

# Coeliac Disease: Increasing Awareness through Legal Intervention

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Food allergies are a common and well-known occurrence in our society, with the top three allergens being milk, eggs, and peanuts (1). Many people with these allergies live without major dietary changes as a result of the prevalent allergen warnings on food labels. This is not the case, however, for people with coeliac disease (gluten-sensitive enteropathy, also referred to as celiac disease in the US), a genetic, autoimmune disorder of the small intestine that affects 1 in 133 Americans (2). The culprit here is gluten, a protein found in wheat, rye, barley, and possibly oats.

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Gluten is a protein responsible for the elasticity in kneaded dough. It accounts for about 80% of the proteins in wheat, and consists of the peptides glutenin and gliadin, of which gliadin actually causes coeliac disease. When ingested, gluten triggers white blood cells of the immune system to attack the villi of the intestinal lining (3). This leads to poor absorption of nutrients, and symptoms including weight loss, fatigue, anemia, and chronic abdominal pain. In addition, an increased number of large protein fragments leak from the intestine into the bloodstream, becoming the targets of an inflammatory attack and further damaging the lining. Currently, there is no cure for coeliac

disease, except for a completely gluten-free diet for life.

With the prevalence of coeliac disease (about 1% of the US population), one might expect that diagnosis should be relatively routine. However, based on epidemiological studies in select communities and a national survey testing the characteristics of adult coeliac disease (6), only 1 in 4700 people in the US are diagnosed each year, with an average diagnostic time of 10 to 11 years (7). Listed as one of the top ten under- or mis-diagnosed diseases in the US (8), coeliac disease is difficult to diagnose because of its wide range of symptoms.

Patients with suspected cases are given blood tests to look for elevated levels of specific antibodies (9). Suspected cases are then confirmed with an intestinal biopsy to test for atrophied or missing villi, which are the site of gluten-related damage in the intestines; this is considered the 'gold standard' for diagnosing coeliac disease.

There are a few therapies in development that show promise, among them the use of prolyl endopeptidases (PEPs) to cleave gluten peptides, and tissue transglutaminase inhibitors to slow down the recruitment of white blood cells. The use of PEPs may allow coeliac patients to consume some gluten in their diets. Silencing of the gluten-reactive white blood cells, and cytokine therapy using antibodies, can also potentially slow down the over reactive immune response (11).

The biggest challenge to treating coeliac disease lies in misleading or incorrect food labeling. Some foods do not have wheat or gluten listed clearly as an ingredient or potential hazard. 'Hidden gluten' is also a major barrier, because foods that naturally do not contain gluten, such as brown-rice flour, may be processed on machines that also handle products that do, leading to contamination (12). In addition, foods that contain less than a certain percentage of an ingredient may not have to list it under law, but even trace amounts of gluten ingestion can cause severe symptoms (9). Currently, the smallest amount of gluten that testing can identify is around 20 parts per million (15),

but the American FDA has not yet come up with a defined limit for 'gluten-free.' This is in stark contrast to Australia, where the limit is 30 parts per million, and Europe, at 200 parts per million (12).



Some products have misleading names that the average consumer is not aware of, such as corn flour, which may be made from finely ground wheat flour, or may contain other additives with gluten, such as hydrolyzed vegetable protein.

The Food Allergen Labeling and Consumer Protection Act (FALCPA), approved on August 2, 2004, is the primary tool in addressing this problem in the US. A study by the American Congress states that 'many parents of children with a food allergy were unable to correctly identify in each of several food labels the ingredients derived from major food

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allergens." (13) Ingredients must be listed by their common name, in addition to the name of the specific food source from which the allergen is derived. The Department of Health and Human Services (HHS) must also submit a report to Congress that analyses how foods are cross-contaminated, how the manufacturing process can be improved to avoid it, and how consumers would like to see allergens labeled. To this end, HHS will conduct inspections on food processing plants. Specifically for gluten labeling, no later than four years after enactment of the bill, HHS will issue a final rule "to define, and permit use of, the term 'gluten-free' on the labeling of food" (13). To raise awareness, the department will also improve and publish the collection of national data on the prevalence of food allergies, and different ways to treat and prevent allergic responses to foods.

A more recent American bill, initiated in 2007 and still in review, focuses specifically on coeliac disease. The bill seeks to promote awareness of coeliac disease, largely by listing important facts about its prevalence, side effects, and treatment. It also recommends the standardization of blood tests and criteria for accurate diagnosis of coeliac disease (14). In addition, it confirms the Celiac Disease Foundation's designation of May as 'National Celiac Awareness Month', and the Association of European Coeliac Societies' designation of May 19<sup>th</sup> through 25<sup>th</sup> as 'International Coeliac Awareness Week'. The bill also aims to increase federal funding for research, as well as interactions between physicians, coeliac disease advocacy, and education organizations to encourage screening and early detection.

With the

high prevalence of coeliac disease, it is important not only for Congress to work with manufacturers, but also for the general public to work with their physicians on early detection. Although the safest policy is still a completely gluten-free diet, future treatments may allow some leniency. With these legal interventions, observant physicians, good self-detection, and ongoing research, increasing awareness is the next step to ensuring a gluten-free lifestyle for those who have been denied one for too long.

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