

## 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<sup>®</sup>, 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.