What is celiac disease? Celiac disease is an inherited autoimmune disorder that affects the digestive process of the small intestine. The small intestine is connected to the stomach; the first parts of the small intestine—the duodenum and the jejunum—are where celiac disease is commonly found.

When a person who has celiac disease consumes gluten—a protein found in wheat, rye, and barley—the individual’s immune system responds by attacking the small intestine, inhibiting the absorption of important nutrients into the body. Specifically, the tiny fingerlike protrusions called villi on the lining of the small intestine are lost. Normally, nutrients from food are absorbed into the bloodstream through these villi. Celiac disease can be associated with other autoimmune disorders and, if undiagnosed and untreated, can lead to osteoporosis, infertility, neurological conditions, and, in rare cases, cancer.

What is dermatitis herpetiformis (DH)?

Dermatitis herpetiformis (DH) is an itchy, blistering skin condition that is a form of celiac disease. The rash usually occurs on the elbows, knees, and buttocks, and is characterized by its bilateral nature, which means that both knees and/or both arms are affected, seldom just one. Many people with DH have no digestive symptoms and only about 40% of them have positive blood tests (serology) for celiac disease; however, they almost always have the same gluten-dependent intestinal damage as people with celiac disease.

Unless otherwise specified, the information pertaining to celiac disease also pertains to people with dermatitis herpetiformis. In addition to the required, strict gluten-free diet, DH is also commonly treated with a medication called dapsone.

Is celiac disease a rare condition?

No. Celiac disease affects at least 1% of Americans, or nearly 3 million people in the United States. By comparison, Alzheimer’s disease affects approximately 2 million people. It is possible to be diagnosed with celiac disease at any age.

Is it possible to have celiac disease but have NO symptoms?

Yes. Research has demonstrated that a significant percentage of children and adults with positive celiac blood tests had no, or minimal, symptoms when they were tested. Further, there are a few patients who carry the gene for celiac disease and have no or minimal symptoms and negative blood tests, yet a positive biopsy shows that the disease is active.

Why is it difficult to find a doctor who knows about celiac disease?

Most physicians learned during medical school that celiac disease is so rare they would likely never see a patient with symptoms in their entire medical career. Lectures on celiac disease in medical schools, even today, are few and far between. When your doctor was in medical school, he or she may have heard a 20 to 30 minute celiac disease lecture during 4 years of classes. Medical textbooks still contain outdated information.

Additionally, celiac disease often presents with seemingly unrelated symptoms, such as fatigue, joint pain, anemia, and infertility, making diagnosis that much more difficult.

The University of Chicago Celiac Disease Center is working hard to properly educate doctors about celiac disease so that those at risk for the disease are screened immediately.

For more information, contact The University of Chicago Celiac Disease Center at www.cureceliacdisease.org.