# Hidden Malnutrition in Down Syndrome Infant

## Major Case Study

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Abstract: This project is a comprehensive assessment of a patient seen at Dayton Children's Hospital from May – November 2024. The patient, a 10-month-old (m.o.) male, complex care infant presented at the outpatient clinic with unexpected weight loss and was subsequently diagnosed with chronic, severe malnutrition. Factors impacting the patient's impaired nutrition status include inherent feeding difficulties associated with Trisomy-21, underfeeding due to lack of energy adjustment for cardiac status, and care giver desire to normalize oral feeding. The Dietetic Intern provided direct care to this patient as a member of an inter-disciplinary team. The supervising Registered Dietitian (RDN) preceptor for this case was Maria Brumfield.
Keywords: Down Syndrome; Trisomy-21; feeding difficulty; infant malnutrition; medical nutrition therapy; enteral nutrition; congenital heart defect; atrioventricular canal repair; estimated energy needs; caregiver fatigue.

General Disease Research – Down Syndrome (DS)

Gene variants that result in extra chromosomal material at the twenty-first chromosome cause all cases of DS. Three types of variations can occur: Trisomy-21, Translocation Trisomy-21 and Mosaic Trisomy-21. The Trisomy-21 variant has the highest incidence rate and is manifested by a third, complete copy of the 21st chromosome, resulting in 47 (vs 46) total chromosomes. Trisomy-21 accounts for 95% of all DS cases and the other 5% are caused by Translocation or Mosaic trisomy[1].

The etiology of the genetic variation that causes DS is still not fully understood, however it is known that recombination errors occur during fetal development due to changes in the methylation of DNA. The physiopathology of the recombinant error is spontaneous cell non-disjunction, when chromosomes fail to separate, during maternal meiosis I and II (95% occurrence) or paternal meiosis II during spermatogenesis (5% occurrence). [2,3] High parental age is a risk factor for both maternal and paternal non-disjunction.[1,2,3] In all cases of DS, the chromosomal change has a substantial and systemic effect on the anatomical, physiological and cognitive function of the affected person – directly impacting nutrition status.

Although phenotype expression is variable, at birth the characteristic symptoms of DS can be identified through anatomical features: hypotonia (low muscle tone), small brachycephalic (short) head, epicanthal fold (eyelid slant towards nose), flat nasal bridge, upward-slanting palpebral fissures (eye slanted upward), Bushfield spots (white spots around the iris), small mouth and ears, protruding tongue, clinodactyly fifth finger and wide spacing between the first and second toes.[1] During infant and child development, other symptoms and features can emerge such as vision and hearing loss, delayed motor development, obstructive sleep apnea, congenital heart defects (CHD), neurological dysfunction, thyroid disease, leukemia

and autoimmune diseases (Type 1 Diabetes (T1D) and celiac).[4] While not apparent at birth, cognitive impairment occurs and can range from a mild to severe reduction in IQ (70 – 20).[4] There is no cure or preventative treatment for the underlying genetic cause of DS, however recent advancements in screening and assisted reproductive technologies have reduced the incidence of live births.[3]

People who have DS can lead productive lives, and life expectancy has significantly increased with early intervention, treatment and effective nutrition care.[4] Treatment focus is on rehabilitative therapies and symptom management to correct or manage anatomical and physiological function.[4,5] Nutrition treatment for patients with DS is multi-faceted and must be individualized. Proper nutrition requires attention to all aspects of feeding, digestion and absorption, tailored to lifecycle and social considerations. Infant related nutrition care is focused on monitoring weight status, feeding issues and swallowing safety.[4] Feeding issues in infants are common due to oral/pharyngeal and gastrointestinal (GI) dysfunction further exacerbated by cognitive impairment which may limit cues for hunger.[6] DS infants that display marked hypotonia, slow feeding, choking and weight loss or that require respiratory support should be referred for additional speech and swallow studies, as up to 90% of all DS infants have dysphagia.[6]

Medical Nutrition Therapy (MNT), and specifically enteral nutrition (EN), are treatments for infants that have impaired oral or GI function, bowel malrotation, or celiac disease.[7] Use of MNT and EN in infants may prevent malnutrition.[4] Small cohort studies have shown that at least 13% of infants with DS require EN therapy, and the rate is higher for those with cardiac complications.[7]

Another important malnutrition consideration in a DS infant is the physiological effect of other comorbidities.[4] There is a direct correlation between the degree and complexity of atrioventricular canal (AVC) abnormalities and the increased incidence of malnutrition in infants – due to the needs for increased energy, and the metabolic effects of pulmonary hypertension.[8] If the infant also has low birth weight (common in babies with CHDs) the chance of malnutrition doubles.[8] Optimal enteral nutrition can prevent malnutrition and improve outcomes of CHD patients; however, it must be closely monitored, with frequent assessment of growth parameters.[9] Age dependent feeding transitions from breast feeding/formula to solids/table foods must be carefully monitored. Behavioral considerations can also emerge in infancy, such as food aversions and general lack of interest in eating.[7] All of these considerations together can lead to an increased risk of pediatric malnutrition, particularly during infancy.[4,8,10]

Plant based diets can have a direct positive effect on DS patients, through all phases of the lifecycle, independent of EN status.[11] In infants, hypotonia and pharyngeal impacts can prevent breastfeeding, requiring formula.[7] Regardless of whether the DS patient is breast or formula fed, balancing the diet requires special attention to energy intake, absorption, nutrient sufficiency (iron stores and vitamin B & D status) all to optimize growth.[10] In clinical practice, hydrolyzed formulas (milk proteins are broken down) and amino acid-based formulas (contain no milk) can provide appropriate nutrient density, and aid in absorption. After the first year of life, plant-based alternative supplements and tube feeding formulas are available (Kate Farms Pediatric Standard, Compleat Pediatric, Liquid Hope); as well as organic plant based whole foods. As a DS child grows, nutrition care shifts to obesity prevention.[4] Obesity is a risk factor in DS children 2 years old (y.o.) or above. The cause is increased high leptin levels, low resting energy expenditure and co-morbidities such as hypothyroidism and heart defects. [11] Hearing and

vision problems have a direct effect on transitions from infant nutrition to childhood and adult nutrition.[10] For those reasons, a balanced plant-based diet high in vegetables & fruit, fiber, nuts and grains and low in dietary fat can lead to improved outcomes. [11] For children, adolescents and adults with DS that can eat food orally, adaptive solutions may be needed to aid in chewing to integrate a plant-based diet.[10] One solution to overcoming some types of dysphagia, chewing and oral motor skill difficulty is to use blended custom foods at home. Careful nutrient balance is required, and oversight of an RDN is advised if home blended foods are the sole source of nutrition.[16]

## Introduction of Case

JO (pseudonym) is a 10-month-old (m.o.) male with Trisomy-21, and an AVC defect, due to a CHD, that has been surgically repaired. He has pulmonary hypertension (HTN), hypoxic ischemic encephalopathy (HIE), hypothyroidism, intestinal malrotation and is oxygen and nasogastric (NG) tube dependent. He presents in the complex care clinic with unexpected weight loss. His current weight is 7.43 kg (Z = -1.2), height is 70 cm (Z= -0.31), based on the World Health Organization (WHO) DS growth chart for (Boys, 0-2 years).[15] Data collection on this case was from 5/20/24 – 11/22/24.

This case was selected for three reasons. First, this patient needs an appropriate low risk enteral nutrition diet prescription change. Second, the feeding plan must be simple for the family to administer at home. Third, the caregivers needed clinical provider emotional support to overcome barriers related to the desire to normalize NG tube feeds in place of oral feeding. The primary focus of this study is the impact of DS and associated co-morbidities on nutrition status and estimated energy needs. The secondary focus of this study is to illustrate how difficult it is to identify malnutrition in complex care infants. Together these focus areas point to the need for

increased inter-disciplinary care coordination in outpatient settings, and the critical role of an RDN to provide patient assessment and caregiver emotional support.

## Social History

JO lives in Ohio with his mother who is the primary caregiver. JO is a result of her first pregnancy and only child Gravida Para (G1P1). The mother of the patient (MOP) expressed food insecurity in May 2024. JO is covered by CareSource insurance (Medicaid) and Women and Infant Children (WIC) benefits for formula. There is no record of the family receiving benefits from the Supplemental Nutrition Assistance Program (SNAP) or assistance from JO's father. The father was not present at any documented care appointments. JO was born at Nationwide Hospital, treated for Complete AVC (CAVC) repair (April 2024) at Cincinnati Children's Hospital and currently lives with the mother and great-grandmother in Dayton.

## Past Medical History

JO has a complex medical history. He was prenatally diagnosed with Trisomy-21 and with a known AVC abnormality. He was delivered via an emergency C-section due to umbilical cord herniation, and concerns for intrauterine growth restrictions at 37 weeks. At birth his recorded Apgar score was 0.0.0 – presumably scored for appearance, pulse and respiration. He received 14 minutes of resuscitation. The lack of oxygen caused Hypoxic Ischemic Encephalopathy (HIE), edema surrounding the brain, and subsequently caused a diagnosis of neurological impairment. Post delivery he spent 139 days in the Neonatal Intensive Care Unit (NICU) and had CAVC repair surgery. He was transferred to Dayton Children's Hospital, as an outpatient, after his CAVC surgery, to establish care as a new patient.

During the period of this case study, JO received care from pulmonary, neurology, gastrointestinal, speech therapy and optometry specialists. He also received care from endocrinology, cardiac, hematology and urinary specialists outside of the study time frame.

## Present Medical Status and Treatment

JO is presently on ¼ L nasal canula (NC) oxygen for breathing support and is being treated for hypothyroidism (low output of thyroid hormone that controls growth and energy production), pulmonary hypertension (high blood pressure in the lungs) and wears glasses (astigmatism). He is fed formula through a nasogastric (NG) tube, attends weekly feeding therapy, has routine bowel movements (BM) and normal urinary output (UOP). He is followed by a Complex Care Primary Care Primary Care Physician (PCP) and the outpatient GI clinic.

MOP reports that JO's diet changed recently to eliminate the overnight feeds and appears to be losing weight with notable "face thinning". She commented that the new diet prescription of 720 mL daily of Similac Alimentum is being tolerated, with occasional spit up. She appreciates that his feeding routine enables him to receive the same volume of formula, six times a day. This is an improvement over his previous diet plan that required both day and overnight feedings with different volumes.

### Problems and Medications

JO receives treatment and medication for Trisomy-21, HIE, pulmonary hypertension and hypothyroidism. As shown in Table 1, his nutritional status is impacted by oxygen support, KEPPRA, LASIX, and EPANED. In the literature, a meta-analysis shows there is no increased energy needs for non-critically ill patients on respiratory support[12]. KEPPRA can impair Vitamin D absorption. Variability in the use of LASIX can create fluid fluctuations, impacting accurate weight data. EPANED requires caution with intake of large amounts of high potassium foods.[13]

JO's need for respiratory support would intuitively imply increased energy needs, however a meta-analysis of infants with pulmonary insufficiency, combined with double labeled water technique has proven there is not a direct relationship – except in the instance of neonatal bronchopulmonary dysplasia.[12] The same study showed there is increased energy needs when the patient has an underlying CHD and energy needs are further increased when the patient has a CHD and is on enteral nutrition.[9]

Table 1: Medication Summary[13]

| Treatment/ Medication Dose | Class Drug/Purpose How it Works | Impact to Nutritional Status |
|---|---|---|
| Respiratory Support, ¼ L Continuous Flow | Supportive therapy/Provides increased oxygen directly to patient through nasal canula (rubber tube inserted in nostrils) | Pulmonary insufficiency does not increase energy needs[12]; the underlying cause (CAVC) does increase needs[9] |
| KEPPRA 100 mg/mL | Levetiracetam/Antiepileptic/Attaches to a protein on synaptic vesicle – limits release of messengers to nerve cells | Impairs Vitamin D absorption |
| LASIX 10 mg/mL | Furosemide/Diuretic to reduce blood pressure and hypertension (HTN) | Furosemide, loop diuretic, can affect electrolytes and fluid status |
| EPANED 1 mg/mL | Enalapril maleate/Angiotensin converting enzyme /(ACE) inhibitor/ lowers blood pressure; potassium sparing | Caution with large amounts of high potassium foods (bananas, sweet potatoes, apricots) |
| REVATIO 10 mg/mL | Sildenafil/Phosphodiesterase 5 (PDE5) inhibitor/Increases blood flow | NONE |
| Synthroid 0.88 mcg | Levothyroxine sodium/Restores thyroid levels by replacing thyroxine | NONE |

Anthropometrics and Labs

At 10 months 3 weeks old, JO's weight was 7.43 kg, a decrease from 7.78 kg recorded at a previous visit, and he lost weight between 6 and 9 m.o., as shown in Table 2, column 1.

JO's weight velocity was less than 25% for norm and weight for length Z score dropped 1 full Z score (see Appendix A & B for Growth Charts), an indication of malnutrition.[14] At the time of visit, his medical record contained 16 weight data points, collected from multiple specialty providers between May – October 2024, with significant variation. Weight variation alone did not create a clear picture of malnutrition until July, which was his first recorded weight

reduction. It is critical to note, that the 2015 revised DS standard is a linear, positive increasing weight trend during ages 5-10 months old[15]. That means that two or more data points of weight loss or slowing weight velocity could have raised flags at his 7 m.o. specialist visit. A Nutrition Focused Physical Exam (NFPE) indicated malnutrition. JO was pale, cyanic, had protruding clavicle, wasting in the shoulders, upper arms, and legs. His temples were not significantly indented; however clinical evidence of malnutrition in the temple could be impaired due to the characteristic rounded face of a DS patient[14]. At the time of visit, the only lab value checked was his TSH for hypothyroidism and it was within normal range.

## Medical Nutrition Therapy – Analysis of Estimated Needs

During the period of study, JO was fed exclusively by NG tube. His diet history from age 5-10 m.o. is shown in Table 2. The third column of the table shows that JO's actual energy intake compared to the Dietary Reference Intake (DRI) for his age. Starting at 6 m.o. his actual intake was 68 kcal/kg/day compared to a recommended minimum 82 kcal/kg/day of energy. JO's intake of 68 kcal/day was prescribed during a visit where the family inquired about dropping overnight feeds and increasing intake by mouth. At the same visit, he was prescribed an optional bolus feed dietary intervention of (77 kcal/kg/d).

The trend of JO's actual intake, being less than his recommended energy needs, continued for four consecutive months. The method used to estimate his needs, DRI for low end, and Recommended Dietary Allowance (RDA) for high end did not account for increased needs due to being NG dependent, have underlying DS and CHD, and baseline risk for malnutrition.[4,8,9,10] At 10 months 3 weeks old, when a diagnosis of malnutrition was made, JO's estimated energy needs increased further.[14] Important to note, the standard of care for *assessing malnutrition in DS infants* is to use WHO guidelines for expected growth. [4] There is no specific metric, but the

unknowns related to estimating energy needs, point to how important it is to have frequent, clinical assessments, of the nutritional status of complex care infants.[9]

**Table 2: History of Actual Dietary Intake vs Estimated Energy Needs**

| Age in Months (Weight) | Nutrition Care Related Events | Actual Diet Intake kcal/kg/d | DRI to RDA Range kcal/kg/d |
|---|---|---|---|
| 5 (6.6 kg) | RDN visit – new baseline established for care | 82 | 82 - 108 |
| 6 (7.22 kg) | Initiate 5 specialty care providers<br>MOP requests to stop overnight feed | 68<br>Optional Bolus | 82 - 108 |
| 7 (7.2 kg) | GI Clinic Evaluation: Reported Intolerance<br>MOP reports good feeding therapy progress to specialist | 67 | 80 - 98 |
| 9 (7.19 kg) | MOP reports heart rate dropping<br>Phone visit to concentrate feeds to 22 kcal/oz | 73 | 80 - 98 |
| 10 + 2 W (7.78 kg) | Specialty care visit<br>No nutrition assessment at this visit | 68 | 80 - 98 |
| 10 + 3W (7.43 kg) | Malnutrition Diagnosis<br>Concentrate feeds to 24 kcal/oz – RDN Intern Recommendation<br>Follow up GI clinic<br>SLP recommends discontinue PO trials | 71 [22 kcal/oz]<br>Changed to:<br>78 [24 kcal/oz] | 80 -120 [Increased Needs Malnutrition] |

Starting a 9 m.o., JO received Similac Alimentum, prepared at 22 kcal/oz (2 scoops per 3.5 oz of water). The formula was pump fed six times a day: 6am, 9am, 12 pm, 3pm, 6pm and 9pm via NG tube. Both caregivers, present at the appointment, confirmed JO's recipe, mixing instructions, and delivery process. In total his formula provided him (per 7.43 kg) 528 kcal/day (71 kcal/kg), 14.52 gm protein (1.95 gm/kg) and 720 mL of fluid. Based on his current weight of 7.43 kg, his estimated protein needs were: 1.2 – 3 g/kg (increased needs for CHD) and his estimated fluid needs were 740 mL/day based on Holliday -Segar[16] (undocumented fluid restrictions).

In parallel, JO was receiving weekly oral feeding rehabilitative therapy, tasting formula and food with a gloved finger to initiate a swallow response. Over a three-month period, he was offered tastes of different puree's, apples, bananas, vegetables and cereal. Care giver and provider perspectives differed on feeding therapy progress. In a specialist report, mom reported

oral therapy was progressing well, with no issues. An interview with the Speech Language Pathologist (SLP) who conducted the therapy indicated that oral food aversion and swallowing difficulty were not improving with therapy.[17]

MNT Diagnosis and Intervention

A diagnosis of chronic severe malnutrition was made based on objective factors. JO lacked appropriate weight gain, reflected in a Z score drop, had actual intake below estimated needs, and showed wasting in NFPE findings.[10,14,16]

1. Anthropometric: Less than 25% of normal weight gain velocity in children 24 months or younger.[16] There was a negative change in one full Z score (weight for length) over 3 months (Appendix A) consistent with 2015 Center for Disease Control (CDC) DS standards.[15] Selective weight data from the different providers masked this trend from visit-to-visit due to inconsistent data at specialty visits and critical missing data points due to phone visits; and lack of a comprehensive malnutrition assessment at key monthly visits.
2. Dietary History: Inadequate dietary intake less than 100% of estimated needs for 4 months; and likely less than 75% of estimated needs due to unaccounted for increased needs related to CHD.[9] Dietary intake history was hidden in three ways. First, historically there is a tendency to monitor DS patients' growth status for unwanted obesity, not malnutrition - despite known feeding issues of DS patients.[4] Second, JO's energy needs were increased due to cardiac complexity. During infancy, cardiac needs are likely a more critical disease state impacting energy needs than DS. Third, during the RDN visit at 6 months old, the diet intervention had two parts: 5 feeds, providing 68 kcal/kg/d and an optional bolus feed that provided 77 kcal/kg/d. The optional diet was not used, perhaps due to caregiver fatigue, or desire to maintain consistent volumes between feeds, or lack of nutrition education.

3. Nutrition Focused Physical Exam: Observed wasting in the shoulders, clavicle and lack of subcutaneous fat in the thigh.

PES Statements

4. 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.
5. Swallowing difficulty – unable to make progress with oral/swallowing function related to DS, motor/neurological impairment as evidenced by NG tube dependence, and SLP recommendation to place permanent gastric tube.
6. Malnutrition – Chronic and severe malnutrition related to complex medical history, inadequate intake as evidenced by less than 25% weight gain velocity for DS infant; drop in one Z score, intake less than 75% of estimated caloric needs for four consecutive months, severe wasting observed in NFPE.

Intervention Options

A malnutrition diagnosis indicates a need to increase calories and protein, so the inter-disciplinary team of PCP, RDN, RDN Intern discussed four different intervention options:

- Concentrate the kcal of the feeds from 22 kcal/oz to 24 kcal/oz; keeping total volume the same; lowest risk, most consistent with the current routine
- Increase total volume, evenly distribute the increase per feed – adds complexity to caregiver routine, unknown impact of fluid changes to cardiac status
- Increase total volume by adding another feed – same as above, but would add complexity to caregiver routine
- Change formula – risk intolerance and increasing malnutrition

The caregiver had become well versed in the intricacies of enteral feeding but was desiring a normative oral eating routine. To address this, the provider team stressed the importance of nutrition for growth and used positive clinical terms and patient centered language such as: enteral nutrition, finding methods to manage care, alternative nutrient delivery method, and options for different formulas. [16,18] The provider team discussed the options with the caregivers, and collaboratively decided to concentrate the formula from 22 kcal/oz to 24 kcal/oz as follows: 120 mL every 3 hours x 6 feedings daily of Similac Alimentum 24 kcal/oz to provide, per 7.43 kg: 576 kcal (78 kcal/kg/d), 15.84 gm protein (2.13 gm/kg/d), total volume of 720 mL (24 oz). Recipe: Add 4 unpacked level scoops of formula to 6 1/2 oz of water.

Other Interventions

- Provide support and encouragement to MOP about progress and for raising concerns about observed weight loss
- Evaluate status of Iron, B-vitamin and Vitamin D
- Review new mixing instructions to ensure understanding
- Coordinate care with the GI team regarding appropriate follow up and diet adjustments to address malnutrition diagnosis
- Continue to follow in PCP clinic one time per month for a weight check

Follow Up Care

After the initial intervention at 10 m.o., the patient was seen three weeks later for a follow up specialty appointment, and his formula was further concentrated to 27 kcal/oz. A second follow-up appointment occurred three days later with the PCP. Positive weight gain was observed, with no formula intolerance issues reported at both visits. As summarized in Table 3

below, transition to toddler formula was discussed, at the PCP visit, including options for plant-based alternatives and longer term organic whole food options.

**Table 3: Intervention and Follow Up Summary**

| 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<br>Concentrate feeds to 24 kcal/oz – RDN Intern Recommendation<br>SLP recommends discontinue PO trials | 78 | 80 -120 [Increased Needs CHD & Malnutrition] |
| 11 + 1W (7.49 kg) | Second Intervention: Chronic Mild Malnutrition Diagnosis<br>Concentrate feeds to 27 kcal/oz<br>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)<br>Continue to discuss the importance of family advocacy in nutrition care - RDN Intern participation | 86 | 80 – 120 [Increased Needs CHD & Malnutrition] |

## Ethical Considerations

There are important ethical considerations related to the follow up care for this patient. JO has a standing order for palliative care for all specialties. He was refused care for cardiac surgery by an outside hospital because he was considered high risk. His current GI specialist and SLP both recommend placement of a permanent gastric tube; however, placement requires cardiac anesthesia. There are unknown effects of bowl malrotation, impacting the location of the tube placement. There are also unknowns related to absorption issues and future tolerance.

There is an important psycho/social consideration related to caregiver fatigue for a complex patient. Substantial research has shown the importance of providing emotional support to the caregivers as prescribed intervention during clinical visits.[19] Because of this, the RDN (and all specialists) are responsible for providing objective support, but also emotional support to facilitate the most positive outcome possible for this patient.

Prognosis

A prognosis for a complex care patient is difficult to estimate. Life expectancy for DS patients is increasing, however DS with cardiac complications shortens life expectancy.[4] The impact of pulmonary insufficiency and HIE also will impact the life expectancy of this patient. However, he was growing, and correcting his energy needs will provide a more optimized nutrition care and outcome. He will remain NG tube dependent and on respiratory support for an indeterminant amount of time. Because of his oxygen dependence, JO is more prone to respiratory infection. Motor development, and the ability to chew and swallow is impacted by both Trisomy-21 and HIE. There is a need for continued surveillance for malnutrition, continuous monitoring of formula intolerance, and careful management of formula transitions, i.e. infant to toddler formula. However, none of these reasons should overshadow the importance of providing the best nutrition possible to facilitate growth. Appropriate care, regular assessment of his nutritional status and caregiver advocacy can provide JO with a dramatically improved quality of life.

## Summary & Conclusions

What I learned from this study – this is the ONLY section to be written in the first person

- (Gap) How this came about – the need to better understand the inter-relationship of feedings issues with other disease states and co-morbidities to help me with future patients. The technical research and treatment course were valuable learning, and more impactful because it was related to a specific patient that I had seen.
- (Gap) The science of estimating energy needs has gaps. Clinical judgement, intuition and common sense can be more important than anything published in the literature.

- (Learned) Ease of missing malnutrition. Going forward, I will assume a child is malnourished and work to "prove" the opposite. The prevalence of hidden malnutrition in a pediatric setting is surprisingly high.
- (Learned) Coordination of care – it was both a collaboration and a learning experience working with my preceptor to find the appropriate language, tempo and method to ensure appropriate follow up care was provided.
- (Strength) My value – this project was very affirming to me personally as I brought life experience, and care giver credibility that was recognized and valued by this family. For example, I understand the importance of simplifying diet prescriptions, recognize the appropriate choice of language in a clinical setting[18] and can provide empathy towards care giver fatigue. With 20 years of caregiver experience, I understand the importance of being the "voice" of your child to advocate in his best interest, and the importance of "norming" care for a complex child. During the first visit, I asked Mom about Halloween, and she showed us a cute picture of the kiddo in a pumpkin. This patient, mom, and family deserve health care support and advocacy.

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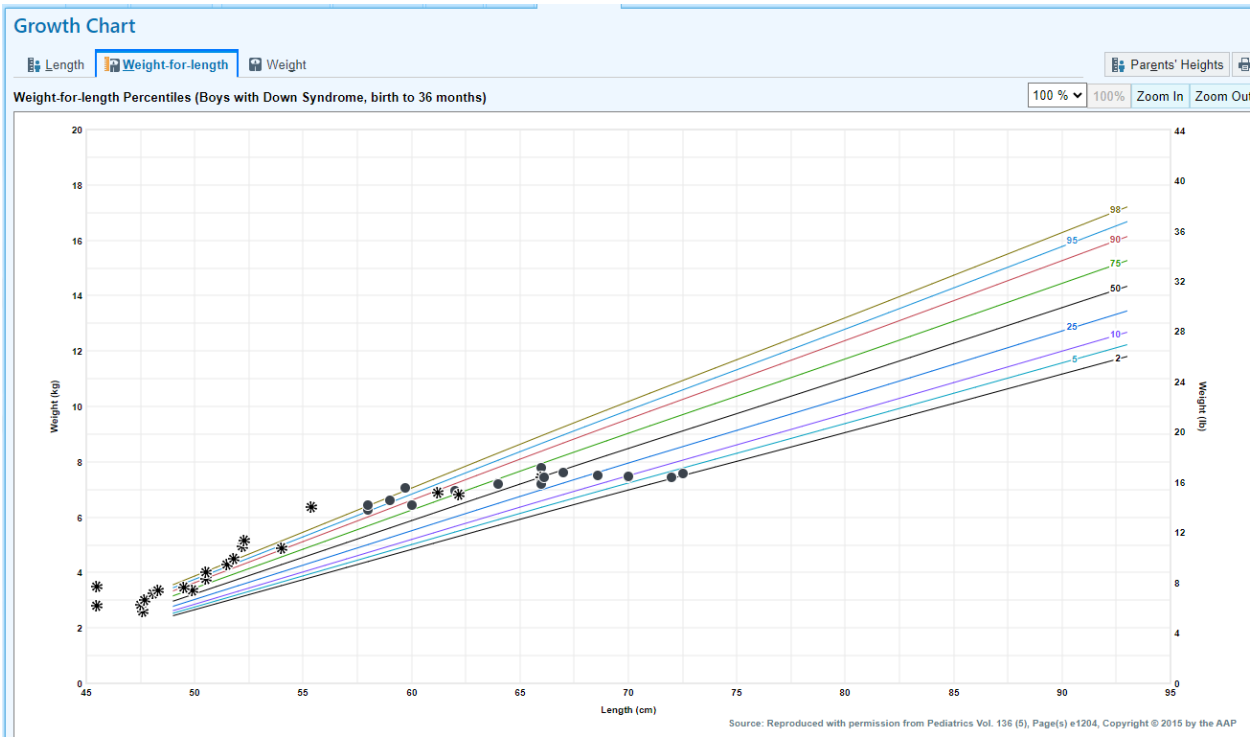
**Appendix A**: JO Weight for Length Growth Chart Using Down Syndrome Standard. Note: To properly diagnose malnutrition in DS infants, as standard WHO chart should be used before age 1; and CDC growth chart after that. [4]



**Appendix B:** JO Weight for Age Growth Chart