



## What Is Celiac Disease?

**Celiac disease is one of the world's most prevalent genetic autoimmune diseases.** 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 can lead to many other devastating health conditions**, including cancer, and **results in extraordinary economic and productivity costs to both the public and private sectors** from employee and student absenteeism, as well as repeated, inconclusive visits to healthcare providers.



## Celiac Disease by the Numbers



Americans with celiac disease. Most studies show that **less than 40%** of all people with celiac disease are diagnosed.

**3 million+**



Average time it takes 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 from pneumonia

**4x**

increased risk of small bowel cancer



## Refractory Celiac Disease

- » **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: A Gluten-Free Diet

- › **Gluten is virtually impossible to avoid, as it is found in 80% of food** including some natural flavors and common products such as salad dressing, meat substitutes, licorice, and soy sauce.
- › **Gluten-free substitutes contain more fat and sugar, and fewer nutrients**, which may increase a patient's risk of heart attack due to a reduced consumption of whole grains.

**>10 g**

A normal diet contains this much gluten per day.

**50 mg**

As little as this much gluten can trigger symptoms.

**10 mg**

This much gluten per day is considered safe—the equivalent of 1/8 teaspoon of flour.



## Who We Are

The Celiac Disease Foundation, established in 1990, is a leading global patient advocacy organization committed to accelerating diagnosis, treatments, and a cure for celiac disease. Our mission is to improve the health and well-being of the millions of individuals around the world affected by this genetic autoimmune disease through our strategic investments in research, advocacy, and education. Our iCureCeliac® patient registry and extensive patient recruitment services at iRecruitCeliac.org enable us to **identify qualified patient candidates and speed their enrollment to advance critical disease research**. Our unparalleled advocacy program has led the way to **secure federal recognition and first-ever research funding from agencies** including the U.S. National Institutes of Health and the Department of Defense. We adhere to the highest scientific and ethical standards as **we work each day to promote understanding of celiac disease**, empower our patient and provider community, and collaborate with partners and stakeholders to carry our mission forward.



## What We Accomplish

The Celiac Disease Foundation plays a key role in securing federal recognition and research funding to improve diagnostic tools, treatments, and a cure for celiac disease.

- » Convened and hosted the 1997 Serology Workshop leading to the development of the celiac disease (tTG-IgA) blood test.
- » Served on the 2004 National Institutes of Health (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 Congressional testimony and worked to secure annual report language since FY2020 directing NIH to study celiac disease.
- » Provided testimony to the 2020 NIH Autoimmune Diseases Coordinating Committee on the need for focused research on **celiac disease as proof of concept for treating other autoimmune diseases** and invited to join as a member.
- » Presented the patient view at the 2021 NIH Accelerating Progress in Celiac Disease workshop.



## What We Ask

### Increase membership in the Congressional Celiac Disease Caucus

In 2021, Congresswoman Betty McCollum launched the bipartisan Congressional Celiac Disease Caucus to support federal funding of celiac disease research and to advance legislation that will ease the suffering of celiac disease patients. **The Caucus will help Members of Congress raise awareness of celiac disease and amplify the voice of the celiac disease patient community.**

### Secure funding for the National Institutes of Health (NIH) to study celiac disease

**Until recently, celiac disease has not been a focus of research funding by the NIH.** The National Institute of Allergy and Infectious Diseases (NIAID) has been directed to better coordinate existing research amongst the Institutes and Centers, and to **focus new research efforts toward causation, diagnosis, management, treatment, and, ultimately, a cure for celiac disease.** Additional resources for NIH are needed to support these efforts.

### Include Celiac Disease in the Department of Defense's (DoD) Peer Reviewed Medical Research Program

For the first time ever in FY2023, celiac disease was included as an eligible condition for study within DOD's Peer Reviewed Medical Research Program (PRMRP), which for over 20 years has supported research for a number of diseases. **Advancements through this research benefit past and present military members** impacted by these diseases. Inclusion in the PRMRP is an annual process and must be advocated for each year.