Nutrition Care in Cystic Fibrosis Curriculum

Course description: Cystic fibrosis (CF) is an autosomal recessive disorder that causes production of thick mucus which can affect normal digestive processes, as well as a host of other systemic affects. Nutrition intervention is critical to prevent malnutrition and malabsorption; to promote growth and development in infants, children, and teens; and contribute to overall health and longevity in the individual. This course will provide an overview of the disease process, specifically as it relates to nutrition-related complications and nutrition therapy. Concepts related to nutrition and lifecycle considerations, interprofessional care, and life course theory will also be discussed. Developed as a 1-unit course for Didactic Program in Dietetics students with a medical nutrition therapy background.

Course Objectives:

After completing the mini-course, students will be able to:

- Explain the CF disease process and the body systems affected, especially digestive and absorptive processes and related impacts.
- Describe common medical and pharmaceutical interventions utilized in treating CF.
- Evaluate and determine appropriate nutrition interventions for CF patients, including diet and lifestyle, nutritional supplements, nutrition-related medications, nutrition support, and nutrition education/counseling.
- Describe the contributions of the members of the interprofessional team, including those of the registered dietitian nutritionist (RDN), in the care of CF patients.
- Describe Life Course Theory principles in the context of CF and how the RDN can utilize these principles to provide effective family- and patient-centered care.
- Discuss the importance of providing care that is culturally sensitive.

Modules:

- 1. Cystic Fibrosis Overview
- 2. Nutrition Assessment and Intervention in Pediatric CF
- 3. Nutrition-related CF Complications
- 4. Patient-centered Behavior Interventions

Text:

Nutrition in Cystic Fibrosis: A Guide for Clinicians Editors: Yen, Elizabeth H., Radmer Leonard RD, Amanda (Eds.) http://www.springer.com/us/book/9783319163864

*Other resources listed in "Reference Materials" section of each module

Module 1 Cystic Fibrosis Overview

Learning Objectives

- Describe the pathophysiology of cystic fibrosis, and specifically how the disease process alters nutrient digestion, absorption, and metabolism.
- Utilize cystic fibrosis resources including the Cystic Fibrosis Foundation (CFF) website.
- Discuss the interprofessional team approach in working with CF patients and their families.
- Describe Life Course Theory and how this is used on the context of CF care.

<u>Optimize Learning</u> – to get the most out of this module it is recommended that the following activities be completed.

- Complete the one page reflection to begin thinking about the course, your experience, and your goals as a learner.
- Review the PowerPoint (PP) slides these are meant to be an outline of the material and not a substitute for reviewing the text and the other reference materials provided.
- Read the book chapters and reference materials, and watch the video on CTFR function. Taking notes while reading will enhance learning and assist with completing the case study.
- Define the vocabulary terms and abbreviations. For some terms it may be necessary to do additional online research.
- When the above is completed, review the case study and answer the questions.

Reference Materials

- Module 1 PP slides/notes
- Nutrition in Cystic Fibrosis, Yen and Radmer Leonard Chapters 1-3
- Stallings et al. Evidence-based practice recommendations for nutrition-related management of children and adults with cystic fibrosis and pancreatic insufficiency: results of a systematic review. J Am Diet Assoc. 2008; 108(5):832-9.
- Cystic Fibrosis Foundation website- <u>https://www.cff.org</u>
 What is cystic fibrosis <u>https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/</u>
 CF Mutations <u>https://www.cff.org/What-is-CF/Genetics/Know-Your-CF-Mutations/</u>
 CF Care Team <u>https://www.cff.org/Living-with-CF/Your-CF-Care-Team/</u>
 Video of CFTR function and dysfunction in CF <u>https://www.youtube.com/watch?v=YzjnxegMWfk</u>
 Basics of Lung Care <u>https://www.cff.org/Living-with-CF/Treatments-and-Therapies/Airway-Clearance/Basics-of-Lung-Care/</u>
- Video of infant airway clearance <u>https://www.youtube.com/watch?v=qIJZUhco6ks</u>
- Video of actual patient completing PFTs <u>https://www.youtube.com/watch?v=QKjkegp8VkM</u>
- Life Course Theory PP slides/notes
- MCH Life Course Resource Guide <u>http://mchb.hrsa.gov/lifecourse/</u>

Vocabulary/Abbreviation List Cystic fibrosis (CF) CFTR Pulmonary function test (PFT) FEV₁ Pancreatic insufficient (PI) Life Course Theory Steatorrhea Malabsorption

Assessments

- 1. Reflection: Clinical Pediatric Nutrition Experience Write a one-page reflection on your experience thus far with clinical pediatric nutrition. What do you know about cystic fibrosis, either from courses you have already taken or personal experience? What do you hope to learn from this course, and how will you apply the information?
- 2. Case Study: CF Overview (see below)

Module 1 Case Study: CF Overview

<u>Case</u>

Juan is a 7-year-old male who was diagnosed with CF through newborn screening. He is pancreatic insufficient and takes digestive enzymes as part of his treatment regimen. His mother brought him to CF clinic today for a routine check-up. She was unable to bring Juan to his previously scheduled appointment, so it has been 6 months since the CF team last saw Juan. The dietitian is the first healthcare provider to see the family and learns that Juan has had a poor appetite the last 3 weeks related to a recent illness. His mother reports that he may have lost a little bit of weight. He missed several days of school because of the illness and is now significantly behind. His mother states that although she tries as much as possible to provide all the medications and treatments to Juan throughout the day, she sometimes forgets to give him his digestive enzymes. She is also not sure if Juan is receiving his digestive enzymes at school. In addition she is concerned that giving Juan so many pills-may ultimately harm him.

<u>CF hx:</u> Diagnosed through newborn screening; CFTR mutations - homozygous ΔF508; baseline FEV₁ is 92% Anthropometrics: Ht- 47 in Wt: 42 lbs

Biochemical: no new labs available

Diet hx: (typical day)

 $B - \frac{1}{2}$ bagel with butter and jam, OJ

L – 5 chicken fingers, canned mandarin orange slices, 8 oz 2% milk

Snack - tortilla chips with salsa or an apple with peanut butter

D – ½ hamburger with cheese, potato chips, 8 oz 2% milk, 2 chocolate chip cookies

<u>Social hx</u>: currently in 2nd grade; lives with mother, parents are divorced; father is not involved which puts a financial strain on the family; one younger brother (Julio) who does not have CF; the family has positive social support from Juan's maternal grandparents

Questions

- 1. What is CF and which areas of the body are affected?
- 2. How does CF affect nutrient digestion and absorption? Why is it important for Juan to take his digestive enzymes? How might this affect Juan's stools?
- 3. How does nutrition status impact lung function? What concerns do you have with regard to Juan's recent bout of poor appetite?
- 4. Write a brief summary of Juan's current nutrition issues.
- 5. Provide two recommendations that Juan's mother could try to help increase Juan's caloric intake.
- 6. Using information and formulas presented in Chapter 2 of the text, calculate Juan's estimated kcal and macronutrient requirements.
- 7. Which micronutrients are of specific concern for CF patients such as Juan?
- 8. What is FEV₁? If Juan completed a pulmonary function test in clinic today, what do you suspect his FEV₁ would be with respect to his baseline and why?
- 9. What is the purpose of the interdisciplinary CF team? Based on the information provided by Juan's mother, as well as his clinical status, which healthcare team member(s) would you consult with regarding Juan's care?
- 10. Related to Life Course Theory, identify Juan's risk and protective factors. Discuss how these might impact Juan's life course and overall health trajectory.

Module 2 Nutrition Assessment and Intervention in Pediatric CF

Learning Objectives

- Determine appropriate energy, macronutrient, and micronutrient needs for pediatric patients with cystic fibrosis.
- Determine appropriate nutrition interventions for pediatric patients with CF.
- Discuss the growth and development goals of pediatric CF patients and how these relate to disease progression and prognosis.
- Describe appropriate culturally competent approaches to patient care.

<u>Optimize Learning</u> – to get the most out of this module it is recommended that the following activities be completed:

- Complete the one page reflection on culture and cultural competence in healthcare.
- Review the PP slides these are meant to be an outline of the material and not a substitute for reviewing the text and the other reference materials provided.
- Read the book chapters and reference materials. Taking notes as while reading will enhance learning and assist with completing the case study.
- Watch the video of a CF RDN and parents of children with CF discuss digestive enzymes.
- Define the vocabulary terms and abbreviations. For some terms it may be necessary to do additional online research.
- When the above is completed, review the case study and answer the questions.

Reference Materials

- Module 2 PP slides/notes
- Nutrition in Cystic Fibrosis, Yen and Radmer Leonard Chapters 4-7, 9-10
- Nutrition Diagnostic Terminology handout
- Centers for Disease Control (CDC) growth charts -<u>http://www.cdc.gov/growthcharts/index.htm</u> Cystic Fibrosis Foundation website- <u>https://www.cff.org</u> Nutrition and GI Care Guidelines - <u>https://www.cff.org/For-Caregivers/Clinical-Care-Guidelines/Nutrition-and-GI-Care-Guidelines/</u>
 Video regarding enzymes and nutrition - <u>https://www.youtube.com/watch?v=a2F92RsbEWU</u> Enzymes - <u>https://www.cff.org/Living-with-CF/Treatments-and-Therapies/Nutrition/Enzymes/</u>
 Video of CF patient talking about TF - <u>https://www.youtube.com/watch?v=GAixW6A1QYc</u> Relizorb - <u>https://www.cff.org/News/News-Archive/2015/FDA-Approves-New-Device-for-Improving-Absorption-of-Essential-Fats-in-Tube-Feeding/</u>

**See also on this page patient handouts listed in the bar on the right under "Downloads"

- Tangpricha et al. An Update on the Screening, Diagnosis, Management, and Treatment of Vitamin D Deficiency in Individuals with Cystic Fibrosis: Evidence-Based Recommendations from the Cystic Fibrosis Foundation. J Clin Endocrinol Metab. 2012; 97(4):1082–1093. Available online: <u>http://press.endocrine.org/doi/abs/10.1210/jc.2011-3050</u>
- Handouts Cultural awareness and culturally sensitive health questions

Vocabulary/Abbreviation List Failure to thrive Meconium ileus Fecal elastase PERT PPI H2 blocker Fibrosing colonopathy

<u>Assessments</u>

- Reflection: Culture in the Healthcare Setting Write a one-page reflection addressing the following questions: How do you define "culture?" How does this compare with the dictionary definition? Describe your family culture and how this has impacted your life. How do you suspect that culture might impact patient care taken from the viewpoint of both the healthcare provider and the patient (and caretakers)?
- 2. Case Study: Pediatric CF Patient Assessment (see below)

Module 2 Case Study: Pediatric CF Patient Assessment

<u>Case</u>

Rosy is a 5-year-old female with CF, which was discovered at birth after she was found to have a meconium ileus. This was successfully treated without surgery. A chloride sweat test later confirmed the diagnosis of CF. Rosy is pancreatic insufficient and is currently on PERT. In the past she has struggled to maintain weight above the 10%'ile for BMI, and her parents report that she "just isn't that hungry" at mealtimes. They also report that she is very active and has poor sleeping habits. Rosy's mother states that Rosy eats three meals and two snacks each day. For each meal and snack, Rosy is given three enzyme capsules. Rosy's mother states that although she knows it was recommended that Rosy receive a different enzyme dose with meals and snacks, it has been easier giving the same number of capsules each time Rosy eats. While Rosy's parents attend each CF clinic visit and are attentive to her healthcare needs, they can become overwhelmed as they have three additional children and are struggling financially to make ends meet. In addition Rosy's paternal aunt has encouraged Rosy's parents to try non-traditional remedies to treat Rosy's CF. Most recently Rosy's parents have asked about over-the-counter digestive enzymes that they believe might be more natural and therefore, beneficial. Rosy's parents have also been limiting dairy, soy, and wheat which they say will, "helps Rosy's lungs work better."

<u>Anthropometrics</u>: Ht: 41 in Wt: 33.5 lbs Previous weight 3 months ago: 33 lbs <u>Biochemical</u>: 25-OH Vit D 19 ng/mL, no other current labs available within the last year <u>Clinical</u>: thin appearance, otherwise unremarkable Diet: (typical day)

B – 4 oz apple juice, 1 scrambled egg in a small corn tortilla, 1 oz cheddar cheese Snack – pop tart or pastry/donut

 $L - \frac{1}{2}$ PB and J sandwich and potato chips, or microwave meals, 4 oz apple juice

Snack – handful iced animal crackers, water or Capri Sun juice

D – whatever the family eats - chicken w/rice or spaghetti w/meat sauce, water or apple juice <u>Related Disease/Illness/Genetics/Previous medical hx</u>: CF mutations homozygous ΔF508 <u>Stool/GI hx</u>: 3 stools/day, generally large stools with some grease/oil noted occasionally <u>Vitamin hx</u>: Poly-Vi-Sol chewable, AQUADEKS drops; parents state patient is receiving as prescribed <u>Pancreatic enzymes</u>: Zenpep 5000, prescribed dosage 5 capsules/meal and 3 capsules/snack; per parents patient is given 3 capsules each meal and snack

<u>Social hx</u>: Rosy is one of four children; will be starting kindergarten next year; parents are Hispanic and speak limited English; interpreter utilized during clinic visits

<u>Questions</u>

- 1. Using the appropriate growth chart for Rosy's gender and age, determine %'iles for stature-for-age, weight-for-age, and BMI. Is Rosy meeting the CFF guidelines for BMI?
- 2. Calculated Rosy's expected weight gain (provide range) using her previous weight, and the weight from today's visit. For ease assume 30 days for each month, and that Rosy's last visit was exactly three months ago.
- 3. Calculate Rosy's estimated kcal and macronutrient needs. Based on her diet history, weight status, and BMI %'ile, do you believe Rosy is meeting her kcal needs?

- 4. Using the enzyme dosage Rosy is currently receiving, calculate the units of lipase/kg/d and units of lipase/kg/meal. How do these compare the CFF guidelines for enzyme dosing? How many enzyme capsules does Rosy take in one day? What are the issues with Rosy's current enzyme regimen?
- 5. Using Rosy's prescribed enzyme dosage, calculate units of lipase/kg/d and units of lipase/kg/meal. How does this compare with the dosage Rosy is currently taking, and with CFF guidelines? On the prescribed enzyme regimen, how many capsules would Rosy take in one day? What recommendations would you suggest to Rosy's family regarding Rosy's enzyme regimen and why?
- 6. Would you suggest an increase in Rosy's pancreatic enzyme dosage? What dosage would provide 2500 units lipase/kg/meal? How might you decrease Rosy's daily pill burden?
- 7. Assess Rosy's vitamin D lab results. What other nutrition-related labs should Rosy have? According to CFF guidelines, how often should these labs be repeated?
- 8. Write a brief summary of Rosy's current nutrition issues and nutrition status. Create two PES statements, which include pertinent nutrition diagnoses.
- 9. Provide 2-3 nutrition intervention recommendations to improve Rosy's nutrition status.
- 10. If you were to provide nutrition education and counseling to Rosy's parents, what would you emphasize and what types of specific suggestions might you make based on Rosy's current preferred foods and dietary intake? What would be your approach to help facilitate behavior change? What would you say to Rosy's parents regarding the connection between BMI and lung function?
- 11. What sort of cultural considerations would you take into account when working with Rosy's family?

Module 3 Nutrition-Related CF Complications

Learning Objectives

- Describe the development and nutrition implications of CF-related liver disease, gastrointestinal complications, and CF related diabetes (CFRD) in CF patients.
- Discuss the nutrition management of CF-related liver disease, gastrointestinal complications, and CFRD in CF patients
- Describe appropriate culturally competent approaches to patient care.

<u>Optimize Learning</u> – to get the most out of this module it is recommended that the following activities be completed:

- Complete the one page reflection regarding culturally sensitive approaches in nutrition care.
- Review the PP slides these are meant to be an outline of the material and not a substitute for reviewing the text and the other reference materials provided.
- Read the book chapters and reference materials. Taking notes reading will enhance learning and assist with completing the case study.
- Define the vocabulary terms and abbreviations. For some terms it may be necessary to do additional online research.
- When the above is completed, review the case study and answer the questions.

Reference Materials

- Module 3 PP slides/notes
- Nutrition in Cystic Fibrosis, Yen and Radmer Leonard Chapters 11-13
- Leeuwen et al. Liver disease in cystic fibrosis. Paediatric Respiratory Reviews. 2014;15(1):69-74.
- CFF website <u>www.cff.org</u>
 CFRD (watch video) <u>https://www.cff.org/Living-with-CF/Cystic-Fibrosis-related-Diabetes/</u>
- Moran et al. Clinical care guidelines for cystic fibrosis-related diabetes. Diabetes Care. 2010; 33(12): 2697-2708.
- Cultural awareness sheet and culturally appropriate health questions

Vocabulary/Abbreviation List

NAFLD Carnitine Gastroesophageal reflux SIBO Polyethylene glycol DIOS Gastrointestinal motility CFRD OGTT HgA1c

<u>Assessments</u>

- Reflection: Culturally Sensitive Approaches in Nutrition Care Write a one page reflection addressing the following: Compare and contrast the tradition Euro-American culture with traditional Hispanic and Native American cultures. How might these differences impact interactions in the healthcare setting? What experience do you have working with different cultures and/or populations? What additional culturally appropriate questions might you include on the question list provided in the "Reference Materials?"
- 2. Case Study: Pediatric Patient with CFRD (see below)

Module 3 Case Study: Pediatric Patient with CFRD

<u>Case</u>

Jessica is a 15-year-old female with CF. She was diagnosed with CFRD one year ago and was placed on insulin therapy. Her weight has been relatively stable, although she is concerned that she will start to gain weight with the insulin therapy. Overall Jessica is diligent with completing pulmonary treatments and taking medications, including PERT. Her parents are supportive of Jessica, although they are less involved in her treatment now that she is a teenager and can "take care of herself," as they stated. Jessica has an insulin pump to manage blood glucose levels. She has been trained in carbohydrate (CHO) counting, but on the last visit it was found that she had some confusion regarding CHO amounts in different foods.

<u>Anthropometrics</u>: Ht: 64 in Wt: 112 lbs Previous weight 3 months ago: 110 lbs <u>Biochemical</u>: 25-OH Vit D 31 ng/mL, fasting BG 145 mg/dL, HgA1c 7.5%, no other current labs available <u>Clinical</u>: unremarkable

Diet: (typical day)

B - oatmeal made with whole milk, toast with butter, banana

Snack – 2 oz cheddar cheese, green apple

L - wheat bagel with cream cheese, chocolate milk, grapes, Oreo cookies

Snack – Carnation instant breakfast with whole milk

D – BLT with extra mayo and bacon, whole milk, potato chips, baby carrots with regular ranch dip <u>Related Disease/Illness/Genetics/Previous medical hx</u>: CF mutations - ΔF508 homozygous

<u>Stool/GI hx</u>: 1-2 stools/d, no grease or fatty streaks noticed in the last six months; patient reports constipation on and off the past three months

Vitamin hx: AQUADEKs

<u>Pancreatic enzymes</u>: Creon 24000, prescribed dosage four capsules/meal and two capsules/snack <u>Other meds</u>: Glargine 1 unit for every 15 grams CHO, Lispro 20 units daily

<u>Social hx</u>: lives with parents, oldest of two children in the family; currently in 10th grade; father is currently out of work, which has put a financial strain on the family

Questions

- 1. Describe how CF impacts normal GI function. How is constipation connected to CF, and what sort of interventions would be suggested for Jessica? Discuss DIOS and the medical/nutrition management of the syndrome. Is Jessica at risk for developing DIOS?
- 2. Discuss the development of CFRD. Why is HgA1c not a good screening tool for CF patients? How does nutrition management of CFRD differ from Type I and Type 2 Diabetes Mellitus (DM)? What general nutrition recommendations would you provide to a patient like Jessica with CFRD?
- 3. Using the appropriate growth chart for Jessica's gender and age, determine %'iles for stature-for-age, weight-for-age, and BMI. Is Jessica meeting the CFF guidelines for BMI?
- 4. Calculated Jessica's expected weight gain (provide range) using her previous weight, and the weight from today's visit. For ease assume 30 days for each month, and that Jessica's last visit was exactly three months ago.
- 5. Calculate Jessica's estimated kcal and macronutrient needs. Based on her diet history, weight status, and BMI %'ile, do you believe Jessica is meeting her kcal needs? Based on Jessica's recommended CHO need, how many units of glargine would she be taking each day?

- 6. Using the enzyme dosage Jessica is currently receiving, calculate the units of lipase/kg/d and units of lipase/kg/meal. How do these compare with the CFF guidelines for enzyme dosing? Would you suggest any changes in Jessica's pancreatic enzyme regimen?
- 7. Assess Jessica's vitamin D lab results. What other nutrition-related labs should Jessica have? According to CFF guidelines, how often should these labs be repeated?
- 8. Write a brief summary of Jessica's current nutrition issues and nutrition status. Create two PES statements, which include pertinent nutrition diagnoses.
- 9. Provide 2-3 nutrition intervention recommendations to improve Jessica's nutrition status.
- 10. What sort of nutrition education and counseling would you provide to Jessica? How important would it be to include Jessica's parents? What would be your approach to help facilitate behavior change?

Module 4 Patient-centered Behavior Interventions

Learning Objectives

- Describe effective strategies for facilitating behavior change in patients.
- Discuss the impact of parental/care-taker "Life Course" on disease management and overall health of the pediatric CF patient.
- Describe appropriate culturally competent approaches to patient care.

<u>Optimize Learning</u> – to get the most out of this module it is recommended that the following activities be completed:

- Complete the one page reflection regarding personal Life Course Theory (LCT) experiences.
- Review the PP slides these are meant to be an outline of the material and not a substitute for reviewing the text and the other reference materials provided.
- Read the book chapters and reference materials. Taking notes reading will enhance learning and assist with completing the case study.
- Define the vocabulary terms and abbreviations. For some terms it may be necessary to do additional online research.
- When the above is completed, review the case study and answer the questions.

Reference Materials

- Module 4 PP slides/notes
- Nutrition in Cystic Fibrosis, Yen and Radmer Leonard Chapter 17
- Cystic Fibrosis Foundation website cff.org
 Nutrition: How to Encourage Health Eating handout
- Health Literacy, Health Resources Services Administration (HRSA) <u>http://www.hrsa.gov/publichealth/healthliteracy/index.html</u>
- Lisa Greene, MA, CFLE Happy Heart Families materials <u>http://www.happyheartfamilies.com/FoodIssues.html</u> <u>http://www.parentingchildrenwithhealthissues.com/index.html</u>

Vocabulary/Abbreviation List Differential attention Contingency management Contracting SMART goals

Assessments

1. Reflection: Your Life Course

Write a one page reflection describing your own life course and how this has impacted who you are today. How might you cope with a diagnosis of a chronic illness?

2. Case Study: Facilitating Behavior Change

Module 4 Case Study: Facilitating Behavior Change

<u>Case</u>

Sebastian is a 4-year-old male with CF. Both of Sebastian's parents are active in Sebastian's CF care and, normally Sebastian's mother, Mona, and maternal grandmother attend CF clinic visits. There is concern because Sebastian has not had steady weight gain. Mona states that he is a picky eater, and she has a hard time getting him to eat full meals. He often will take bites of food and then wants to play. Mona complains that she is constantly stressed about Sebastian's weight and trying to get him to eat enough food. The situation is causing a lot of stress at home, especially around meal times. The grandmother reports that when Sebastian is at her house, he eats larger quantities of food, and there doesn't seem to be as many problems. Mona agrees and is frustrated. The CF team is considering supplemental tube feeding (TF) since Sebastian does not seem to be improving with diet and dietary supplements. Sebastian's parents would like to give diet intervention one more try before starting tube feeding.

Anthropometrics: Ht: 38.5 in Wt: 29 lbs Previous weight 3 months ago: 29.5 lbs

Biochemical: 25-OH Vit D 19 ng/dL

Clinical: overall small, thin appearance, otherwise unremarkable

Diet: (typical day)

 $B-\ensuremath{\ensuremath{\mathcal{B}}}$ peanut butter and jelly sandwich, chocolate milk

Snack – bites of apple or banana

L – beans and rice with cheese, canned pineapple or mandarin oranges

Snack – Pedisure offered, but often only sips taken

D - chicken tenders (from frozen), grapes or banana, whole milk

Related Disease/Illness/Genetics/Previous medical hx: CF mutations - ΔF508 and W1282X

Stool/GI hx: 1 stool/d, generally no grease or fatty streaks noticed recently

Vitamin hx: AQUADEKs, Poly-vi-sol drops

<u>Pancreatic enzymes</u>: Creon 3000, prescribed dosage 3 capsules/meal and 2 capsules/snack <u>Social hx</u>: lives with parents, youngest of two children; both parents work and the family is relatively financially stable; significant support provided by maternal grandmother

<u>Questions</u>

- 1. Using the appropriate growth chart for Sebastian's gender and age, determine %'iles for stature-for-age, weight-for-age, and BMI. Is Sebastian meeting the CFF guidelines for BMI?
- 2. Calculated Sebastian's expected weight gain (provide range) using her previous weight, and the weight from today's visit. For ease assume 30 days for each month, and that Sebastian's last visit was exactly three months ago.
- 3. Calculate Sebastian's estimated kcal and macronutrient needs. Based on his diet history, weight status, and BMI %'ile, do you believe Sebastian is meeting his kcal needs?
- 4. Using the enzyme dosage Sebastian is currently receiving, calculate the units of lipase/kg/d and units of lipase/kg/meal. How do these compare the CFF guidelines for enzyme dosing? Would you suggest any changes in Sebastian's pancreatic enzyme regimen?
- 5. Write a brief summary of Sebastian's current nutrition issues and nutrition status. Create two PES statements which include pertinent nutrition diagnoses.

- 6. What would you communicate to Sebastian's parents regarding supplemental tube feeding? What more do you want to know from them regarding supplemental tube feeding? If supplemental tube feeding were to be initiated, what sort of information and education would provide to his family?
- 7. Who else on the CF team might you consult regarding Sebastian's eating behavior?
- 8. What specific questions might you ask to get a better understanding of the food environment and Sebastian's eating behaviors? What questions might you ask to better understand the family's culture and beliefs regarding nutrition, healthcare and eating?
- 9. What nutrition education would you provide to Sebastian's family? Describe behavior change strategies you would suggest for Sebastian's parents. What might you want to know from the grandmother? Should the grandmother be involved in the education/counseling sessions?
- 10. Discuss how Sebastian's parents' life course may impact Sebastian's treatment today. What are Sebastian's risk and protective factors? Describe Sebastian's current health trajectory and how this might impact him later in life.