FUTURE OF PEDIATRICS TALKS!

A VIRTUAL SUMMER SERIES

Pediatric Health Network

Children's National

You've Diagnosed Celiac Disease..... Now What?

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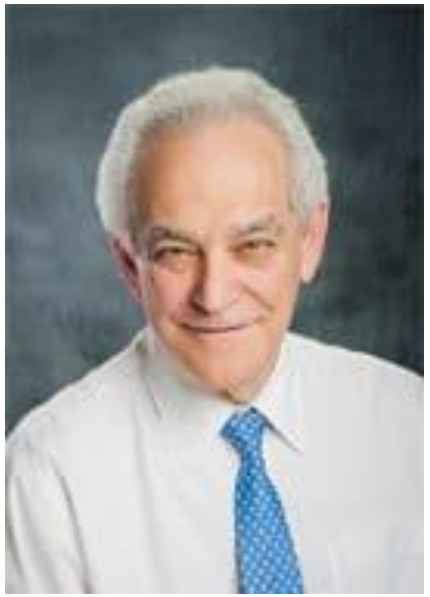
Joyana McMahon, *Education Specialist*

FUTURE OF PEDIATRICS

Agenda

No MD/PhD presenter?
No problem!

Dr. Benny Kerzner



Dr. Vahe Badalyan

At the conclusion of this presentation, providers will be able to:

1. Recognize and screen patients with typical and atypical presentations of celiac disease
2. Understand nutritional needs of celiac patients in various populations
3. Recognize food insecurity and provide families with support and resources for accessing treatment (food)

1. Recognize and screen patients with typical and atypical presentations of celiac disease

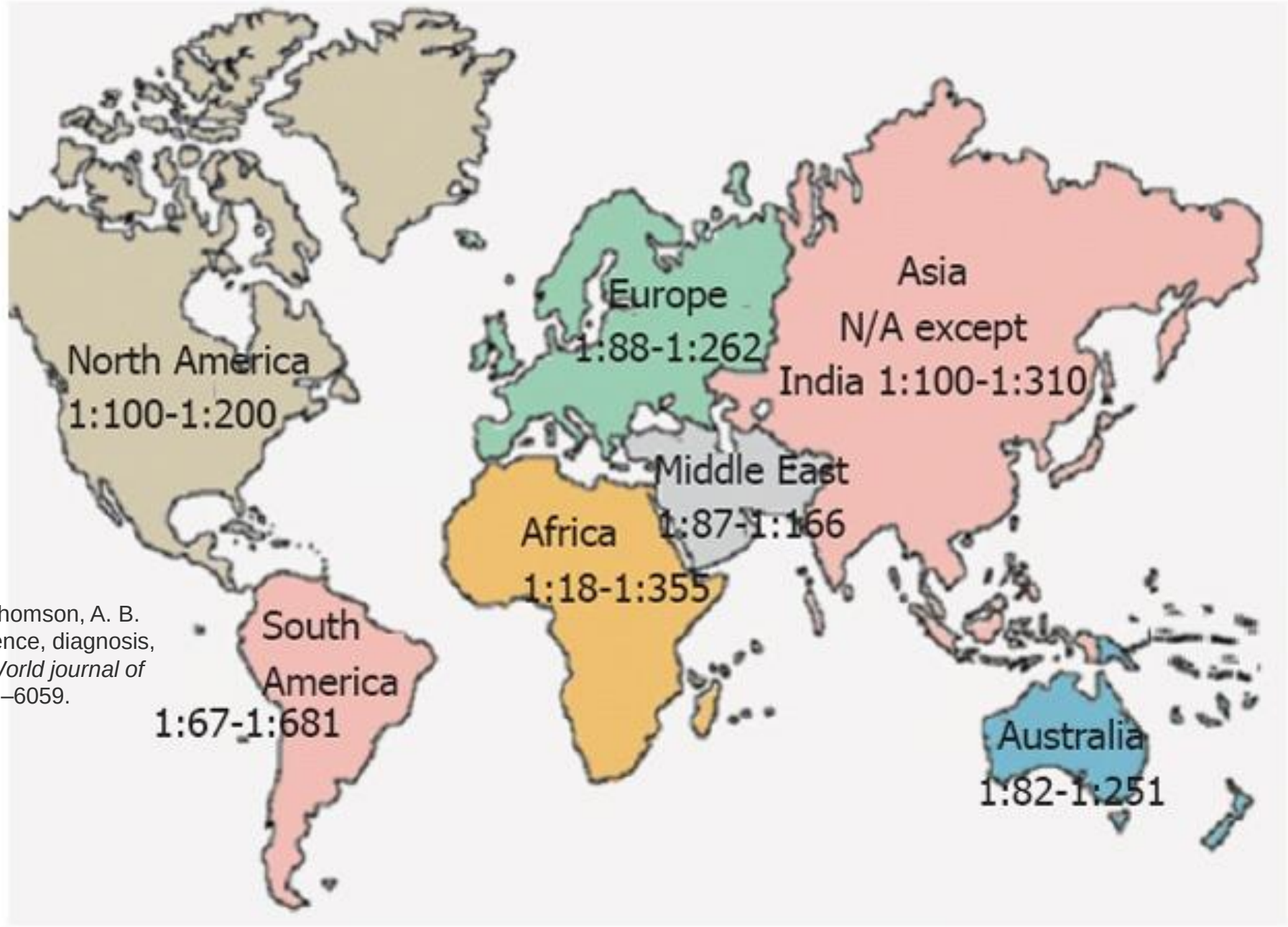
Kate Raber

How Does Celiac Disease Hide?

- "Classic Celiac" presentation
  - Diarrhea
  - Malabsorption
  - Failure to thrive
  - European descent

Celiac is so much more than a paragraph in a textbook!

Where in the World?



Gujral, N., Freeman, H. J., & Thomson, A. B. (2012). Celiac disease: prevalence, diagnosis, pathogenesis and treatment. *World journal of gastroenterology*, *18*(42), 6036–6059.

Typical vs. Atypical Presentations

TYPICAL

- Diarrhea
- Constipation
- Abdominal Pain
- Abdominal distension
- Vomiting
- Heartburn

ATYPICAL

"Absence of or few GI symptoms"

- Anemia
- Vitamin deficiency
- Osteoporosis/Osteopenia
- Headaches/Migraines
- Sleep difficulties
- Chronic infections
- Poor weight gain
- Poor growth
- Fatigue

Admou, B., Essaadouni, L., Krati, K., Zaher, K., Sbihi, M., Chabaa, L., Belaabidia, B., & Alaoui-Yazidi, A. (2012). Atypical celiac disease: from recognizing to managing. *Gastroenterology research and practice*, *2012*, 637187.

Most Common Comorbidities

LIVER

- Transaminitis (detected in >20% of CD cases; up to 10% d/t CD)

ENDOCRINE

- Type 1 Diabetes (2-11%)
- Hashimoto's & Grave's (2-7%)
- Addison's (5-12%)

OTHER

- Down Syndrome (5-12%)
- Turner Syndrome (4-8%)
- Williams Syndrome (up to 15%)
- IgA Deficiency (up to 8%)
- First-degree family member (up to 44.4%)

Screen ALL first-degree relatives!

Lauret, E., & Rodrigo, L. (2013). Celiac disease and autoimmune-associated conditions. *BioMed research international*, *2013*, 127589.

Nellikkal, S. S., Hafed, Y., Larson, J. J., Murray, J. A., & Absah, I. (2019). High Prevalence of Celiac Disease Among Screened First-Degree Relatives. *Mayo Clinic proceedings*, *94*(9), 1807–1813.

Other Common Comorbidities

LIVER

- Primary Biliary Cirrhosis (3-7%)
- Autoimmune Hepatitis (3-7%)
- Primary Sclerosing Cholangitis (up to 3%)
- Nonalcoholic Fatty Liver Disease (~3%)

NEUROLOGICAL

- Gluten ataxia, multiple sclerosis, peripheral neuropathy (10-12%)
- Idiopathic Neuropathy (up to 34%)

RHEUMATOLOGICAL/CONNECTIVE TISSUE

- Sjögren's Syndrome (4.5-15%)
- Lupus (unclear, but celiac pts 3x more likely to develop)
- Juvenile Idiopathic Arthritis & Rheumatoid Arthritis (2.5-7%)

OTHER

- Dilated Cardiomyopathy (up to 5.7%)
- Psoriasis (up to 4.34%)
- Microscopic colitis (i.e., collagenous & lymphatic colitis) (up to 15%)

Lauret, E., & Rodrigo, L. (2013). Celiac disease and autoimmune-associated conditions. *BioMed research international*, *2013*, 127589.

PCP Role in Celiac Diagnosis

- Front lines on symptom awareness, often first to catch comorbidities
- Ensure correct tests are run!
- Always refer to GI (preferably with celiac specialty)
- Referrals – if referring, especially for biopsy, the patient MUST NOT start the GF diet
- DO NOT officially diagnose if you are unsure
- Communication, communication, communication!

Questions? Referrals? Education?
celiac@childrensnational.org

TESTING

tTG IgA
Total IgA
Endomysial Antibody

If IgA Deficient:
tTG IgG
DGP IgG

Also acceptable:
"Celiac Panels"

ESPGHAN Criteria

No need for biopsy if
tTG IgA > 10x upper limit of test

For T1DM, tTG IgA must be >11x upper limit of test

Co-Management and Follow-Up

- PCP management not ideal, but….
  - Children with celiac disease should always have access to a qualified dietitian for gluten-free diet education and nutrition support. Too many patients turn to Google!
  - Poor long-term follow-up in GI clinics for well-controlled celiac (1)
  - Specialty follow-ups can be cost-prohibitive
- What if a PCP is the patient's only option (or refuses to see GI?)
  - Ensure proper blood tests are run
  - Screen for common comorbidities if symptoms persist or if new symptoms appear
  - Provide support for families (or refer them to support)

- CBC w/ diff
- CMP
- tTG IgA*
- TSH & Free T4
- Iron + TIBC
- Ferritin
- 25-Hydroxy Vitamin D
- Hepatitis B Surface Ab (Quantitative)

* If patient is IgA deficient, use tTG IgG *AND* DGP IgG

1) Blansky, B. A., Hintze, Z. J., Alhassan, E., Leichtner, A. M., Weir, D. C., & Silvester, J. A. (2019). Lack of Follow-up of Pediatric Patients With Celiac Disease. *Clinical gastroenterology and hepatology : the official clinical practice journal of the American Gastroenterological Association*, *17*(12), 2603–2604. https://doi.org/10.1016/j.cgh.2018.12.027

2. Understand nutritional needs of celiac patients in various populations

Lauren Pavone, RD

Nutritional Considerations in Celiac Disease

Malnutrition & malabsorption of Nutrition

- Poor weight gain/weight loss
- Short Stature

Micronutrient deficiencies

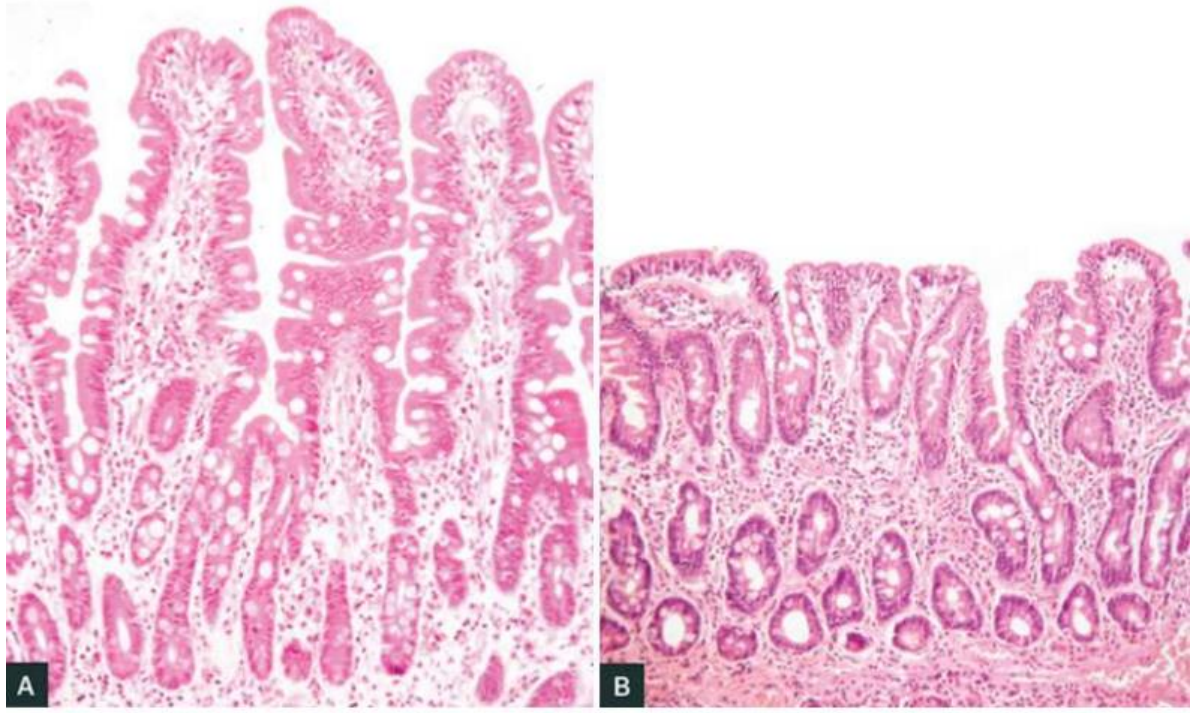
- Calcium / Vitamin D **(35 – 60%)**
- Iron deficiency anemia **(25 -85%)**
- Folate **(15.7 -18.3%)**
- Vitamin B12 **(4.3 – 8%)**
- Zinc

Osteoporosis/osteopenia **(53.8 – 58%)**

Avoidance of entire food groups

Overweight/Obesity

Healthy Villi VS. Damaged Villi



Gluten-Free Diet Pattern

Strict avoidance of all wheat, rye, barley and their derivatives

Education

- Label reading
- Choosing nutrient –dense GF foods in the diet
- Strategies for avoiding cross contamination of GF foods with gluten-containing foods and ingredients
- Strategies for eating in restaurants and while traveling away from home

Table 1
Grains: Gluten-free and Gluten-containing Flours and Starches

Gluten-Free Grains, Flours, and Starches	*Toxic (Gluten-Containing) Grains, Flours, and Starches*
Amaranth	Barley
Arrowroot	Bulgur
Bean flours (garbanzo, fava, romano)	Cereal binding
Buckwheat (pure buckwheat flour, buckwheat bran [Farinetta™], kasha [toasted buckwheat])	Chapatti flour (atta)
Corn (cornstarch, cornmeal, corn bran, corn grits, hominy)	Couscous
Fava	Dinkel
Flax seed	Durum
Garbanzo bean (chickpea, besan, gram, or channa)	Einkorn
Garfava™ flour (garbanzo + fava bean flours)	Emmer
Hominy, hominy grits	Farina
Mesquite flour	Farro (or faro)
Millet	Fu
Montina™ flour (made from Indian rice grass)	Gluten, gluten flour
Nut flours and nut meals	Graham flour
Oats (uncontaminated, if recommended by patient's healthcare team. See "Oats in the Gluten-Free Diet' section.)	Kamut
Pea flour	Malt (malt extract, malt flavoring, malt syrup, malt vinegar)
Potato flour, potato starch	Matzoh meal
Quinoa	Oats (most commercial brands, oat bran, oat syrup. See "Oats in the Gluten-Free Diet" section.)
Rice, all forms (brown, white, sweet, sticky, wild, jasmine, basmati, glutinous rice, rice polish, rice bran)	Orzo (sometimes used as a substitute for rice (orzo is not a grain, but a pasta that looks like rice)
Sago	Rye
Sorghum flour	Seitan (also known as "wheat meat")
Soy (soya) flour	Semolina
Tapioca (manioc, cassava, yucca)	Spelt
Teff (or tef) flour	Triticale
	Wheat (wheat bran, wheat germ, wheat starch)

Adapted from Case, *Gluten-Free Diet: A Comprehensive Resource Guide*, 2006 (29)

Nutritional Gaps on the Gluten-Free Diet Pattern

Inadequate nutrient intake

Risk of deficiency in iron, Vitamin D, Vitamin B6/B12, niacin, riboflavin, zinc, magnesium and fiber

- ✓ Gluten-containing grains excluded on the GFD are major sources of iron, dietary fiber, B vitamins and iodine
- ✓ Rice, corn, potatoes, tapioca are widely used as natural substitutes but are generally less nutrient dense
- ✓ Gluten free grains are not fortified like their gluten-containing equivalents

Several studies suggest that GFD is characterized by lower intake of complex carbohydrates and fiber, and higher intakes of protein and fat

Comparison: Gluten-Containing vs. Gluten-Free

Ingredients:
SEMOLINA (WHEAT), DURUM WHEAT FLOUR. VITAMINS/MINERALS: VITAMIN B3 (NIACIN), IRON (FERROUS SULFATE), VITAMIN B1 (THIAMINE MONONITRATE), VITAMIN B2 (RIBOFLAVIN), FOLIC ACID. THIS PRODUCT IS MANUFACTURED ON EQUIPMENT THAT PROCESSES PRODUCTS CONTAINING EGGS.

NUTRITION VALUES	UNITS (per 2 oz)	DAILY VALUE %
Calories	200	N/A
Fat Cal	9	N/A
Total Fat	1 g	1 %
Saturated Fat	0 g	0 %
Trans Fat	0 g	N/A
Cholesterol	0 mg	0 %
Sodium	0 mg	0 %
Potassium	118 mg	2 %
Total Carbohydrate	42 g	15 %
Dietary Fiber	3 g	11 %
Soluble Fiber	2 g	N/A
Insoluble Fiber	1 g	N/A
Sugar	1 g	N/A
Protein	7 g	N/A
Vitamin A	0 %	N/A
Vitamin C	0 %	N/A
Calcium	0 %	N/A
Iron	10 %	N/A
Vitamin D	0 %	N/A
Thiamin	40 %	N/A
Riboflavin	15 %	N/A
Niacin	30 %	N/A
Folate	50 %	N/A

Allergen Values (FDA)

Contains: Wheat, Cereals w Gluten
May Contain: Eggs
Free From: Peanuts, Tree Nuts, Milk, Fish, Molluscs, Crustacean, Soy

Ingredients:
CORN FLOUR, RICE FLOUR, MONO AND DIGLYCERIDES. NO WHEAT INGREDIENTS. PRODUCED ON A DEDICATED GLUTEN FREE LINE.

NUTRITION VALUES	UNITS (per 2 oz)	DAILY VALUE %
Calories	190	N/A
Fat Cal	9	N/A
Total Fat	1 g	2 %
Saturated Fat	0 g	0 %
Trans Fat	0 g	N/A
Cholesterol	0 mg	0 %
Sodium	0 mg	0 %
Potassium	77 mg	2 %
Total Carbohydrate	44 g	16 %
Dietary Fiber	2 g	7 %
Soluble Fiber	1 g	N/A
Insoluble Fiber	1 g	N/A
Sugar	0 g	N/A
Protein	4 g	N/A
Calcium	0 %	N/A
Iron	0 %	N/A
Vitamin D	0 %	N/A

Allergen Values (FDA)

Free From: Peanuts, Tree Nuts, Eggs, Milk, Fish, Molluscs, Crustacean, Soy, Wheat, Cereals w Gluten

Nutritional Management

Lifelong adherence to the gluten free diet

Referral to a Register Dietitian with expertise in celiac disease

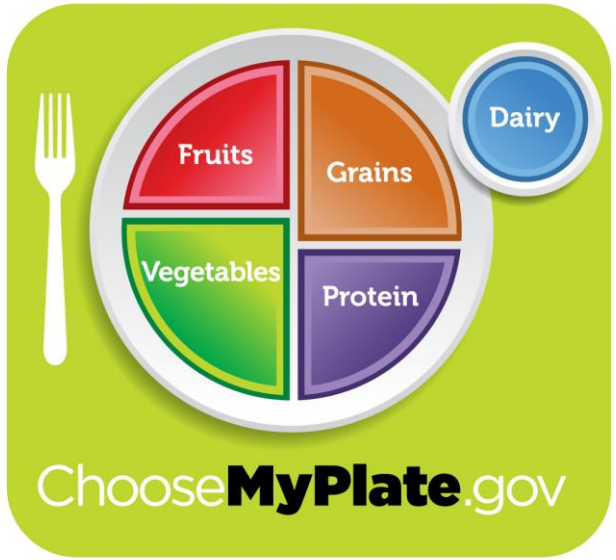
Identification and treatment of nutritional deficiencies

- Screening – Vitamin D, CBC, Serum iron, TIBC, and ferritin, vitamin B12, RBC folate
- Start Age-Appropriate multivitamin with iron and minerals
- DXA if presenting with a history of fractures, and/or avoiding dairy

Encourage variety and balance

- 2-3 servings of dairy/dairy alternatives
- Healthier gluten-free grains
- Minimally processed foods, <5 ingredients on the food label

Continuous long-term follow up with multidisciplinary team



Gluten-Free Complete Multivitamin with Iron

18 mg iron

9 mg iron

18 mg iron

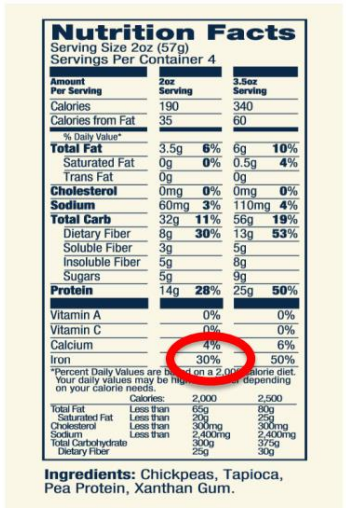
10 mg iron

10 mg iron

Choose Nutrient-Dense Gluten-Free Grains

Flour Nutrition Comparison

Ingredient	Fiber (per ¼ cup)	Protein (per ¼ cup)	Carbohydrates (per ¼ cup)
Almond Flour	3g	4g	6g
Coconut Flour	11g	5g	8g
Brown Rice Flour	2g	3g	31g
White Rice Flour	1g	2g	32g
Teff Flour	5g	5g	29g
Millet Flour	4g	3g	22g
Sorghum Flour	3g	4g	25g
Tapioca Flour	0g	0g	26g
Soy Flour	3g	10g	8g
Corn/Potato	0g	0g	7g/10g
Quinoa Flour	2g	4g	18g
Buckwheat Flour	4g	4g	21g



3. Recognize food insecurity and provide families with support and resources for accessing treatment (food)

Joyana McMahon

Barriers to access

- The gluten-free diet IS a celiac patient's medicine. However, when a person is on a fixed income, it can be difficult and stressful for them to obtain that medicine.
  - No insurance covers the cost of GF food (unlike in Europe)
  - On average, GF products were 159% more expensive than regular products
  - Median cost of GF brown & GF white bread was over four times the price of their gluten-containing counterparts
  - Several studies have found increased costs of 76% – 518% for gluten-free products

Cost of GF Products in USA

$6.49

For **14 ounces** of gluten-free bread

155% more expensive for gluten-free bread!

$4.19

For **24 ounces** of gluten-containing bread

$2.39

For **12 ounces** of gluten-free pasta

202% more expensive for gluten-free pasta!

$1.33

For **16 ounces** of gluten-containing pasta

GF Food Insecurity

- Because of price and nutritional deficits, the issue of food insecurity for patients with celiac disease is prevalent around the world.
  - Food insecurity in celiac disease is extremely under-researched, but we are in a collaborative effort with 12 pediatric celiac programs to assess it.
- Approximately two million Americans live in poverty with food allergies or celiac disease (Weissman, 2015)

Federal Benefits and GF Food Insecurity

- SNAP Benefits are not adjusted for the elevated food prices for safe, gluten-free or allergen-free food (Harmon, 2014)
- SNAP users spend over half of their allotment in the first week after receiving it, leaving very little room in the budget to purchase safe, gluten-free foods for the rest of the month (Center on Budget and Policy Priorities, 2019)
- WIC requires that a grain be listed as the first ingredient to qualify for purchase, but no GF whole grain bread lists a GF grain as the first ingredient. Therefore, most GF products are disqualified.
- The Healthy, Hunger-Free Kids Act of 2010 – which authorizes all federal child nutrition programs like School Breakfast and National School Lunch – provides packages that include eggs, milk, yogurt, cheese, and peanut butter, but also MANY gluten-containing foods. In other words, foods that many families are restricted from consuming.

How Do We Fix This?

- Ask screening questions from the Hunger Vital Signs questionnaire
- 504 Plans in schools can help a student get GF breakfast and lunch
- Celiac Disease Program at CNH has some resources through partnerships to help (currently limited)
- Allergy Strong program can help set up an Amazon wish list for a family in need
- Participate in advocating for change to current policies
- Celiac Disease Program Food Insecurity Fund

Thank you!

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