**U.S. Preventive Services Task Force Opportunity for Public Comment on Draft Research Plan: Preventive Services for Food Insecurity**

The Celiac Disease Foundation, the Society for the Study of Celiac Disease (SSCD), and Boston Children's Hospital would like to thank the U.S. Preventive Services Task Force for the opportunity to provide comments on the **Draft Research Plan: Preventive Services for Food Insecurity**.

We, the undersigned organizations, agree with the U.S. Preventive Services Task Force's proposed framework to investigate how food insecurity is assessed by healthcare providers, as well as the impact of proposed interventions on food security status, intermediate outcomes, and health outcomes for the patient. We seek assurance that celiac disease is included in the list of "stable common chronic conditions" under the populations category of the Proposed Research Approach, and that recommended interventions include accommodations for adherence to a gluten-free diet (GFD).

Celiac disease is an autoimmune disease that occurs in genetically susceptible individuals who develop an immune response to ingested gluten. This disease affects greater than 1% of the US population, and incidence appears to have been increasing over the last several decades. The only known treatment is life-long strict avoidance of all forms of wheat, rye, and barley. Although a gluten-free diet is an effective treatment in many individuals, recent research has revealed that up to 50% of individuals following a gluten-free diet are inadvertently exposed to gluten, and a substantial minority develop persistent or recurrent symptoms.[1]

Failure or inability to adhere to a gluten-free diet, including accidental exposure to gluten, triggers the autoimmune response which can have devastating and debilitating consequences for patients by increasing 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.

Gluten restriction in celiac disease patients significantly decreases the risk of certain malignancies to the level of the general population.[2] Other research shows that for patients following a gluten-free diet for at least five years, the risk of "developing cancer over all sites is not increased when compared with the general population. The risk is increased, however, in those taking a reduced gluten, or a normal diet, with an excess of cancers of the mouth, pharynx and oesophagus…and also of lymphoma...The results are suggestive of a protective role for a GFD against malignancy in coeliac disease and give further support for advising all patients to adhere to a strict GFD for life."[3] A greater risk of small bowel cancer has also been shown in celiac disease patients who don't maintain a gluten-free diet.[4]

The one protective factor for most celiac disease patients is access and adherence to a gluten-free diet. Food insecurity can make a gluten-free diet out of reach for many celiac disease patients. The struggle with food insecurity is also amplified by the following facts:

- On average, gluten-free products are less available and approximately 183% more expensive than their gluten-containing counterparts.[5]

- Despite celiac disease being a lifelong, autoimmune health condition, there is no insurance coverage or financial provision for the only approved, evidence-based medical treatment, a gluten-free diet.

- For celiac disease patients, gluten-free foods must be carefully prepared to avoid cross-contact with foods containing gluten. The FDA requires that foods labeled gluten-free contain less than 20 ppm of gluten.

- Food banks and pantries often don't carefully label gluten-free products or carry a diverse inventory of gluten-free products, and the gluten-free products are not distributed to the people who really need them.[6]

- Schools and other congregate meal environments typically offer limited, if any, gluten-free options.

- It is recommended that celiac disease patients and/or their caregivers consult with a registered dietitian trained in celiac disease to understand what foods they can eat and how they can be best prepared.

Additionally, recent research from Boston Children's Hospital on food insecurity in a pediatric celiac community found that 24% of patients experienced general food insecurity over a 12-month period. When asked specifically about gluten-free food, 27% of the patients experienced food insecurity over a 12-month period. The research also identified that intentional gluten ingestion due to unavailability of GF foods rose during the pandemic and was more likely among those who screened positive for food insecurity.

We strongly believe that the USPSTF should move forward to evaluate how healthcare practitioners assess food insecurity and intervene to improve health outcomes. We also strongly believe that celiac disease should be included in the proposed framework and that interventions should be tailored to adequately accommodate the gluten-free diet, the only approved treatment for the disease.

References:

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