

Who We Are

The Celiac Disease Foundation is the nation's leading voluntary health organization for celiac disease, one of the world's most common and least diagnosed genetic autoimmune conditions. Through a comprehensive program of research, education, advocacy, and support, we drive diagnosis, treatments, and a cure to improve the quality of life for all those affected by celiac disease.

What We Accomplish

Since our founding in 1990, the Celiac Disease Foundation has played a key role in achieving federal recognition of celiac disease, improving diagnostic tools, and accelerating research for better treatments and a cure.

- Convened and hosted the 1997 Serology Workshop leading to the development of the celiac disease (tTG-IgA) blood test
- Served on the 2004 NIH Consensus Development Conference on Celiac Disease Planning Committee
- Convened the American Celiac Disease Alliance (ACDA) to lobby the FDA for the Gluten-Free Labeling Rule
- Developed the nation's largest celiac disease registry, iCureCeliac[®], a Patient-Centered Outcomes Research Institute (PCORI) Patient-Powered Research Network
- Provided testimony to House Appropriations Subcommittee and worked to secure FY2020 report language directing NIH to study celiac disease

What We Ask

Increase funding for the National Institutes of Health (NIH) for the study of celiac disease.

Until recently, celiac disease has not been the focus of research funding by the NIH. For FY2020, NIH has been directed to devote sufficient, focused research to the study of celiac disease. NIAID has been directed to coordinate existing research amongst the Institutes and Centers, and to focus new research efforts toward causation, and, ultimately, a cure for celiac disease. Additional resources for NIH are needed to support these efforts.

Co-sponsor H.R.2074 or S.3021, the Gluten in Medicine Disclosure Act of 2019.

Following a strict gluten-free diet is the only treatment for celiac disease. These bipartisan bills require drug manufacturers to label medications intended for human use with the list of ingredients, their source, and whether gluten is present to allow consumers to make safe, informed purchases of needed medications.

What is Celiac Disease?

- Celiac disease is a multi-system genetic autoimmune disorder affecting 1-2% of people worldwide.
- For people with celiac disease, eating gluten (a protein found in wheat, rye, and barley) causes the immune system to create antibodies that attack the small intestine. Villi, small finger-like projections that line the small intestine, atrophy and eventually flatten, causing them to lose the ability to absorb nutrients.

Celiac Disease by the Numbers

- 3 million+ Americans have celiac disease. Most studies show that less than 40% of all people with celiac disease are diagnosed.
- The prevalence of celiac disease has increased 4 or 5 fold since 1950 for unknown reasons.
- On average, it takes 4 years to be correctly diagnosed.
- There is no medication or cure for celiac disease—the only treatment is a lifelong, strict gluten-free diet.
- Studies show that 30-50% of people on a gluten-free diet continue to experience symptoms and have intestinal damage, revealing the ineffectiveness of the gluten-free diet as a treatment.
- iCureCeliac[®] patient registry participants report missing 23 days of work/school annually due to celiac-related illness, with 74% having been accidentally exposed to gluten within the past 30 days.
 - 96% reported “always” or “often” maintaining a strict gluten-free diet, but only 41% reported low symptom burden.
 - 93% said they want a treatment other than a gluten-free diet.

Increased Mortality Risk Associated with Celiac Disease

- 6x increased risk of death from non-Hodgkin’s lymphoma
- 3.1x increased risk of death from liver disease
- 2.6x increased risk of death by pneumonia
- 4x increased risk of small bowel cancer

Refractory Celiac Disease (RCD)

- 1 in 200 patients have RCD I or II, meaning they don’t respond to a strict gluten-free diet.
- RCD-II patients have a 50% increased risk of developing enteropathy-associated T cell lymphoma (EATL).
- The average survival time for patients with RCD-II is 3-10 years post-diagnosis.

The Only Treatment: The Gluten-Free Diet

- As little as 50 mg/day of gluten triggers symptoms - a normal diet contains > 10 g/day of gluten.
 - 10 mg/day is considered “safe” for people with celiac - this is the equivalent of 1/8 teaspoon of flour.
- Gluten is virtually impossible to avoid, as it is in 80% of foodstuff.
- Gluten-free substitutes contain more fat and sugar, and fewer nutrients. This may increase risk of heart attack due to a reduced consumption of whole grains.