Celiac Disease

National Institutes of Health

National Institute of Allergy and Infectious Diseases (NIAID)

Once thought to be a rare, childhood disease, celiac disease is now recognized as one of the world's most common genetic autoimmune disorders. Despite this recognition, it is estimated that 60-70 percent of Americans who have celiac disease remain undiagnosed. Prevalence has increased significantly (5-fold) since 1950 for reasons not understood, though large-scale awareness campaigns led by patient advocacy groups have helped significantly.

There is currently no medication or cure for this chronic disease. The only course of action for more than 3 million Americans with celiac disease is strict adherence to a gluten-free diet. However, studies show that 30 to 50 percent of people on a gluten-free diet continue to report symptoms and/or have intestinal damage.

Living with celiac disease is a daily struggle – and having the disease increases the mortality risks for other diseases, including cancer, cardiovascular disease, and respiratory disease. Beyond mortality risk, celiac disease is also associated with an increased risk of other chronic illnesses including thyroid disease, type 1 diabetes, additional autoimmune diseases and cancers including intestinal malignancy and lymphoma.

Innovative research is required to find a cure for any disease. Until recently, however, federal funding for celiac disease has been very limited, creating a significant shortage of resources for researchers.

A consensus among leading celiac disease researchers has been developed to focus critical resources on the following research priorities:

- Understand the immunological basis and pathogenesis of celiac disease;
- Identify triggers for celiac disease and how to prevent it; and
- Find a cure for celiac disease: how to induce tolerance, how to inhibit Transglutaminase 2, gluten-specific CD4 T cells and/or intraepithelial lymphocytes

FY 27 draft report language for NIAID

National Institutes of Health (NIH):

Celiac Disease. – The Committee commends the NIH for supporting celiac disease research through the issuance of Notice of Special Interest and urges a continuation of NOSI to spur additional research on the study of celiac disease. Today, the only known treatment for this chronic disease is a gluten-free diet; however, recent public and private sector research confirms that such a "treatment" is challenging for many who suffer from celiac disease. Following a gluten-free diet can be difficult, socially restrictive, and up to 500% more expensive than a regular diet, placing a significant burden on individuals with celiac disease and complicating effective management of their condition. Studies show from 30 to 50 percent of celiac disease patients on a gluten-free diet continue to report symptoms and/or have intestinal damage despite attempting to follow a strict gluten-free diet. Novel therapeutics are highly desired by the celiac community. Therefore, the Committee includes sufficient funding for NIH to devote focused research on the study of celiac disease and continues to urge NIAID to: support new research on diagnosis and novel therapeutics for celiac disease; to better coordinate existing research; and, to focus new research efforts to improve understanding of the mechanisms underlying clinical manifestations of celiac disease and to define objective biomarkers that could serve to compliment histology and/or symptoms in pharmaceutical development programs. The Committee directs NIH to include updates on research, projects, and programs in the fiscal year 2028 Congressional Justification for celiac disease.