

The Celiac Disease Foundation is the Leading Advocacy Organization for the Estimated 3 Million Americans Suffering from Celiac Disease.

Medical Research

- **Increase funding for the National Institutes of Health (NIH) for the study of celiac disease.**
The federal government is the biggest provider of medical research funding, but up until recently federal funding for celiac disease has been nonexistent. Beginning with CEO Marilyn G. Geller's testimony before the House Appropriations Subcommittee in April of 2019, the Celiac Disease Foundation has worked to secure FY2020 Appropriations report language directing the NIH to devote sufficient, focused research to the study of celiac disease. Funding is needed to determine causation, find treatment alternatives to a gluten-free diet, and ultimately, cure celiac disease. The FY2020 Appropriations report language tasks NIDDK and NIAID to coordinate efforts for existing and new celiac disease research.
- **Include celiac disease in the DOD Peer-Reviewed Medical Research Program (PRMRP).**
The PRMRP supports medical research projects that are relevant to enhancing the health, care, and well-being of military families. While celiac disease is a disqualifying condition for military service, its prevalence has increased among service members, veterans, and their family members.
- **Establish a National Celiac Disease Patient Registry at the Centers for Disease Control and Prevention (CDC).**
Congressionally established national patient registries help to identify the incidence and prevalence, as well as the burden of disease. A National Celiac Disease Patient Registry needs to be established to examine what causes celiac disease, to examine the impacts of the disease, and to implement public health programs that raise awareness of celiac disease and speed the time to diagnosis.

Access to Care

- **Protect chronic disease patients from discrimination and bolster patient protections.**
As Congress and the Administration contemplate changes to the US healthcare system, it is critical for celiac disease patients that pre-existing condition discrimination continues to be prohibited and that individuals be able to equitably access comprehensive healthcare coverage regardless of their health status, diagnosis, and related factors.
- **Extend Medicare and Medicaid coverage for Medical Nutrition Therapy to beneficiaries with celiac disease.**
Adapting to a strict, gluten-free diet is a complex process, where lack of compliance significantly affects mortality, including a 6x greater risk from non-Hodgkin's lymphoma and a 4x greater risk from small bowel cancer. Newly diagnosed celiac disease patients, and those who continue to be symptomatic, require nutritional diagnostic, therapy and counseling services furnished by a registered dietitian or nutrition professional as referred by a physician.
- **Co-sponsor H.R.2074 or S.3021, the Gluten in Medicine Disclosure Act.**
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.
- **FDA funding for enforcement of the Gluten-Free Labeling Rule.**
The 2014 FDA Gluten-Free Labeling Rule was a tremendous achievement for celiac disease patients as it requires that a gluten-free label on a packaged food product ensures that the product contains less than 20 parts per million of gluten, which is the safe threshold of gluten consumption for those with celiac disease. The FDA requires sufficient resources to maintain its ongoing compliance program.