

Submitted by Dr. Stefano Guandalini and Dr. Bana Jabri of the University of Chicago

**Public Witness Testimony
Senate Appropriations Committee
Subcommittee on Labor, Health and Human Services, and Related Agencies
Department of Health and Human Services**

Chairman Blunt, Ranking Member Murray and distinguished Members of the Subcommittee, thank you for the privilege of submitting written testimony.

Celiac disease is a serious autoimmune disease that is not being taken seriously enough by our government.

Celiac disease is one of the world's most common genetic autoimmune diseases. Approximately 40% of us carry the genetic marker and about 1% of us actually develop celiac disease. Yet, this is nearly double the number of people with Crohn's disease and ulcerative colitis combined, and nearly triple the number of those with Type 1 Diabetes.

And, regrettably, researchers are finding that the disease prevalence is doubling approximately every 15 years, making it a public health epidemic.

It is estimated that no more than 40% of the 3 million Americans with celiac disease have been correctly diagnosed. The other almost 2 million continue to suffer and have no idea why. In celiac disease patients, gluten, a protein found in wheat, barley and rye, triggers an immune response leading the body to attack the small intestine.

This intestinal damage causes more than 200 debilitating symptoms. Moreover, gluten ingestion for people with celiac disease causes **permanent** immunological scarring, doubles the risk of heart disease, and **acts as a carcinogen**, quadrupling the risk of small intestinal cancers.

Strict adherence to a gluten-free diet is the *only* available treatment. But, as our celiac disease researchers agree, "There is no such thing as a truly gluten-**FREE** diet" because of the constant risk of cross-contact with gluten, and gluten is in 80% of our foodstuffs.

It is imperative that celiac disease be recognized as an important threat to the health of our citizens by the US government, including and especially by the NIH, the FDA, the CDC, and CMS. Celiac disease research receives virtually no investment from the private sector, and little to no resources from NIH, especially when compared to diseases with similar impact.

Celiac disease is very serious:

- The lifetime burden of the gluten-free diet is perceived by patients to be second only to end-stage renal disease, and by caregivers, comparable to caring for a patient with cancer.

- Our **diagnosed** patients report that they miss, on average, 23 days of work and school annually, resulting in excess utilization of our healthcare resources.

Thank you for your time today and thank you for anything this distinguished Subcommittee can do to assist us in this fight to end this serious disease.

Background information regarding Dr. Guandalini and Dr. Jabri

Stefano Guandalini, MD, is an internationally recognized expert on celiac disease, a digestive disease that damages the small intestine and interferes with absorption of nutrients from food. He is also known for his expertise in the research and treatment of other diarrheal diseases in children.

Dr. Guandalini's clinical and research efforts have greatly influenced the way celiac disease is diagnosed and treated today. His work contributed to the revision of 20-year-old guidelines for celiac disease diagnosis.

Dr. Guandalini created the University of Chicago Celiac Disease Center in response to the low rate of celiac disease detection in the United States. This innovative program is dedicated to patient care services, research, medical education and public awareness initiatives in order to increase the rate of celiac diagnoses and improve the lives of celiac patients. The Celiac Disease Center serves patients of all ages.

Dr. Guandalini is the past president of the Federation of International Societies for Pediatric Gastroenterology, Hepatology and Nutrition. He was selected from a worldwide pool of candidates to be the first president of this federation.

Dr. Guandalini founded and has been the first president of the North American Society for the Study of Celiac Disease.

He is also a widely recognized expert in probiotics and their effects in children and teenagers.

Dr. Bana Jabri is a pediatric gastroenterologist and an expert in innate and mucosal immunity. She has followed a career interest in celiac disease, autoimmune disorders and inflammatory bowel disease. She is the 2009 recipient of the William K. Warren, Jr. Prize for Excellence in Celiac Disease Research. Dr. Jabri has extensive experience in human immunology, especially in designing and performing studies on human intestinal tissue samples. More recently, she has been developing mouse models that mimic key aspects of immune dysregulation found in patients with inflammatory intestinal disorders. Using human and mouse models, Dr. Jabri aims to identify key immune pathways involved in the initiation and development of autoimmune diseases and intestinal inflammatory disorders. Identification of such pathways will yield insights that lead to new, targeted therapeutic strategies.