

Celiac Disease Facts and 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 individual's 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 are celiac: 1 in 22
- In people with second-degree relatives (aunt, uncle, cousin) who are celiac: 1 in 39
- Estimated prevalence for African-, Hispanic- and Asian-Americans: 1 in 236
- 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 could not receive a biopsy due to the refusal of their physician to perform the procedure or the insurance company 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.

- Celiac disease affects at least 3 million Americans.
- The average length of time it takes for a symptomatic person to be diagnosed with celiac disease in the US is four years; this type of delay dramatically increases an individual's risk of developing autoimmune disorders, neurological problems, osteoporosis and even cancer.

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.

- 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 between 2-4 years of age had a 10.5% chance of developing an autoimmune disorder. Additional findings are outlined in the table below:

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

Source: A multi-center study on the sero-prevalence of celiac disease in the United States among both at risk and not at risk groups. Fasano et. al., Archives of Internal Medicine. February 2003.

- Early diagnosis of celiac disease thus is important, as it might prevent complications, and awareness is the key.

A recent study in North America shows that an active case-finding strategy in the primary care setting is an effective means to improve the diagnostic rate of Celiac Disease: by screening with the blood test all subjects belonging to known “at-risk” groups such as those listed above, the diagnosis rates increased more than 40-folds.

Source: Duration of exposure to gluten and risk for autoimmune disorders in patients with celiac disease. SIGEP Study Group for Autoimmune Disorders in Celiac Disease. Ventura A, et.al. Gastroenterology 1999 Aug;117(2):297-303. Rampertab SD et al. Trends in the Presentation of Celiac Disease Am J Medicine 2006 Catassi C et al. Detection of Celiac disease in primary care: a multicenter case-finding study in North America. Am J Gastroenterol 2007

Celiac disease affects 1% of healthy, average Americans. That means at least 3 million people in our country are living with celiac disease—97% 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 1,000,000 individuals
- Ulcerative colitis affects 500,000 people
- Crohn’s disease affects 500,000 Americans
- 2.1 million Americans are living with rheumatoid arthritis
- Lupus affects 1.5 million people
- Multiple sclerosis affects 400,000 people in the United States

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 U.S. 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 Comiskey Park (now US Cellular Field, with 40,000 seats) to watch the Chicago White Sox 55 times.
- U.S. 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 U.S. 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 2,200,000 the number of people living with celiac disease in the United States.

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 and makes 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. The University of Chicago Celiac Disease Center helped to pass this law.
- There are more than 2,000 gluten free food items available in the United States, and consumers are more likely to find these foods in regular grocery stores.
- From 2004 – 2005, sales of gluten-free foods increased by 77.8 million dollars (a growth of 14.6%).
- The US Department of Agriculture projects that the gluten-free industries revenues will reach \$1.7 Billion by 2010.

Data from www.bakingbusiness.com August 2005.

For more information contact the University of Chicago Celiac Disease Center at 773.702.7593 or www.CeliacDisease.net.