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The following response to Federal Register, Volume 70, Number 137 (July 19, 2005) is from
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To Whom it May Concern:

Thank you for inquiring about the very important issue of “gluten-free” labeling. Americans generally enjoy a high degree of safety relative to the overall supply of food in this country. This is not true, however, for those with Celiac Disease and related conditions for whom simply eating can cause serious illness. For celiacs, a disease that manifests in various ways and to varying degrees, a tiny bit of gluten can be as toxic as a full serving of pasta. Recent research suggests that 1 in 130 Americans has the disease, though many don’t know it. This is a staggering figure.

The good news is that Celiac Disease can be completely controlled though diet. If a person with celiacs is diagnosed early and consumes a completely gluten-free diet, s/he can live a healthy and normal life. This can include preventing many of the companion diseases (e.g., lymphoma, colon cancer, Chrones’ disease, diabetes) that often accompany undiagnosed and/or untreated Celiac Disease. By providing food safety information “on demand,” food free of cross contamination and clearly labeled as described herein, will benefit not only individuals with celiacs but the larger society/economy by reducing health care costs. This labeling and related manufacturing process changes can be completed for very little cost and will yield great public health benefits.

What should “gluten-free” mean on the food label and why?

“Gluten-free” should be a labeling “gold standard” and a guarantee that signifies the highest possible level of purity and thus, safety. In order to have the privilege of labeling a product “gluten free,” a manufacturer should have to prove that from the production and harvest of the whole food to its finished, processed form the product contains no gluten and has not been subject to cross contamination with gluten at any stage. This process must be regulated.

Thus, “gluten-free” should mean that a product is 100% free of rye, wheat, barley, and oats (until conclusive proof that oats contain no gluten is available) in their whole and processed forms. Products containing ingredients that can be derived (but aren’t always) from rye, wheat, barley,

and oats should be required to include their source (e.g., maltodextrin should be followed in parentheses by its source, such as (from corn)). Ingredients such as “modified food starch,” “natural ingredients,” “natural flavors,” and “spices” should no longer be allowed to remain vague. The argument that ingredients are proprietary should NOT outweigh the rights of consumers with Celiacs and related conditions to make informed decisions about their health.

In addition, products that might be altered or affected in their production processes and thus contain gluten should also be required to be labeled that they contain gluten/wheat (e.g., Altoids and Almond Roca, both contain gluten because the conveyor belts in the factories are dusted with wheat). A helpful example (and potential model) of this labeling is provided voluntarily by Amy’s products; when they include wheat, it is listed in the ingredients and “contains wheat” is written in bold letters below the ingredient list. This labeling requirement should also be true for medications, lotions, soaps, etc that may use wheat and other forms of gluten for thickeners or other purposes.

WHY?

“Gluten-free” should be the gold standard because people with Celiac Disease and related conditions shouldn’t have to run the risk of getting sick because something isn’t properly labeled. “Gluten-free” needs to mean something. A food can’t be kinda gluten-free. That’s like being kinda pregnant—you either are or you aren’t. In the end, it’s about trust and safety. “Gluten-free” is a promise that a manufacturer is making to consumers. Consumer safety has to be the most important thing. The label needs to be forthrightly truthful.

How do you identify foods that do not contain gluten? Time spent identifying foods?

The general answer to the first question is resourcefulness, vigilance, and perseverance. It’s an unrelenting and time-consuming process that sometimes feels more like solving a mystery than shopping for groceries. What used to be a quick 15-minute trip to the grocery store can turn easily into an hour. The result is that for several hours every month, we spend time trying to figure out whether food is gluten-free and therefore safe to eat. Some of the ways we identify gluten-free foods include the following:

1. Celiac Sprue Association binder and Celiac chapter newsletters, which we bring to the grocery store
2. Cell phone at the store to call manufacturers, and have them send product lists of their gluten-free items to our homes
3. Personal recommendations from fellow celiacs through product research and personal experience
4. Labeling from known, trusted producers of gluten-free products
5. Advertisements in publications aimed at celiacs (e.g., *Living Without* magazine)

If there’s any doubt, we don’t buy it.

What percentage of foods and which types purchased are marked gluten-free?

Percentage = 5-10%

Which types: breads; cookie, pancake, and cake mixes; pastas; soups (Amy's); frozen entrées (Amy's); and some locally produced baked goods.

Does “gluten-free” printed on a product label influence your decision to purchase products having the same ingredients? To what extent?

No, because you can't necessarily trust the process, ingredients, or risk of cross contamination from one product to another and one manufacturer to another. Each manufacturer needs to be responsible for the purity and safety of their products. We currently buy products because they are from reputable sources and are labeled gluten-free and listed in the CSA book. Countless examples available upon request.

Would you consider a two or more level definition of gluten-free helpful?

This type of system would be an unacceptable second option to the gold standard, “all or nothing” approach we strongly encourage herein. For a person with Celiac Disease, ANY amount of gluten is toxic. Period. Thus it is an “all or nothing” kind of disease requiring an “all or nothing” labeling standard. A tiered system as suggested in this question would not be helpful because if a product has a trace of gluten in it, it is not gluten-free. And if it is not gluten-free, it should not be labeled as such.

In conclusion

Food labeling is serious business. The fact that this question is being raised on a national level gives us great hope that positive changes will be made. Hidden gluten in food as well as cross contamination are serious issues for those with Celiac Disease. In addition, people with Celiacs have other food allergies and related conditions. Thus we encourage labeling as detailed above and broader labeling standards that include other common allergens such as soy, peanuts, and dairy. This can be done with little cost and huge benefits. The bottom line is that “gluten-free” needs to mean that. Thank you for reading our response.

Sincerely,

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