

Family Talk:

Getting Your Family Tested for Celiac Disease

Being diagnosed with any disease can be difficult. Knowing why you haven't been feeling well can be a relief. But, not all people with celiac disease have symptoms. Those family members not experiencing symptoms may not understand that they could actually have the disease. They may not recognize their own risk for developing celiac disease either. What's more, they may not comprehend the potential health risks of undiagnosed celiac disease.

Three million Americans are living with celiac disease. An estimated 95% of them don't know they have it.

Talk to your untested family members and tell them the facts.

Who is at risk for celiac disease?

- 1 in 22 first-degree family members (parent, child, sibling) and 1 in 39 second-degree family members (aunt, uncle, niece, nephew, cousin, grandparent, grandchild and half-sibling) are at risk for celiac disease.
- Your risk may double if your brother or sister has celiac disease.
- An estimated 1 in 10 individuals with Type 1 diabetes in the U.S. have celiac disease.
- Celiac disease affects 1 out of every 133 Americans.

What are the sign and symptoms?

- A 2012 survey found that 35% of people at risk for celiac disease had no reason to suspect that the symptoms they were experiencing were due to undiagnosed celiac disease.
- Classic symptoms include diarrhea, weight loss or growth failure and anemia.
- Non-classic symptoms include constipation, abdominal pain, and foul smelling and bulky stools.
- Other symptoms include rash, unexplained infertility, fatigue, headaches and nutritional deficiencies.

What happens if celiac disease is left untreated?

- Left untreated, undiagnosed celiac disease can increase your risk of other problems: Osteoporosis, infertility, thyroid disease and even certain cancers like lymphoma.

You have a special role in informing your family members.

Getting Tested Is Easy. You Can Lead The Way.

Tell your story. Explain to your untested family members that a simple blood test is the first step to diagnosis. An intestinal biopsy may be required as well. Remind them to remain on a diet containing gluten until after testing is complete. To start, your untested family members need to **ask for an IgA-tTG along with a total IgA level.**

- ✓ Most major health insurers cover the cost of testing.
- ✓ Let your relatives know to contact their primary care provider about getting tested. A primary care provider can be a family medicine doctor, an internist or an Ob-Gyn.
- ✓ If they do not have a primary care provider, suggest that they contact their insurance company to find one. Many insurance companies offer a “Doctor Finder” tool. Family and friends can also help provide referrals for a trusted medical provider.



Genetic testing is another way to rule out celiac disease and may be a good option for at-risk or high-risk children, or at-risk or high-risk people already on the gluten-free diet.

Personal risk information is easy to ignore.

With so much health information in the news each day, it's easy to stop listening.

This is especially true when someone feels perfectly healthy and is not aware of symptoms.

You give celiac disease a face to go along with it.

Your diagnosis of celiac disease makes it personal for your relatives. Your experience and advice is hard to ignore.

In a 2012 study, 64% of those with a diagnosed family member said they would get tested for celiac disease if a family member asked them to.

Untested at-risk family members are difficult to reach.

Without understanding the signs, symptoms and risk of celiac disease, getting your untested family member's attention is difficult.

You play a key role in getting them the information they need to keep themselves healthy.

Help Keep Your Family Members Healthy. Ask Them To Get Tested For Celiac Disease.

www.BIDMC.org/CeliacCenter | www.CeliacCentral.org | www.CeliacNow.org