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The Honorable Tammy Baldwin
Chair
Subcommittee on Labor-HHS-Education
Senate Appropriations Committee
Washington, DC 20510

The Honorable Shelley Moore Capito
Ranking Member
Subcommittee on Labor-HHS-Education
Senate Appropriations Committee
Washington, DC 20510

Dear Chair Baldwin and Ranking Member Capito,

I write to you today to respectfully request that your subcommittee include increased funding for celiac disease research at the National Institutes of Health's (NIH) National Institute of Allergy and Infectious Disease (NIAID) for Fiscal Year (FY) 2024. This research funding is critical to achieving a better understanding of one of the world's most common genetic autoimmune disorders, celiac disease.

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 – and 1 in 100 worldwide suffer from the disease. Prevalence has increased fivefold since 1950 for reasons not understood.

There is currently no medication or cure. 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 nearly half of the 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 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 24 draft report language for NIAID

Celiac Disease. – The Committee commends the NIH for issuing a Notice of Special Interest to spur additional research on the study of celiac disease. Today, the only known treatment for this disease is a gluten-free diet; however, recent public and private sector research confirms that such a "treatment" is insufficient for many who suffer from celiac disease. 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 celiac disease; to better coordinate existing research; to focus new research efforts toward causation, diagnosis, management, treatment, and, ultimately, a cure of this disease. The Committee directs NIH to include updates on research, projects, and programs in the fiscal year 2025 Congressional Justification for celiac disease.

Increased funding and inclusion of this report language for FY2024 is critical to the lives of all those who have been diagnosed with celiac disease, and all of those who have yet to receive a diagnosis. Thank you for your consideration of this request

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