

**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



Wells, C., & Wicksman, P. E. (2016). Preoperative nutrition and the Pediatric Surgical Patient: Why, how and what? *Anesthesiology*, 124, 17-33. <https://doi.org/10.1016/j.anes.2016.02.006>

35

---

---

---

---

---

---

---

---


**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



Wells, C., & Wicksman, P. E. (2016). Preoperative nutrition and the Pediatric Surgical Patient: Why, how and what? *Anesthesiology*, 124, 17-33. <https://doi.org/10.1016/j.anes.2016.02.006>

36

---

---

---

---

---

---

---

---

**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

April 23  
Wong, C. & Robinson, T.F. (2019). The specific evidence and the Pediatric Surgical Diet: Why, how and what? *Journal of Pediatric Surgery*, 54(4), 1011-1019. 1011

37

---

---

---

---

---

---

---

---

**We are honored to introduce...**

**Natalie Seabolt, DNP, RD, PNP**  
Nurse Practitioner,  
Pediatric Otolaryngology

Le Bonheur Children's Hospital

Honorarium provided by Nutricia  
No conflict of interest for this presentation  
The opinions reflected in this presentation are those of the speaker and independent of Nutricia North America and the speaker's employer

38

---

---

---

---

---

---

---

---

**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.). <https://www.nidcr.nih.gov/research/data-statistics/craniofacial-birth-defects/prevalence>

39

---

---

---

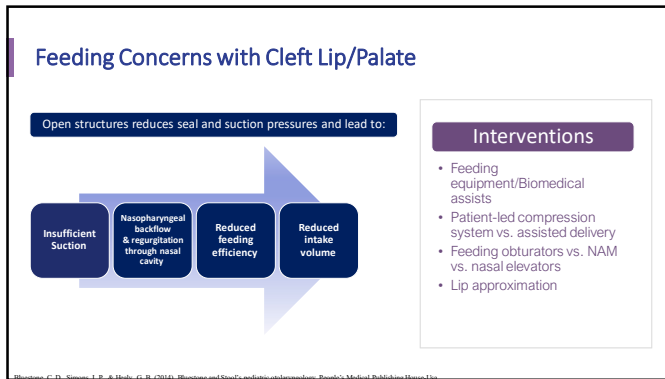
---

---

---

---

---



40

---

---

---

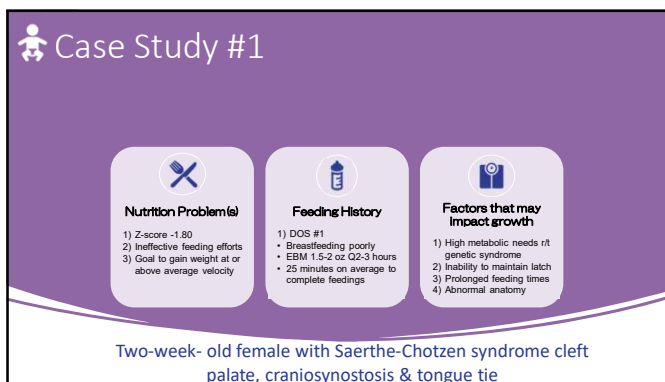
---

---

---

---

---



41

---

---

---

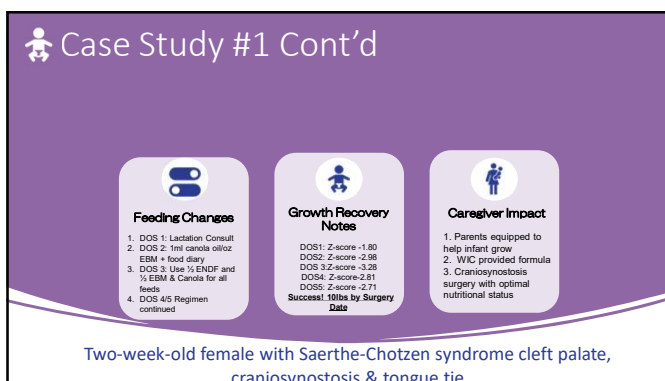
---

---

---

---

---



42

---

---

---


---


---

---


---

---


 **Case Study #2**

 **Nutrition Problem(s)**

- 1) 25<sup>th</sup> 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 male with Cleft Palate**

43

---

---

---


---


---

---


---

---


 **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: 25<sup>th</sup> percentile
- 2) DOS 2/3: Process of obtaining ENDF from WIC
- 3) DOS 4: Weight increased +27g/d X 11 days  
**Successful 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 male with Cleft Palate**

44

---

---

---

---

---

---

---

---

**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



45

---

---

---

---

---

---

---

---




## 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
- DRI'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



46

---

---

---

---

---

---

---

---

## 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
- DRI's for the typically developing child
- Feeding devices to maximize
- Rule of 10's for surgery
- Adapt feeding techniques as necessary
- Monitor micronutrients (Vitamin D)

**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



47

---

---

---

---

---

---

---

---

## References

**NLC**  
NUTRITION LEARNING CENTER

1. Sai Sankar, A., Sujatha, B., Devi, Es., & Manoj Kumar, M. (2012). Maiden morsel - feeding in cleft lip and palate infants. *Journal of International Society of Preventive and Community Dentistry*, 2(2), 31. <https://doi.org/10.4103/2231-0762.109350>
2. Pandya, A. N., & Boorman, J. G. (2001). Failure to thrive in babies with cleft lip and palate. *British Journal of Plastic Surgery*, 54(6), 471-475. <https://doi.org/10.1054/bjps.2001.2638>
3. Baylis, A. L., Pearson, G. D., Hall, C., Madhoun, L. L., Cummings, C., Neal, N., Smith, A., Eastman, K., Stocker, C., & Kirschner, R. E. (2018). A Quality Improvement Initiative to Improve Feeding and Growth of Infants With Cleft Lip and/or Palate. *The Cleft Palate-Craniofacial Journal*, 55(9), 1218-1234. <https://doi.org/10.1177/1055666518766053>
4. Kaye, A., Thaele, K., Swell, A., Chesser, C., Goldkne, C., & Huff, H. (2017). Initial Nutritional Assessment of Infants with Cleft Lip and/or Palate: Interventions and Return to Birth Weight. *The Cleft Palate-Craniofacial Journal*, 54(2), 127-136. <https://doi.org/10.1597/13-163>
5. Goday, P. S., Lewis, J. D., Sang, C. J., George, D. a. R., Mcgoogan, K., Safta, A., Seth, A. K., & Krekel, C. (2021). Energy- and protein-enriched formula improves weight gain in infants with malnutrition due to cardiac and noncardiac etiologies. *Journal of Parenteral and Enteral Nutrition*, 46(6), 1270-1282. <https://doi.org/10.1093/jpen/2309>
6. SUPPORTING COMPREHENSIVE CLEFT CARE THROUGH NUTRITION AND FEEDING 1. (n.d.). Retrieved April 21, 2023, from <https://www.smiletrain.org/sites/default/files/2021-01/nutrition-feeding-trainee-manual.pdf>
7. About Cleft Lip and Palate. (n.d.). [www.nationwidechildrens.org](https://www.nationwidechildrens.org). Retrieved April 21, 2023, from <https://www.nationwidechildrens.org/spa/cleft/cleft-lip-and-palate-center/about-cleft-lip-and-palate/-text=Cleft%20lip%20and%20%20cleft>
8. Prevalence of Cleft Lip & Cleft Palate | Data & Statistics | National Institute of Dental and Craniofacial Research. (n.d.). [www.nidcr.nih.gov](https://www.nidcr.nih.gov). <https://www.nidcr.nih.gov/research/data-statistics/craniofacial/birth-defects/prevalence>
9. Bluestone, C. D., Simons, J. P., & Healy, G. B. (2014). *Bluestone and Stool's pediatric otolaryngology*. People's Medical Publishing House-Usa.
10. "Guidelines and Clinical Resources." ASPEN | Guidelines and Clinical Resources, [https://www.nutritioncare.org/guidelines\\_and\\_clinical\\_resources/](https://www.nutritioncare.org/guidelines_and_clinical_resources/)
11. Karrell, J., Lowe, J., Blandford, M., McCaslin, R. "Early Use of Energy and Nutrient-Dense Formula for Infants with Growth Failure in the United States". ASPEN Nutrition Science and Practice. Las Vegas, Nevada. April 2023.
12. Gillis, C., & Wischmeyer, P. E. (2019). Pre-operative nutrition and the Elective Surgical Patient: Why, how and what? *Anaesthesia*, 74, 27-35. <https://doi.org/10.1111/anae.14506>

48

---

---

---

---

---

---

---

---