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The Honorable Jon Tester Chair Subcommittee on Defense Senate Appropriations Committee Washington, DC 20510 The Honorable Susan Collins Ranking Member Subcommittee on Defense Senate Appropriations Committee Washington, DC 20515

Dear Chairman Tester and Ranking Member Collins:

As the Senate Appropriations Subcommittee on Defense begins to make important decisions about Fiscal Year (FY) 2024 funding, I respectfully ask that the Subcommittee include celiac disease in the list of conditions eligible for research under the FY24 Congressionally Directed Medical Research Programs (CDMRP) and provide \$12 million for celiac disease research and treatment.

Celiac disease is recognized as one of the world's most common genetic autoimmune disorders, affecting 1% of the population. Despite this recognition, most cases remain undiagnosed. Prevalence has increased four to fivefold since 1950 for reasons not understood. Incidence has also increased in the general population and in active service military personnel, with a peak onset in the second or third decade of life.

Not only is living with celiac disease a daily struggle, but it is also a disease that 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 a variety of chronic illnesses including additional autoimmune disease and cancers such as intestinal malignancy and lymphoma.

Currently, there is no medication or cure for celiac disease. Nor is there an effective method for prevention. The only course of action is to follow a strict gluten-free diet. This treatment places a significant hardship on service personnel and veterans as gluten is more than 80 percent of our foodstuffs.

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. There is a wide range of both gastrointestinal and extraintestinal symptoms, and some patients are asymptomatic entirely. Fatigue and chronic abdominal pain are common symptoms. Increased fracture risk, anemia, and other consequences of malabsorption can have substantial impact on patients' quality of life.

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

A consensus among top celiac disease researchers has been developed to focus critical resources on research priorities.

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

Demographics support the estimate that thousands of active, Guard, and Reserve service members are currently suffering from celiac disease or are in danger of developing the disease, making them eligible for service-connected disability. Based upon TRICARE covered lives, it is estimated that an additional 77,000 veterans and family members may also suffer from celiac disease.

Further research will benefit those suffering from celiac disease by generating strategies to prevent the disease and providing critical guidance on mitigation efforts affecting readiness.

Celiac Disease. —The Committee recognizes the growing prevalence of celiac disease and its effect on service members. Currently, there is no medication or cure for celiac disease. Nor is there an effective method for prevention. The only course of action is to follow a strict gluten-free diet. 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. Fatigue and chronic abdominal pain are common symptoms. Increased fracture risk, anemia, and other consequences of malabsorption can have substantial impact on patients' quality of life. Celiac disease increases the mortality risks for other diseases, including cancer, cardiovascular disease, and respiratory disease and is associated with an increased risk of chronic illnesses including additional autoimmune disease and cancers such as intestinal malignancy and lymphoma. The Committee encourages the Department to place a priority on celiac disease research to better understand the magnitude of the problem and improve patient care and long-term outcomes. To assist in these efforts, the Committee recommends \$12,000,000 in support of celiac disease research.

Thank you for your consideration of our requests to make celiac disease eligible for research funding in the FY24 CDMRP and provide \$12 million for celiac disease treatment and research. I look forward to working with you on this important matter.

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