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6/20/01

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Food and Drug Administration  
Docket OOP-1322  
Dockets Management Branch  
HFA-305 FDA  
5630 Fishers Lane Room 1061  
Rockville Maryland, 20852

RE: FOOD ALLERGAN LABELING GUIDELINES must protect celiacs.

I am very interested in the Food Allergen Consumer Protection Act because my daughter has celiac disease, which requires us to be as careful about what she eats as does an individual with a specific food allergy. The proposed Food Allergy Labeling Guidelines do not go far enough to protect patients with celiac disease. These individuals need to know all the sources of gluten in their foods, which can come from barley and rye, as well as wheat. Only wheat is included in the proposed labelling guidelines, and this is insufficient.

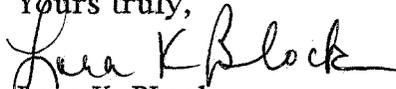
Celiac disease is an autoimmune disease which makes individuals intolerant of gluten (found in wheat, barley, rye). Although individuals with gluten intolerance do not suffer an immediate anaphylactic reaction to gluten, they become very sick with exposure over time because the autoimmune response destroys the villi of the small intestine, making it impossible to absorb nutrition, vitamins and minerals properly. The only treatment is to strictly adhere to a gluten-free diet. Dr. Anthony Fassano of the Univ. of Maryland School of Medicine, one of the country's leading researchers into celiac disease, estimates that 1/300 Americans suffer from this condition, most not adequately diagnosed. This is a much higher incidence than that of more dramatic allergies to other food products.

It is very important to have legislation requiring accurate labeling of allergens. We should not leave this disclosure to the voluntary practices of the food manufacturers. In particular, it is very important to have accurate labeling of "additives" and "flavorings" because it is those very substances which are most mysterious and confusing to individuals with celiac disease.

These flavorings can cause serious problems for celiac patients if they are derived from wheat, barley or rye. Some examples: Malt flavoring is ubiquitous, and it is dangerous for celiacs to unwittingly consume. Labels should disclose if it's made from barley or corn. The same is true for maltodextrin--sometimes it's made from corn, sometimes from barley. Modified food starch can come from any number of grains--we need to know if it's barley, wheat or corn.

Legislation is necessary to insure that all food companies comply with accurate labelling. In addition, it is also imperative to protect the hundreds of thousands of Americans who suffer from celiac disease by expanding the labeling requirements to include not just "wheat" as is the case in the "Code of Practice" now suggested by the Grocers Association, but also barley and rye. Celiacs need to know about all possible sources of "gluten"--which is found also in barley and rye--in order to know which foods to avoid.

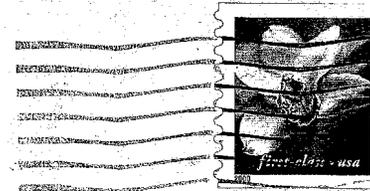
Yours truly,

  
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