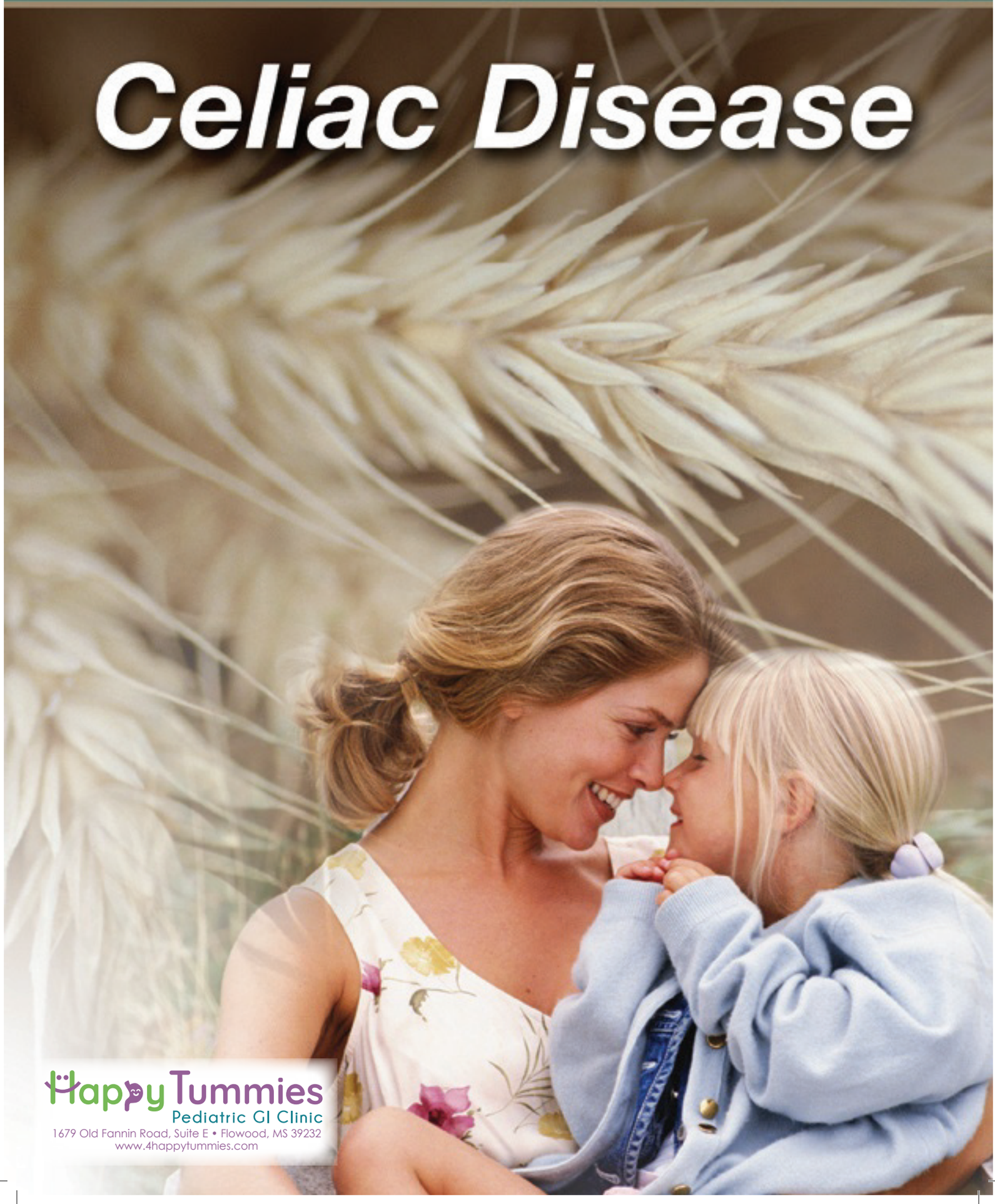
The Children's Digestive Health and Nutrition Foundation

Celiac Disease



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What is celiac disease?

Celiac disease is an chronic condition mainly affecting the small intestine. It is a permanent sensitivity to gluten, a protein from wheat, rye, and barley. In affected individuals, eating food containing gluten leads to damage to the finger-like projections, or villi, lining the small intestine. Other names include celiac sprue and gluten sensitive enteropathy. Celiac disease is considered an auto-immune disorder, in which the body attacks itself.

What are the symptoms of celiac disease?

Symptoms may begin at any age after gluten is introduced in the diet. Intestinal symptoms include chronic diarrhea or constipation, bloating and gas, irritability, and poor weight gain. Patients may have growth and pubertal delay, iron deficiency anemia, fractures or thin bones, abnormal liver tests, and a chronic itchy rash called dermatitis herpetiformis. Celiac disease may also occur without symptoms.

How is celiac disease diagnosed?

Celiac disease may go undiagnosed for years. Blood tests are widely used to test for celiac disease. Both the anti-tissue transglutaminase antibody (tTG) and the anti-endomysial antibody (EMA) tests are highly accurate and reliable but are insufficient to make a diagnosis.

Celiac disease must be *confirmed* by finding certain changes to the villi which line the small intestine. To see these changes, a tissue sample from the small intestine is obtained, using a procedure called an endoscopy with biopsy. (A flexible tube-like instrument is placed through the mouth, down the throat, past the stomach and into the small intestine to obtain small tissue samples).

How is celiac disease treated?

Treatment consists of life-long avoidance of gluten-containing foods (such as bread, cereal, cakes, pizza, and other food products or additives containing wheat, rye, and barley). Medications and over the counter products may also contain gluten. Once gluten is removed from the diet, complete healing is expected. Although a total gluten-free diet seems overwhelming at first, families have been very successful with the diet. Dietitians and support groups can help families adjust to this life-altering diet, yet it may take several months to get used to the gluten-free diet.

What can you expect with treatment?

Symptoms may begin to improve within the first 1-2 weeks of starting the diet. Lactose intolerance caused by the intestinal injury also improves. By 6-12 months of the gluten-free diet, most people's symptoms have gone away, and the lining of the intestine has healed. In children, growth and bone strength return to normal. Regular follow-up with a dietitian and a health care team experienced with celiac disease are important for continuing to stick with the diet and for monitoring for complications.

Even though some people are able to resume gluten without immediate symptoms, they do not "outgrow" celiac disease, and it is not "cured". The gluten free diet treatment should be continued for life.

How common is celiac disease and who is at risk?

It is estimated that 1 in every 100 to 200 people in the United States and Europe have celiac disease. People at higher risk for celiac disease are those that have type 1 diabetes, autoimmune thyroid disease, dermatitis herpetiformis, Down syndrome, Turner syndrome, Williams syndrome or have a relative with celiac disease. You may still have celiac disease even though you are not in a group at higher risk.

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