Celiac Disease: Common Myths and Misconceptions

Paulina Ordonez, MD
Kimberly P. Newton, M.D.
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Disclosures

• None
Celiac Disease: Essentials

- caused by ingestion of gluten
- genetically susceptible individuals (high risk groups)
Celiac Disease and Children: Common Myths and Misconceptions

“My baby can be born with celiac disease.”
Celiac Disease: Necessary Factors

A baby is not born with celiac disease, but may be born with *the potential* to develop celiac disease...
Until gluten is introduced into the diet, even a baby with celiac genes cannot get celiac disease.
Breastfeeding will decrease the chance my child will develop celiac disease.

**FACT**
Celiac Disease and Breastfeeding

- Breastfeeding has a protective effect on the development and presentation of celiac disease
  - Fewer breast-fed children develop celiac disease
  - Breast-fed infants develop celiac disease, generally at a later age
    - with milder (silent) symptoms
  - Infants that are breast fed when gluten is introduced are half as likely to develop celiac disease.

Peters U et.al., Ann Nutr Metab 2001; 45:135--42
Ivarsson A. et.al., Am J Clin Nutr 2002; 75:914-921
Celiac Disease and Children: *Myths and Misconceptions*

“Celiac disease risk is lessened by delaying introduction of gluten into the diet.”

**FACT**
Timing of Gluten Introduction and Risk of Celiac Disease

- 1560 at risk children followed over time

It is recommended that gluten be added to an infant’s diet between 4 and 6 months of age.

Adapted from Norris JM et.al., JAMA 2005; 293:2343-2351
Celiac Disease and Children: *Facts, Fiction, and Controversies*

“A child must have gastrointestinal symptoms in order to have celiac disease.”

**MYTH**
‘Classic’ Presentation of Celiac Disease

- “Malabsorption” Symptoms
  - Diarrhea
  - Vomiting
  - Belly pain
  - Loss of appetite
  - Failure to Thrive
- Starts ~ 6 - 24 months, following gluten introduction into diet
Non-gastrointestinal Manifestations of Celiac Disease

MOUTH - dental enamel defects, mouth sores

GROWTH - short stature

DEVELOPMENT -

MUSCULOSKELETAL - low bone density

NEUROLOGIC/PSYCHIATRIC - headaches, ADHD, depression

SKIN - dermatitis herpetiformis

LIVER - inflammation of liver

BLOOD - iron deficiency anemia (resistant to iron)

MOUTH - dental enamel defects, mouth sores

CDHNF/NASPGHAN
Silent Celiac Disease

- **NO SYMPTOMS** even though there is damage to the lining of the gastrointestinal tract
- Often found in populations at high risk for celiac disease
  - Close relatives of people with celiac disease
  - Other conditions associated with celiac disease
    - Type 1 diabetes mellitus
  - Other syndromes associated with celiac disease
    - Down syndrome
Celiac Disease and Children: *Myths and Misconceptions*

“My child has a hearty appetite and is overweight, so she cannot have celiac disease.”
Childhood Obesity and Celiac Disease

➢ Among 143 children diagnosed with celiac disease at Children’s Hospital Wisconsin 1986-2003
  • 11% overweight
  • 4.5% obese

Celiac disease can occur in children with various body shapes and sizes.
“If my child has a positive TTG blood test for celiac disease, this means he has celiac disease.”
How to Test for Celiac Disease in Children

Step #1:

**Celiac Disease antibody screen: for kids >2 yo**
**Simple blood test**
- Check levels of tissue transglutaminase (TTG IgA)
- Check total amount of IgA

**Note**: for children younger than two years of age

**Celiac Disease antibody screen: for kids <2 yo**
- **Simple blood test**
  - Check levels of **anti-gliadin** antibodies
Sometimes the TTG screening test is **negative** even when a child **has** celiac disease...
- If child is not eating gluten
- If child < 2 years old, not enough ‘auto-antibody’ produced
- If child has IgA deficiency

Sometimes the TTG screening test is **positive** when a child **does not have** celiac disease...
- When there are other autoimmune conditions
- In the presence of chronic liver disease
- Transient positivity in childhood
Celiac Disease and Diagnosis

Caution:
Celiac Disease should not be diagnosed based on single blood test ALONE!!

- Sometimes the TTG screening test is **negative** even when a child *has* celiac disease...
  - If child < 2 years old, not enough ‘auto-antibody’ produced
  - If child has IgA deficiency
- Sometimes the TTG screening test is **positive** when child *does not have celiac disease*...
  - When there are other autoimmune conditions
  - In the presence of chronic liver disease
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How to Test for Celiac Disease in Children

Step #1: Celiac Disease antibody screen
- Simple blood test
  - Check levels of tissue transglutaminase (TTG IgA)
  - Check total amount of IgA

Step #2: If TTG is elevated
Upper endoscopy with biopsies
- Invasive procedure to sample small intestinal tissue
  - Look for evidence of tissue damage
Upper Endoscopy with Biopsies in Children

- Confirm celiac disease diagnosis
- Establish level of damage to the lining of the GI tract
- Evaluate for other problems

Small Intestine
If celiac serology is negative, my child will never develop celiac disease.

MYTH
Genetic Testing for Celiac Disease

- HLA class II genes known as *HLA-DQ2* and *HLA-DQ8* located on chromosome 6p21
- Approximately 95% of CD patients express *HLA-DQ2*, and the remaining patients are usually *HLA-DQ8* positive. However, the *HLA-DQ2* allele is common and is carried by approximately 30% of Caucasian individuals.
- *HLA-DQ2* or *HLA-DQ8* is necessary for disease development but is not sufficient for disease development; its estimated risk effect is only 36-53%.
Genetic Testing for Celiac Disease

In high-risk, asymptomatic children with negative TTG, consider HLA testing:

If HLA DQ2/DQ8 positive:
- Continue surveillance while asymptomatic (frequency unclear but every 3 years reasonable)
- If symptomatic proceed with endoscopy

If HLA DQ2/DQ8 negative:
- Development of CD highly unlikely, discontinue screening but clinical review if symptoms develop
"My child will eventually grow out of celiac disease."
Celiac Disease is Lifelong

- Celiac Disease diagnosis must be confirmed
  - Positive screening blood tests (TTG)
  - Biopsy of intestine shows celiac disease
  - Improvement in symptoms after GFD initiated

- Children can not “grow out of celiac disease”
  - Need for a gluten free diet is lifelong, although inflammation of the intestines and other manifestations do heal!
  - It is not OK to have gluten-containing foods every once in awhile
“I have a child with celiac disease. My other two children don’t have symptoms, so I do not need to get them tested.”

MYTH
Celiac Disease in Family Members

- One study found 23% of 168 siblings with no symptoms had celiac disease.

- Silent celiac disease 24 - 48 times more frequent in siblings of celiac patients.

- In silent celiac disease:
  - Damage to the intestines is occurring.
  - By diagnosing early, complications can be prevented.

General population: 1:133 (1-2%)
Family history: 1:22 (4-5%)
Celiac Disease in Family Members

Screening recommendations:

- Screen family members; screen siblings @ 3 years old.
- Even if initial celiac disease screen is negative, siblings should be screened every 2 years (or sooner) if celiac disease manifestations arise.
- Consider genetic testing at the time of initial screening; if sibling does not have DQ2 or DQ8 gene, further screening is not necessary.
Question #1
Who should not be screened for celiac disease?

A. 4yo sibling of celiac disease patient
B. Overweight child with persistent abdominal pain
C. Child with type 1 DM and negative DQ2/DQ8 genetic testing
D. Sibling of CD patient with negative TTG 1 year ago and new GI symptoms
Question #1
Who should not be screened for celiac disease?

A. 4yo sibling of celiac disease patient
B. Overweight child with persistent abdominal pain
C. **Child with type 1 DM and negative DQ2/DQ8 genetic testing**
D. Sibling of CD patient with negative TTG 1 year ago and new GI symptoms
Question #2
What is/are good intervention(s) after obtaining a positive TTG result:

A. Referring child for upper endoscopy and biopsies
B. Confirm IgA levers are normal
C. Doing a trial of gluten restriction
D. Screen for another autoimmune conditions
Question #2

What is/are good intervention(s) after obtaining a positive TTG result:

A. Referring child for upper endoscopy and biopsies
B. Confirm IgA levers are normal
C. Doing a trial of gluten restriction
D. Screen for another autoimmune conditions
Breast feeding reduces the risk of celiac disease and/or at least delays its onset.

Introducing gluten after 4 months of age is associated with a decreased risk of celiac disease.

Celiac disease has a variable presentation in childhood.

Screening for celiac disease in childhood is similar to adults – except if less than 2 years old.

Celiac disease is prevalent in siblings, and siblings should be screened, even if asymptomatic!

Gluten restriction is NEVER advised before confirming the diagnosis by endoscopy.
Thank you!

Paulina Ordonez-Naranjo, MD
858-966-4003
pordonez@ucsd.edu