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

Presenters:

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

Hillary Hart, MS, RD, CNCS -Medical Science Liaison, Nutricia North America

Live event date:

April 2, 2024- *Recording on NutriciaLearningCenter.com within ~2 weeks of live event*

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:

Nutricia North America supports the use of breast milk wherever possible.

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1

Disclosures

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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

2

NUTRICIA NORTH AMERICA SUPPORTS THE USE OF HUMAN MILK WHEREVER POSSIBLE

3

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

4

How often do you manage the nutrition of infants with a Cleft Lip or Cleft Palate?

A. Never

B. Rarely (a few times annually)

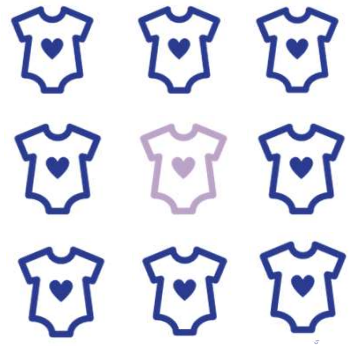
C. Periodically (a few times a month)

D. Frequently (on a weekly basis)

5

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



About Cleft Lip and Palate. (n.d.). Www.nationwidechildrens.org. Retrieved April 21, 2021, from https://www.nationwidechildrens.org/specialties/cleft-lip-and-palate-center/about-cleft-lip-and-

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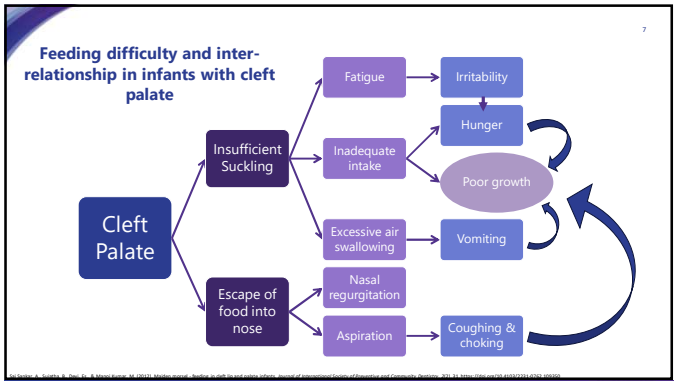

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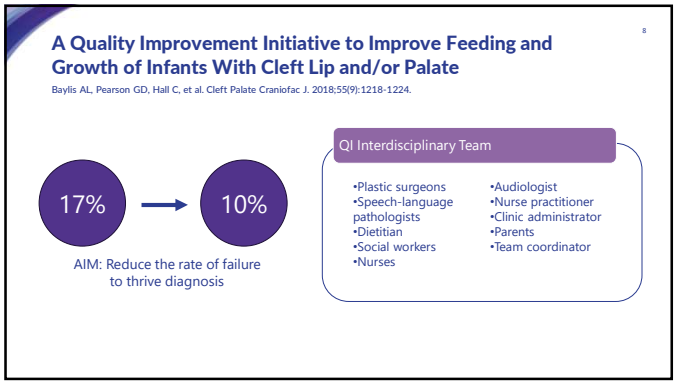

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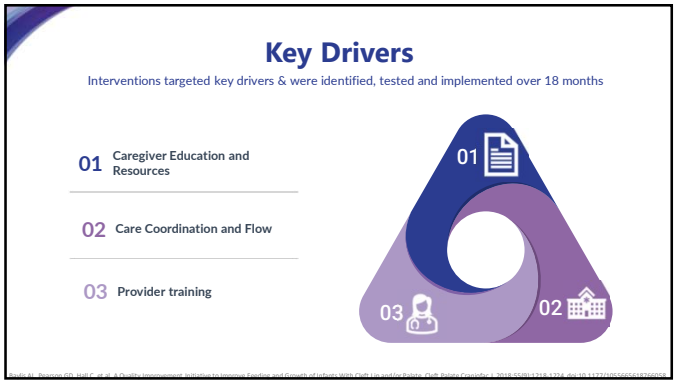

9

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

Kavitt AL, Pearson GD, Hall C, et al. A Quality Improvement Initiative to Improve Feeding and Growth of Infants With Cleft Lip and/or Palate. Cleft Palate Craniofac J. 2018;55(8):1218-1224. doi:10.1177/1055665618766905

10

Surgery and CLP patients – Why is nutrition important?

Promotion of Wound Healing

Gibbs, C. & Wischmeyer, P. E. (2019). Preoperative nutrition and the Elective Surgical Patient: Why, how and what?. Anaesthesia, 74, 77-91. https://doi.org/10.1111/anae.14596

11

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Decreased Time Spent on Mechanical Ventilation

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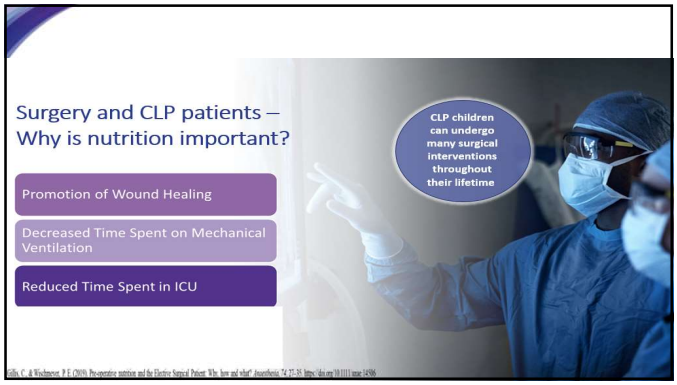

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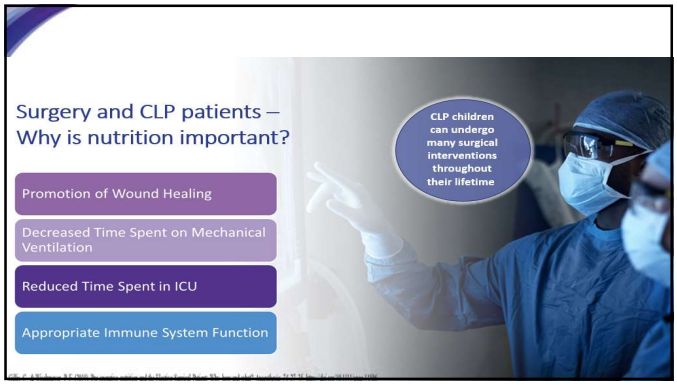

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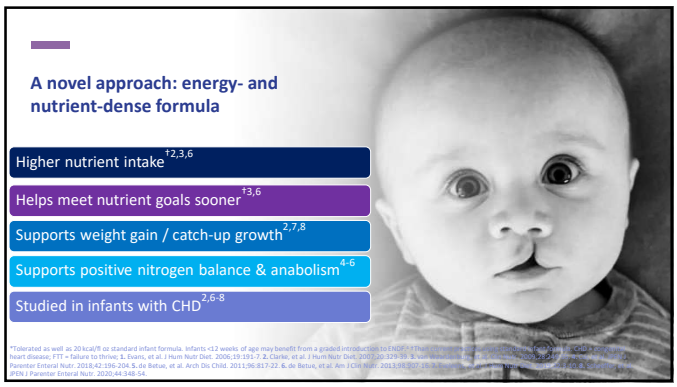

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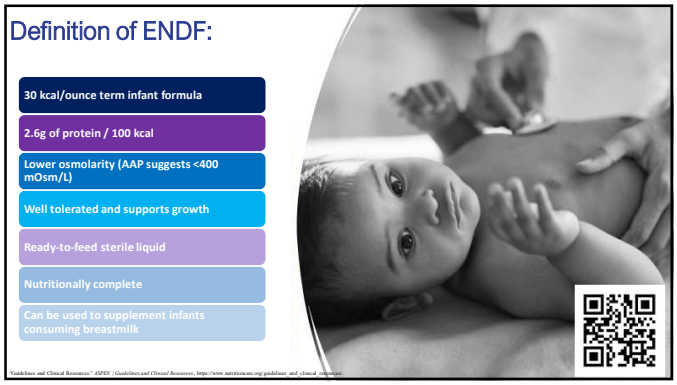

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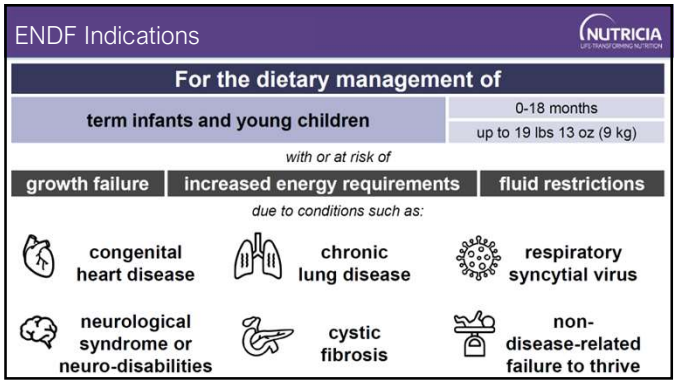
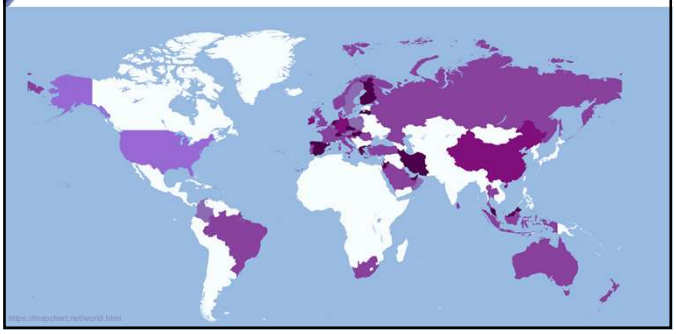


18

ENDF AVAILABLE IN 30+ COUNTRIES



19

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

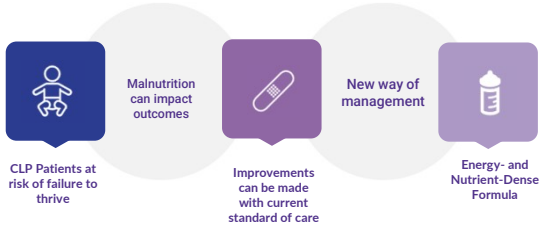
D. Start with a base and then supplement or fortify with modulars

E. All of the above

F. None of the above

20

Malnutrition in Craniofacial Patients



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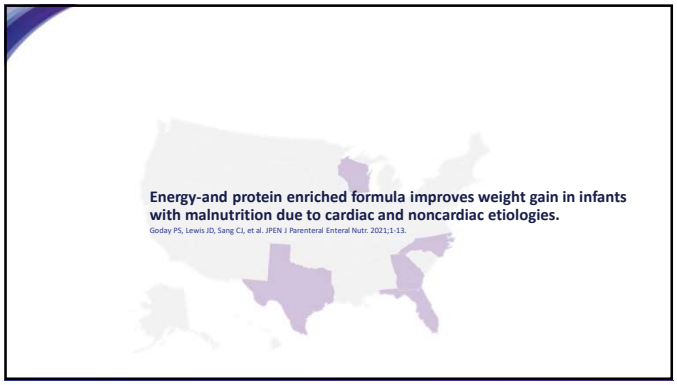

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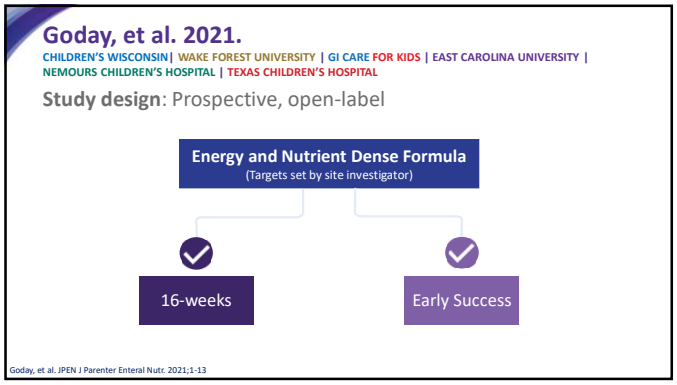

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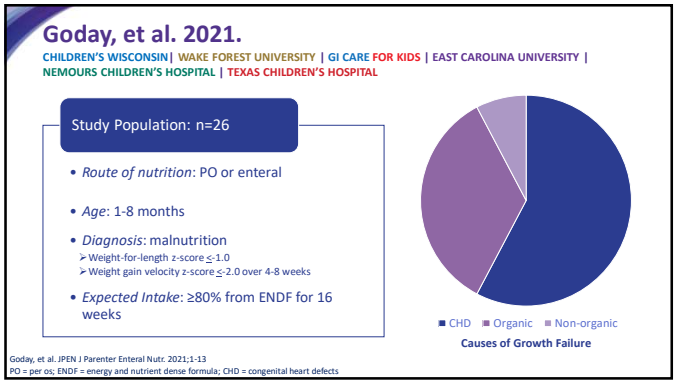

24

Goday, et al. 2021.

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

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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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Goday, et al. 2021.

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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

27

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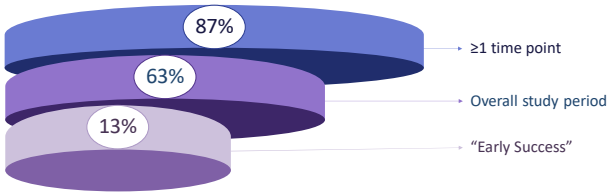
Outcomes: Growth

Percentage of infants who achieved weight gain velocity > WHO median:



Goday, et al. JPEN J Parenter Enteral Nutr. 2021;1-13
WHO = World Health Organization

28

Goday, et al. 2021.

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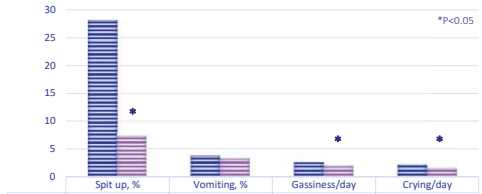
Outcomes: Tolerance



	Spit up, %	Vomiting, %	Gassiness/day	Crying/day
Baseline	28.2	3.8	2.6	2.2
16 Weeks	7.4	3.2	1.9	1.5

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

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Goday, et al. 2021.

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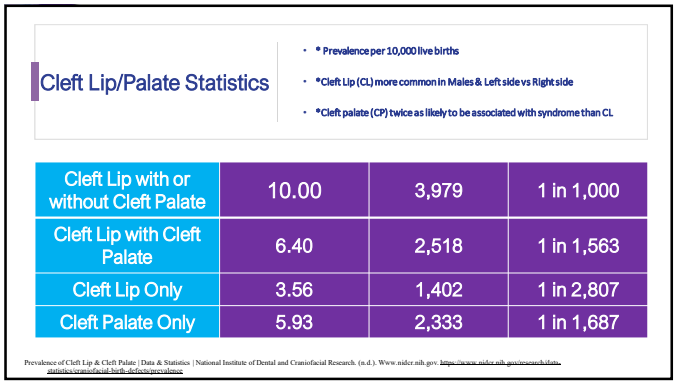
31



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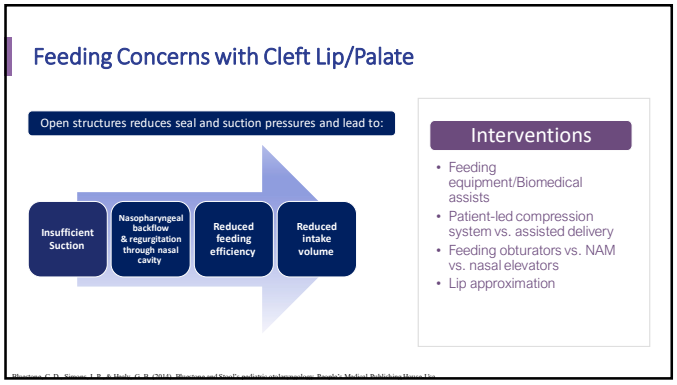


33

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

34

Case Study #1 Cont'd

Feeding Changes

1. DOS 1: Lactation Consult
2. DOS 2: 1ml canola oil/oz EBM + food diary
3. DOS 3: Use ½ ENDF and ½ EBM & Canola 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

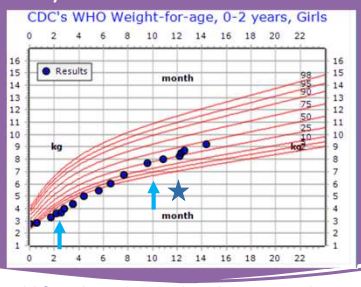
Caregiver Impact

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

35

Case Study #1 Cont'd



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

36

Case Study #2

Nutrition Problem(s)

1) 25th percentile for wt/age
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

37

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

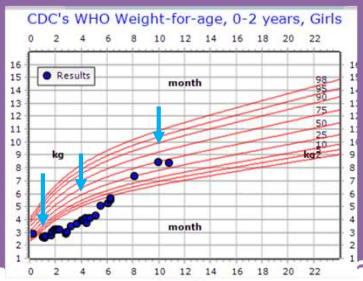
Caregiver Impact

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

38

Case Study #2 Cont'd



Five-month-old female with Cleft Lip and Palate

39

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

40

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

41

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 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

42

References

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.2001.3618
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), 1218–1224. https://doi.org/10.1177/1055665618760058
4. Kaye, A., Thaete, K., Snell, A., Chesser, C., Goldak, 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/10.1597/15-163
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/10.1002/jpen.2308
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-trainer-manual.pdf
7. About Cleft Lip and Palate. (n.d.). Www.nationwidechildrens.org. Retrieved April 21, 2023, from https://www.nationwidechildrens.org/specialties/cleft-lip-and-palate-center/about-cleft-lip-and-palate#:~:text=Cleft%20lip%20and%2For%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/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/.
11. Karrell J, Lowe J, Blandford M, McCandlish R. "Early Usage of Energy and Nutrient-Dense Formula for Infants with Growth Faiulre 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

43

44

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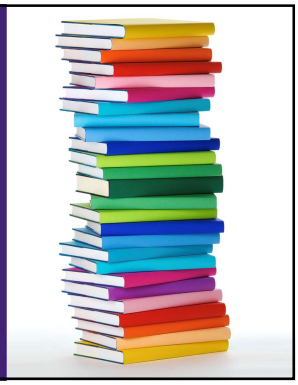

46