

Celiac disease facts & figures.

Celiac disease is an inherited autoimmune disorder that affects the digestive process of the small intestine. When a person who has celiac disease consumes gluten (a protein found in wheat, rye, and barley), the immune system responds by attacking the small intestine and inhibiting the absorption of important nutrients into the body. Undiagnosed and untreated, celiac disease can lead to the development of other autoimmune disorders, as well as osteoporosis, infertility, neurological conditions, and, in rare cases, cancer.

Prevalence of celiac disease in the United States

- In average healthy people: 1 in 133
- In people with related symptoms: 1 in 56
- In people with first-degree relatives (parent, child, sibling) who have celiac disease: 1 in 22
- In people with second-degree relatives (aunt, uncle, grandparent) who have celiac disease: 1 in 39
- In the landmark prevalence study on celiac disease, investigators determined that 60% of children and 41% of adults diagnosed during the study were asymptomatic (without any symptoms)
- During the prevalence study, researchers found that 21% of patients with a positive anti-endomysial antibody test did not receive a biopsy because the physician refused to perform the procedure or the insurance company refused to pay for it
- Only 35% of newly diagnosed patients had chronic diarrhea, dispelling the myth that diarrhea must be present to diagnose celiac disease

Source: Fasano A, Bertl I, Gerarduzzi T, et al. Prevalence of celiac disease in at-risk and not-at-risk groups in the United States: a large multicenter study. *Arch Intern Med.* 2003;163(3):286-292.

- Celiac disease affects about 3 million Americans. Recent research shows that 83% of them are not diagnosed

Source: Green PHR, Stavropoulos SN, Panagi SG, et al. Characteristics of adult celiac disease in the USA: results of a national survey. *Am J Gastroenterol.* 2001;96(11):126-131.

- The average length of time it takes for a symptomatic person to be diagnosed with celiac disease in the US is 4 years; this type of delay dramatically increases an individual's risk of developing autoimmune disorders, neurological problems, osteoporosis, and cancer
- The incidence of autoimmune diseases in the general US population is 3.5%. In a 1999 study, Ventura et al found that those diagnosed with celiac disease from 2 to 4 years of age had a 10.5% chance of developing an autoimmune disorder. Additional findings are outlined in the table below

Source: Characteristics of adult celiac disease in the USA: results of a national survey. Green, P.H. et al. *American Journal of Gastroenterology*, 2001, 2006.

Age at diagnosis	Chance of developing autoimmune disorder
4 – 12 years of age	16.7%
12 – 20 years of age	27%
Over 20 years of age	34%

- Early diagnosis of celiac disease is important as it might prevent complications, so awareness is key. A study in North America showed that an active case-finding strategy in the primary care setting is an effective means to improve the diagnostic rate of celiac disease. By using the blood test to screen all subjects belonging to known at-risk groups, the diagnosis rates increased more than 40-fold.

Sources: Ventura A, Magazzu G, Greco L. Duration of exposure to gluten and risk for autoimmune disorders in patients with celiac disease: SIGEP Study Group for Autoimmune Disorders in Celiac Disease. *Gastroenterology.* 1999;117(2):297-303.

Rampertab SD, Pooran N, Brar P, Singh P, Green PH. Trends in the presentation of celiac disease. *Am J Med.* 2006;119(4):355.e9e14.

Catassi C, Kryszak D, Louis-Jacques O, et al. Detection of celiac disease in primary care: a multicenter case-finding study in North America. *Am J Gastroenterol.* 2007;102(7):1454-1460.

Celiac disease affects 1% of healthy, average Americans. That means at least 3 million people in our country are living with celiac disease — 83% of them are undiagnosed.

Chronic illness in the United States

Below is a list of some commonly known chronic illnesses and the number of people affected in the United States:

- Epilepsy affects 2.7 million
- Cystic fibrosis affects 30,000 people
- 17,000 people are living with hemophilia
- Parkinson's disease affects 1 million individuals
- Ulcerative colitis affects 500,000 people
- Crohn's disease affects 500,000 people
- 2.1 million people are living with rheumatoid arthritis
- Lupus affects 1.5 million people
- Multiple sclerosis affects 400,000 people

Putting celiac disease in perspective

- Type 1 diabetes affects 3 million people; 6% (180,000) of those diagnosed also have celiac disease
- 610,000 women in the US experience unexplained infertility; 6% (36,600) of these women might never learn that celiac disease is the cause
- 350,000 people in the United States are living with Down syndrome; 12% (42,000) of them also have celiac disease
- The number of people with celiac disease in the US would fill 4,400 Boeing 747 airplanes
- It would take 936 cruise ships to hold every American with celiac disease
- Americans with celiac disease could fill the 40,000 seats in US Cellular Field to watch the Chicago White Sox 55 times
- US Chicago Bears fans with celiac disease could fill Soldier Field, the home of the Chicago Bears, 37 times
- The number of people with celiac disease in the US is roughly equal to the number of people living in the state of Nevada
- Alaska, Delaware, Washington, DC, Hawaii, Idaho, Maine, Montana, Nebraska, New Hampshire, New Mexico, North Dakota, Rhode Island, South Dakota, Utah, and Vermont all have populations that are less than 2.2 million, the number of people living with celiac disease in the US

Facts about the gluten-free diet

- In 2004, the Food Allergen Labeling and Consumer Protection Act became law. This legislation went into effect in 2006, making it possible, for the first time, for people with celiac disease to read a food label and determine in a few easy steps if a product is safe to eat
- In August 2013, the FDA ruled on gluten-free labeling, establishing the threshold of 20 ppm for foods to be considered gluten-free. The University of Chicago Celiac Disease Center helped pass this law
- There are more than 2,000 gluten-free food items available in the US, and consumers are now more likely to find these foods in regular grocery stores
- According to a market research report published by Packaged Facts, the gluten-free foods market in the US hit \$4.2 billion. At this rate, by 2017 gluten-free sales could grow to more than \$6.6 billion