

Most with celiac disease unaware of it, others go gluten-free without diagnosis

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Roughly 1.8 million Americans have celiac disease, but around 1.4 million of them are unaware that they have it, a Mayo Clinic-led analysis of the condition's prevalence has found. Meanwhile, 1.6 million people in the United States are on a gluten-free diet even though they haven't been diagnosed with celiac disease, according to the study published Tuesday in the *American Journal of Gastroenterology*.

Researchers have estimated the rate of diagnosed and undiagnosed [celiac disease](#) at similar levels prior to this study, but this is the most definitive study on the issue. "This provides proof that this disease is common in the United States," says co-author Joseph Murray, M.D., a Mayo Clinic gastroenterologist. "If you detect one person for every five or six (who have it), we aren't doing a very good job detecting celiac disease."

Celiac disease is a [digestive disorder](#) brought on when genetically susceptible people eat wheat, rye and barley. A gluten-free diet, which excludes the protein gluten, is used to treat celiac disease. Roughly 80 percent of the people on a gluten-free diet do so without a diagnosis of celiac disease.

"There are a lot of people on a gluten-free diet, and it's not clear what the medical need for that is," Dr. Murray says. "It is important if someone thinks they might have celiac disease that they be tested first before they go on the diet."

To determine its prevalence, researchers combined blood tests

confirming celiac disease with interviews from a [Centers for Disease Control and Prevention](#) (CDC) nationwide population sample survey called National Health and [Nutrition Examination Survey](#). The survey, designed to assess the health and nutrition of U.S. adults and children, is unique in that it combines interviews and physical examinations.

Researchers found that celiac disease is much more common in [Caucasians](#).

"In fact, virtually all the individuals we found were non-Hispanic Caucasians," says co-author Alberto Rubio-Tapia, M.D., a Mayo Clinic gastroenterologist. But previous research in Mexico has shown that celiac disease could be just as common as it is in the U.S.

"So that is something we don't fully understand," Dr. Rubio-Tapia says. The study found the rate of celiac disease in the U.S. is similar to that found in several European countries.

Provided by Mayo Clinic

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