Hidden Malnutrition in Complex Care Patient

Clinical Case Study

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Bottom Line Up Front

- Down Syndrome infants are at high risk of malnutrition[1]
  - Systemic feeding difficulties due to physical and cognitive impacts
  - Multiple specialties increases the likelihood of inaccurate weight data
  - Caregiver decision fatigue can impair intervention options
- There are gaps in nutrition standards of care for infants with Down's syndrome[2]
  - High variability in patient presentation
  - Limited size of cohort [637 patients used to develop 2015 growth standard]
  - Impact of comorbidities
- Complex care infants require continuous malnutrition surveillance [1,2,3]
  - Secondary conditions may be the cause of malnutrition
  - Malnutrition can trigger new secondary comorbidities

Case Study Introduction

- JL is a 10-month-old male with Trisomy-21, atrioventricular canal (AVC) defect post repair, hypoxic ischemic encephalopathy (HIE), pulmonary hypertension (HTN), hypothyroidism, intestinal malrotation; and is oxygen and NG tube dependent

- Presented in outpatient clinic (Oct. 2024) with unexpected weight loss
  - Current weight: 7.43 kg
  - Current diet prescription:
    - Alimentum 22 kcal/oz, 120 ml x 6 feedings per day
      - Run over 1 hour via NG tube
      - Provides 528 kcal (71 kcal/kg) 14.52 g protein (2.0 g/kg/protein) 720 ml volume
    - Feed at 6 am, 9 am, 12 pm, 3 pm, 6 pm, 9 pm
    - Recipe: 2 scoops of powder + 3.5 oz water

- Physician requests nutrition assessment

Weight, Intake and NFPE Assessment

Date	Total Volume of EN/day (mL)	Concentration (kcal/oz)	Number Feeds/day	Weight in kg	Intake kcal/kg/d	Energy Needs DRI - RDA kcal/kg/d
10/25/24	TODAY's Visit			7.43		80-98
9/27/24	720	22	6	7.455	71	80-98
9/13/24	720	22	6	7.19	73	80-98
7/16/24	660	22	6	7.22	67	80-98
6/19/24	645	22	6	7.22	66	82 - 108
6/11/24	645	22	7	6.97	68	82 - 108
5/8/24	720	22	8	6.27	84	82 - 108

Weight Assessment

- Gained 46 grams in 134 days
- Expected 804 g – 1.47 kg (6-11 g/d)
- Less than 25% of norm (6-8%)

Intake Assessment

- Intake was below DRI-RDA estimated needs

NFPE

- Severe wasting - clavicle & thigh

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Malnutrition Assessment

Primary Indicators for Identification and Diagnosis of Pediatric Malnutrition (age 1 month – 18 years) When Two or More Data Points Available

Indicator	Mild Malnutrition	Moderate Malnutrition	Severe Malnutrition
Weight Gain Velocity (<2 yrs.)	<75% of norm	<50% of norm	<25% of norm
Weight Loss (2-20 years)	5% UBW	7.5% UBW	10% UBW
Decline in Weight for Length/Height Z-score	Decline of 1 Z- score	Decline of 2 Z- scores	Decline of 3 Z- scores
Inadequate Nutrient Intake	51-75% estimated energy/protein	26-50% estimated energy/protein	≤25% estimated energy/protein

UBW = usual body weight

Always use the higher degree of malnutrition if different indicators indicate different degrees.

(Becker, 2014)

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Trisomy- 21: Overview[4,5]

- Trisomy disorders, extra 3rd chromosome
  - Multiple Trisomy disorders
  - Trisomy – 21, extra 21st chromosome
    - Down Syndrome
- Caused by spontaneous cell recombination errors (95% maternal)
- Increasing incidence in U.S.
  - 10.1 per 10,000 live births in 1980s
  - 12.3 per 10,000 live births in 2000s
- Increasing life expectancy
  - 30 – 60 years of age (1973) (2002)
  - 10-year survival rate is 58% if cardiac comorbidity exists

https://www.cdc.gov/birth-defects/about/down-syndrome.html

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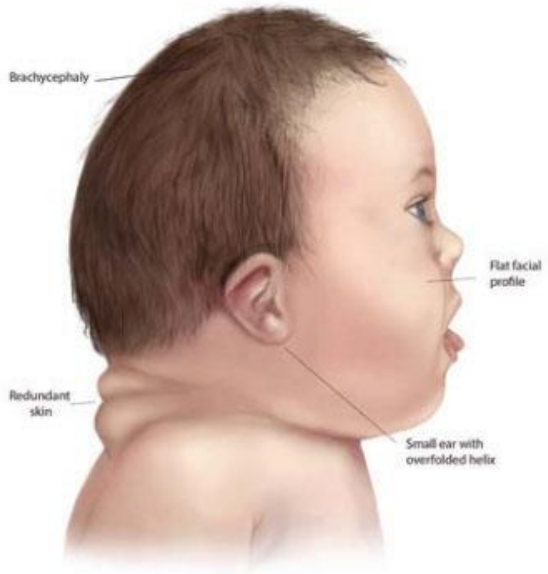
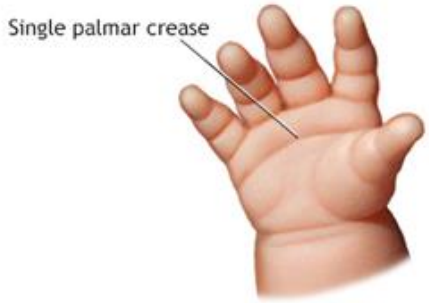
Trisomy-21: Physical Characteristics[6]



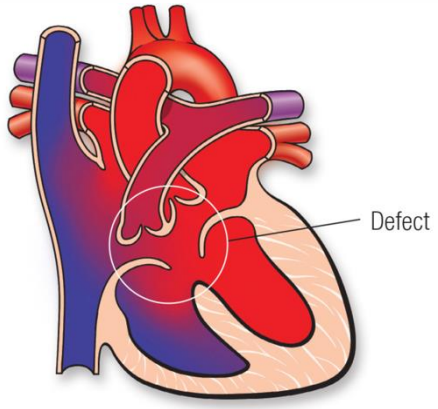


Trisomy 21: Impact to Nutrition Status[(1)]

- Trisomy 21 creates anatomical and functional impacts to feeding, digestion and nutrient utilization
  - Anatomical Impacts – oral difficulty is most significant
    - Small mouth/ chewing impairment
    - Pharyngeal function – swallow/respiratory
    - Hypotonia
  - GI function: bowel malformation, gastroparesis, GERD, anal/rectal malformation
- Unintended weight loss
  - Reduced nutrient absorption
  - Constipation/Blockage
  - Early satiety - Aversion
  - Low voluntary intake
- There is a 60% increased risk of malnutrition in infants

AV Canal Defect: Impact to Nutritional Status[7]

- AtrioVentricular Canal (AVC) defect
  - Severe congenital heart disease that occurs when a hole forms in the center of the heart between the upper and lower chambers
  - Weight loss can be a symptom
- Incidence of acute or chronic malnutrition is 50%
- 10-year survival rate is 58%
- This patient, surgical repair at 5 m.o.
  - Complete AVC (CAVC) repair
  - Rastelli type C - Large unattached valve
  - Released from NICU after 143 days



www.heart.org/en/healt-topics/congenital-heart-defects

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Severe Hypoxic Ischemic Encephalopathy (HIE): Impact to Nutritional Status(3)

- Neurological Impairment
  - Global parenchymal edema, low blood flow, ongoing diffusion restriction.
    - Brain swelling due to excess fluid build up
    - Increased Intracranial Pressure (ICP)
    - Can lead to irreversible nerve damage
  - Contributes to general developmental delays
  - Is a risk factor for malnutrition
- This patient
  - Diffuse medullary and cortical venous congestions with multifocal thrombosis
  - Spectroscopic markers of profound brain injury
    - Greater in white matter than basal ganglia

Case 4: global HIE

https://radiopaedia.org/articles/hypoxic-ischemic-encephalopathy-adults-and-children-1?lang=us

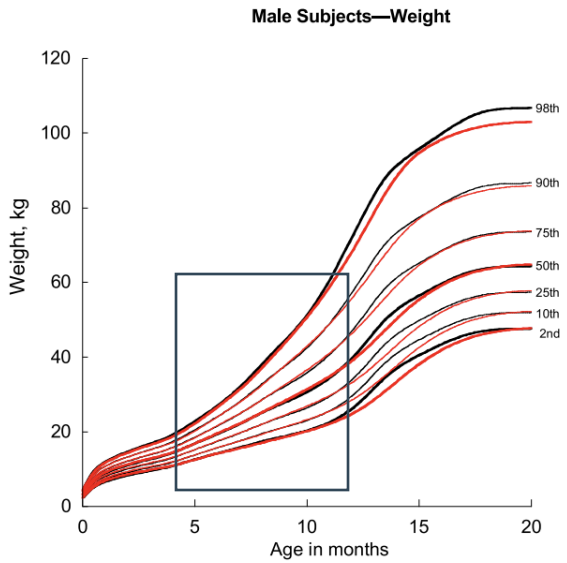
Problems, Medications and Malnutrition Risk

Problem	Physiological Contribution to Malnutrition (Top 3)	Current Medications	Malnutrition Link [Intervention Consideration]
Trisomy21 Down Syndrome[1]	Oral function, pharyngeal function, gastroparesis	Feeding, Speech, Physical Therapy	60% increased risk
CAVC Repair[7]	Increased energy needs	LASIX - 10 mg/mL	50% incidence rate [Fluid Restriction]
HIE[3]	Impaired oral/motor skills, swallow coordination, communication	KEPPRA - 100 mg/mL	50- 65% increased risk
Hypothyroid	Poor appetite, lethargy, slow growth	SYNTHROID - 88 mcg	Cause or symptom of malnutrition
Respiratory Failure[3]	Increased energy needs, decreased appetitive, malabsorption	VENTOLIN - 90 mcg	Altered pulmonary defense mechanisms [Respiratory Infection]
Pulmonary Hypertension[3]	Increased energy needs Decreased energy intake	REVATIO - 10 mg/ML EPANED - 1 mg/ML	Underdiagnosed [Electrolytes and Fluid]

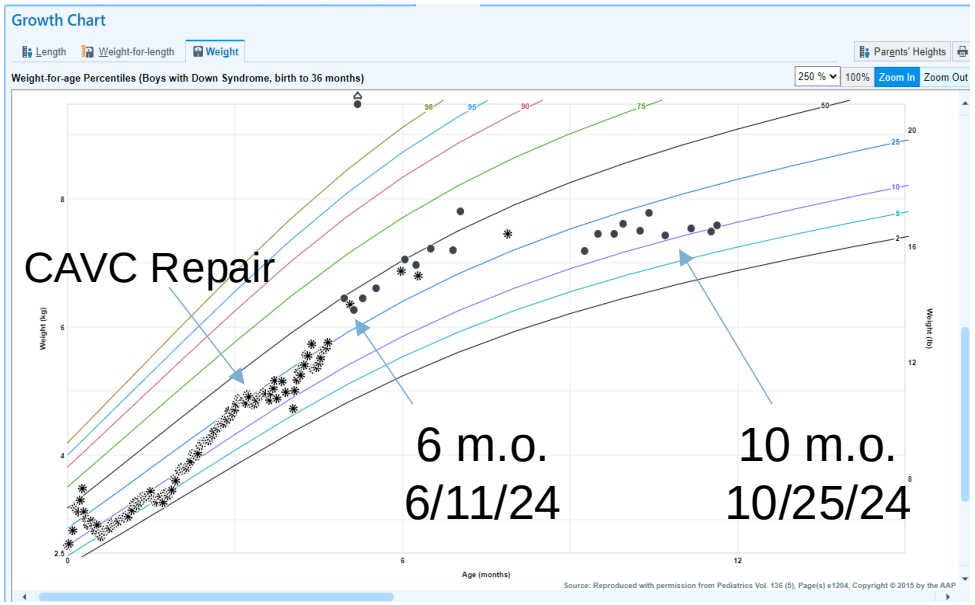
Growth Chart Assessment[8]

Weight for Age
Age 0-36 Months, Male

Supplemental Information



JL Growth Chart: Birth – 11 m.o.



- (2015) CDC Zemel DS Growth Chart standard for age 0-20 y.o.
- (2020) Peditools + Weight for Length

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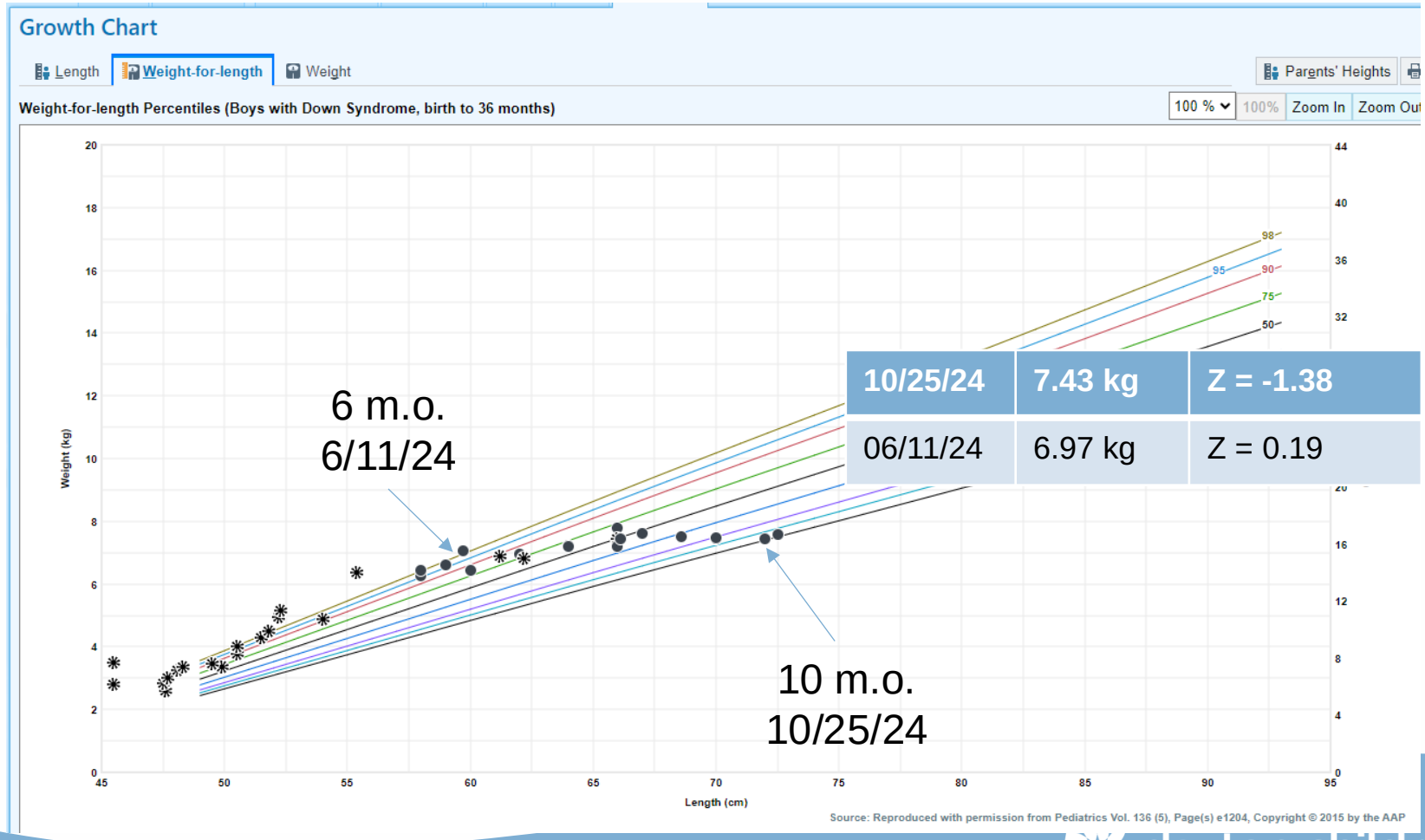
Weight for Length (WFL)



Diagnosis

- Weight – unintended weight loss, related to complex medical history and need for increased calories for growth as evidenced by 0.35 g weight loss since specialty care visit at age 10 months, 2 weeks old.
- Swallowing difficulty –related to DS, motor/neurological impairment as evidenced by NG tube dependence, and SLP recommendation to place permanent gastric tube.
- Malnutrition – Chronic and severe malnutrition related to complex medical history, inadequate intake as evidenced by less than 25% weight gain velocity for DS infant; intake less than 75% of estimated caloric needs for four consecutive months, severe wasting observed in NFPE.

Intervention Options

- Current diet prescription:
  - Alimentum 22 kcal/oz, 120 ml x 6 feedings per day
    - Run over 1 hour via NG tube
    - Provides (per 7.43 kg) 528 kcal (71 kcal/kg) 14.52 g protein (2.0 g/kg/protein) 720 ml volume
  - Feed at 6 am, 9 am, 12 pm, 3 pm, 6 pm, 9 pm
  - Recipe: 2 scoops of powder + 3.5 oz water

- Options
  - Increase calorie concentration – leave volume same
  - Add more formula to each feed – increase total volume
  - Add a seventh daily feed – increase total volume

Intervention

Date	Total Volume of EN/day (mL)	Concentration (kcal/oz)	Number Feeds/day	Weight in kg	Intake kcal/kg/d	Energy Needs DRI - RDA kcal/kg/d
10/25/24	**720**	**24**	**6**	7.43	**78**	80-98
9/27/24	720	22	6	7.455	71	80-98
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Deciding Factors

- Critical to increase kcal/kg/d
- Unknown fluid restriction (cardiac)
- Vague intolerance
- Caregiver considerations

Monitoring and Evaluation Summary

- Short term goal is to address/correct malnutrition and continue to monitor nutritional status across specialties
  - Ongoing Monitoring and Evaluation
    - Evaluate status of Iron, B vitamins and D[(2)]
    - Continue once per month weight check
    - Discuss Toddler formula transition
    - Provide encouragement and support to MOP about progress
  - Long Term Considerations
    - Need for permanent tube placement – bowl malrotation and cardiac anesthesia considerations
  - Prognosis
    - Cardiac co-morbidity is the biggest driver to life expectancy
    - Unknown motor impacts due to HIE
    - Trisomy-21 increased risk of obesity, T1D, Celiac

Monitoring and Subsequent Interventions

Age in Months (Weight)	Nutrition Care Related Event	Actual Diet Intake kcal/kg/d	DRI to RDA Range kcal/kg/d
10 + 3W (7.43 kg)	First Intervention: Chronic Severe Malnutrition Diagnosis Concentrate feeds to 24 kcal/oz – RDN Intern Recommendation SLP recommends discontinue PO trials	78	80 -120 [Increased Needs CHD & Malnutrition]
11 + 1W (7.49 kg)	Second Intervention: Chronic Mild Malnutrition Diagnosis Concentrate feeds to 27 kcal/oz SLP recommends discontinue PO trials	86	80 – 120 [Increased Needs CHD & Malnutrition]
11 + 2W (7.58 kg)	Third Intervention: Provide counseling about options for plant-based toddler formulas – specifically Kate Farms, and longer-term whole food EN options (Complete) Continue to discuss the importance of family advocacy in nutrition care - RDN Intern participation	86	80 – 120 [Increased Needs CHD & Malnutrition]

Follow up at 12-month-old visit, weight was 8.0 kg

Case Study Conclusion

- Need for acute awareness of malnutrition risk in all complex care infants
  - Risk is increased for infants
    - Has Down Syndrome (Trisomy 21) – 50% increase[1]
    - Has cardiac co-morbidities – 60% increase[7]
    - Is dependent on enteral nutrition[3]

- RDN plays a critical role cutting across multiple specialties to provide timely intervention in infant care
  - Need to continuously screen and then conduct full assessments for malnutrition in Down and Complex Care patients
  - Clinical best practices and judgement are required

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Backup

Root Causes of Hidden Malnutrition

1. Gaps in standards for Down Syndrome infant care
   - Growth chart is a guideline for assessment
   - Malnutrition is assessed per Academy standards
   - Need for specific energy DRI – RDA metrics
2. Care-giver fatigue, desire to normalize oral feeding
   - Complex diet order (optional bolus feed)
   - Desire to drop overnight feed at 6 months old
   - Report to ENT specialist – good progress with feeding therapy
3. Complex care patient with multiple comorbidities
   - Acute weight/fluid fluctuations across specialty care visits
   - Gaps in time between full nutrition assessment
   - Point of care decision about which co-morbidity drives energy needs

Trisomy 21: Secondary Impact on Nutrition Status[1]

Beyond infancy, there are other feeding and intake issues that can impact children or adults with Down Syndrome

- Ability to taste, texture aversion, ability to sit and eat, difficulty communicating feeding desire and ability
- Behavioral & social impacts
- Predisposition for other immunological nutrition related co-comorbidities: Celiac, T1D, HTN

Assessment: Diet History

- Following Mixing Instructions & Recipe
  - Similac Alimentum 22 kcal/oz
    - 2 scoops formula to 3.5 oz of water
  - 120 mL q 3 hours x 6 feedings per day via NG tube
    - Using pump, 1 hour duration
- Following feeding frequency and volume
  - "Much easier" nutrition plan – getting 720 mL per day
    - Providing same volume at each feed
    - No more overnight feed
  - Occasional intolerance – spit up after feeding
- Other
  - MOP: Noticeable face thinning and weight loss
  - Ongoing SLP rehabilitation – going slow, likes bananas
  - Looking forward to Halloween – picture in the pumpkin

Assessment: Presentation and NFPE

- Complex care 10 m.o. presents in clinic with mother and grandmother – 10/25/24
  - Unexpected weight loss
  - Lethargic, hypotonic, on 1/4 L O2 support 24 x 7
  - Hx of formula intolerance, spit up mixed w/ saliva
- Nutrition Focused Physical Exam
  - Pale, cyanic coloring
  - Slight wasting in temple region, cheeks – face rounded and puffy
  - Significant wasting in clavicle area, more pronounced in scapula
  - No body fat “rolls” evident in arm or leg regions
- MOP reports no significant change in tolerance

Malnutrition Assessment

- Severe Malnutrition Indicators
  - Weight gain velocity
    - Weight Loss (- 25 grams) in 28 days is < 25% of expected weight gain of 168 gms (low end of baseline Goal wt gain (6-11 g/d))
  - Decline in >2 weight Z-scores; decline in > 1 Z-score WFL
    - Dropped from 50th %-ile to 10th %-ile
  - NFPE – severe wasting: clavicle, shoulders, triceps, thigh
- Acute vs Chronic Malnutrition Indicators
  - Zero weight gain in 3 months (July, August, September)
    - Meets requirements for Acute Malnutrition
  - Signs of acute malnutrition as early as 6/11/24 – 4 months prior
    - Gained 21 g/d, should have been 33 g/d (estimated 10 g/d)
- <u>Dx: Chronic Severe Malnutrition</u>

Nutrition Intervention

- Key Factors to Justify MNT Intervention of concentrating formula
  - Energy needs 80 kcal/kg/d – 98 kcal/kg/d with increased need 1.2 – 1.5
    - [80 kcal/kg/d – 147 kcal/kg/d]
    - Malnutrition
    - Respiratory need (O2 dependent)
  - Cardiac and pulmonary HTN - unknown fluid restriction
  - MOP reported
    - Better management with the same volume at each feed
    - Additional intolerance when she tried 130 mL per feed
  - Respiratory Failure/O2 dependent – Increased energy needs
- *Concentrate patient feed of Alimentum from 22 kcal/oz to 24 kcal/oz – maintain same volume (120 mL) per feed and frequency q 3 hours.*
  - Provides, per 7.43 kg: 576 kcals (78 kcal/kg), 15.84 gm (2.13 gm/kg of protein), 24 oz (720 ml)

Monitoring 10/25/24 – 11/21/24

- GI Visit – 11/19/24
  - Adjusted diet to 27 kcal/oz, 120 ml per feeding x 6 feedings per day'
  - Recommended G-tube placement – requires cardiac anesthesia
- SLP Therapy Follow Up
  - Pt. has severe food aversion
  - Recommend placing G tube
- Complex Care Visit - 11/21/24
  - Weight increased +90g in two days since GI visit
  - Feeding therapy – not progressing
    - Dx with Food aversion
    - Planned to discontinue therapy
  - Swallow insufficiency directly related to increased respiratory infection risk
  - Education about toddler formula transition

Monitoring and Evaluation: Additional Information

- Clinical Care Considerations
  - JL and family had 20 different care visits 06/03/24 – 10/25/24
    - High variability in weight data clouded chronic weight velocity problem
    - Fluid considerations
  - Unclear feeding baseline: Documented required vs optional plans
    - Optional Bolus Feed, 10 mL per week increase on Monday
    - One of the diet interventions seemed to be based on MOP recall vs clinical documentation
- Family Care considerations
  - June appointment– requested drop of overnight feed and cereal feeding
  - Initiated PO feeding trials - Reported progress to other specialists
- G tube placement limiters
  - Need for cardiac anesthesia
  - Risk of respiratory infection
  - Desire for oral feeding