

Muralidhar Jatla, M.D., Ritu Verma, M.D., Series Editors

# Hidden Sources of Gluten

by Karen H. Hlywiak

## INTRODUCTION

**R**emaining gluten-free (GF) is a life long challenge, complicated by the difficulty of identifying hidden gluten in food and non-food products. Many families easily identify obvious gluten products but encounter challenges identifying hidden sources of gluten. Children and families must learn to read and interpret labels and know how or who to contact to verify gluten-free status of any product. Ideally, all families should be provided the opportunity to participate in celiac disease (CD) education following a new diagnosis. Education is paramount. Basic celiac education should provide specific GF diet information, disease specific information including the risk factors, diagnosis and health consequences of celiac disease, discussion focused on coping skills related to celiac disease, support group information and descriptions of social situations encountered with celiac disease and GF diet choices (1–6).

To create a gluten-free environment, families quickly learn that label reading alone is not enough. Families benefit from dietary education to recognize gluten containing grains and potential hidden sources of gluten in products. This education is best delivered by a registered dietitian familiar with celiac disease. To achieve this level of sophistication, families need to learn and practice several basic rules:

1. Read every product label
2. Any product that comes into contact with the mouth and can be ingested must be GF

- This includes non-food items such as playdough
  - This can be a major challenge in the pediatric age group
3. Wheat free is not the same as gluten-free
  4. Any multi-ingredient product has the potential to be contaminated with gluten
    - This is important in restaurants and social situations
  5. Obtain knowledge about cross contamination issues
  6. Acquire an assertive approach when contacting manufacturers to clarify GF status of products (1,3,4)

Prior to applying these rules, families need to acquire a clear understanding of the definition of gluten and the FDA definition of GF labeling. Gluten is defined as a protein found in the prolamin fraction of wheat (gliadin), rye (secalin) and barley (hordein). It is also found in a grain called triticale which is a blend of wheat and rye. Although controversial, oats are currently excluded from a GF diet in the US, due to the risk of contamination when harvested and/or milled (2,4,7).

In the US, food labeling is governed by the FDA Food Act 2004. Manufacturer's product labels are required to indicate the presence of any of the eight food groups (Table 1) and the presence of flavoring, colorings or additives contaminated with any of these food allergens. A food is considered gluten-free when the final product includes the absence of any ingredient derived from a prohibited grain and the absence of gluten after the processing is complete. Section 201 exempts highly refined oils and products that are produced from these oils from GF guidelines (7,11,14,20,21).

The specific GF guidelines and testing protocols are currently under FDA review. Until labeling issues are resolved, health care providers (HCP) and families

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Karen H. Hlywiak, BSN, Outpatient Nurse Coordinator, Division of Gastroenterology and Nutrition, The Children's Hospital of Philadelphia, Philadelphia, PA.

**Table 1  
FDA food allergen listing requirements (7)**

Milk	Egg	Fish	Crustacean
Shellfish	Tree nuts	Wheat	Peanuts
Soybean			

**Table 2  
Natural GF food choices (3,8)**

Egg	Almonds	GF Grains	Lentils
Fish	Peanuts	Milk	Butter
100% Fruits	Juices	Fresh fruit without waxing	

will need to be knowledgeable about the definition of gluten sources (5,9,21). The remainder of this article will focus on identifying hidden gluten in foods, medications and non-dietary sources.

**GLUTEN-FREE FOOD CHOICES**

So, what can we offer families? How can we help them effectively choose GF products and establish a GF lifestyle? What foods can they choose? There are many single ingredient, naturally occurring gluten-free foods (Table 2).

However, any of the foods listed in Table 2 may contain gluten when they are part of a multi-ingredient product, malted product or a prepared or “ready to cook” product. Examples include malted or flavored milk, egg mixes, seed/snack mixes, or cheese mixes and grain products including gluten containing grains (1,9).

Families usually require additional guidance to identify the risk of gluten contamination in multi-ingredient products. Reading labels will often reveal the presence of seasonings, thickeners, malt, flavorings, sauces and starch. Below is a description of each ingredient.

**Multi-ingredient product list: definitions of agents and risk of gluten contamination (1,6,10)**

**Seasonings**—blend of flavoring agents. The source of all ingredients must be verified.

**Extenders/thickeners**—used in packaged foods to enhance the final product and may contain gluten. An example is baked beans.

**Sauces**—may have wheat protein, hydrolyzed wheat starch or wheat flour.

**Malt**—barley malt may be used and listed as barley malt, malt, extract or vinegar.

**Modified food starch/gelatinized food starch**—source of starch must be identified. Wheat is a common

source of starch. The safe forms of starch sources are rice, potato, and tapioca. (3)

**Hydrolyzed food starch**—HVP, HPP, TVP (Table 3)  
**Milk**—as a single ingredient is GF. If it is malted or flavored, may contain gluten.

**Flavorings**—may be present in any prepared food, teas, drinks, juices, flavored waters and baked products.

**GLUTEN IN NON-DIETARY SOURCES: OUTSIDE SOURCES**

Following a diagnosis of CD, families focus their energy towards GF food choices. In addition to identifying gluten in foods, families must also evaluate non-dietary items. This involves identifying gluten in items their child comes in contact with on a daily basis. While counseling families, one needs to remember the age and degree of social involvement of the child. HCP and families need to explore all aspects of the child’s environment, remembering that any item the child comes into contact with needs to be GF. Some items are related to the child’s age and developmental level while others are universally used such as suntan lotion, toothpaste and medication. For example, a preschool child will need GF play dough and paints while a female adolescent needs to use GF gum or makeup such as lipstick and powder (1,12).

School and social activities can be challenging for children with celiac disease and their families. When networking with schools or social activity coordinators, families should insure that any item their child may ingest is GF (1,12). Often, the staff involved with the child’s activity require educational materials regarding the importance of a GF environment, includ-

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**Table 3**  
Adapted from 1,3,4-7,10-12

**Food products that may contain Gluten:**

Flavored foods	Thickeners
Seasoning (because is a blend of ingredients)	Sauces
Egg mixes	Fillers or extenders
Cheese spreads	Syrup
Canned soups	Malt (cereals/beverages)
Breading	Malt vinegar (barley)
Canned baked beans (may have a thickener)	Creamed foods
Seed/snack mixes	Colorings
Salad dressing	Flavorings
Cereals (may have gluten grains or malt)	Icing/frosting

**Gluten containing grains:**

Einkorn	Wheat	Farro	Kamut	Rye
Triticale (wheat + rye)	Barley	Spelt	Farina	Emmer
Oats—concern about cross contamination				
Matzoh balls (OK if with potato flour)				

**Pre-packaged foods:**

Frozen meals	Hotdogs (some brands)	Breaded Foods	Sausages
Lunch meats	Instant tea/coffee	Marinades	Gravy
Chips (may have wheat starch or wheat protein)			

**Condiments:**

Mustard	Pickles	Mayonnaise	Ketchup	Soy sauce
Worcheshire sauce	Curry sauce			

**Miscellaneous:**

Fried food—check the ingredients and the oil that is used to fry				
Beer	Cough drops	Toothpaste	Ice cream	Sour cream
Chocolate syrup	Candy			

Dextrin—usually from corn but possibly from wheat source  
 HPP = Hydrolyzed Plant Starch  
 HVP = Hydrolyzed Vegetable Protein  
 TVP = Texturized Vegetable protein

**Remember: Wheat-free is not the same as gluten-free**

ing good hand washing and cleaning of contact surfaces. Additionally, younger children need to be monitored to avoid putting their fingers in their mouth or sharing food or other items which may come into contact with their mouth. Families benefit from having a reference list of potential gluten containing products (Table 4).

### ENVIRONMENTAL SOURCES OF CROSS CONTAMINATION

Gluten can also be hidden in environmental sources. This ranges from avoiding products stored in a bulk container to food preparation in the home or restaurant. Maintaining clean counter surfaces and using clean utensils, bowls and pans is essential. GF food should be clearly labeled and separately stored from non-GF food. Young children benefit from GF food being brightly labeled and stored in a consistent location. The use of separate toasters or toaster ovens and squeeze bottles for condiments prevents gluten contamination in the home.

Food preparation issues also exist in restaurant environments. In addition to the above cleanliness issues, celiac patients should avoid breaded foods, sautéed foods, marinate sauces, seasonings and prepared foods. When food is cooked on a grill, the grill must be cleaned. When oils are used in cooking, it should be clarified that the oil was not previously used to cook non-GF foods. Buffet style dining is an issue due to the risk of cross contamination from serving utensils.

### GLUTEN IN MEDICATIONS

Another area families need to focus their knowledge involves hidden gluten in medications. The same premise of reading labels and developing the expertise

**Table 4**  
**Possible gluten containing products. Adapted from 1,12**

Make-up	Lipstick	Lip balm
Play dough	Paints	Toothpaste
Stamps	Envelopes	Suntan lotion
Pet food	Baby power	Bath salts

**Table 5**  
**FDA drug product definitions. Adapted from 14–16**

- **Incipients**—filler ingredients added to the active form of the drug. Example are fillers, colorings, dextrates, malt and starches. The purpose of incipients is to add bulk, act as a lubricant for the power form of the drug or to absorb water. Both the sources and composition of the incipients must be identified.
- **Inactive ingredients**—“any component other than an active ingredient.” Involves all aspects of the manufacturing process including processing, packing or holding of a drug product.
- **Active ingredients**—Any ingredient the pharmaceutical company intends to use in the manufacturing of the drug product.

Note: The source and composition of each of these incipients must be identified to assure a GF drug product.

in questioning manufacturers about the GF status of their product transfers to this area as well. Any medication that comes in contact with the GI tract, whether oral, rectal, or inhaled, prescription or OTC, must be GF (12,13). The family’s mastery of label reading skills is critical in developing the expertise to identify gluten sources in medications. To acquire this mastery, families need to understand how medication is produced, the documentation a manufacturer can reference to identify gluten and the scope of the FDA regulations and related terms. Manufacturers of both prescription and OTC medications are required to follow the FDA Food /Allergy Labeling and Consumer Protection Act of 2004. Section 210 and 211 identify quality assurance (QA) guidelines for all aspects of drug production and processing. These QA guidelines include procedures to document equipment cleaning, monitoring of environmental conditions during processing, tracking of all components to assure “uniform character and quality” of each batch and lot, and tracking of the testing of the components, product and container. The manufacturer can access this data to provide accurate information regarding the GF status of all of the components of their product. This includes

the raw medication ingredient and any ingredient supplied by outside manufacturers (14).

The FDA defines the final form of any medication, as the combination of the raw material and inactive ingredients. Specific definitions are listed in Table 5.

Success in identifying GF medications depends on several factors involving the pharmaceutical manufacturer and the family. Pharmaceutical manufacturers need to realize that gluten may exist in any ingredient or occur during environmental cross contamination in the manufacturing of the final product. Identifying the source of the drug's components and inactive ingredients is the first major step for families and drug companies. Due to this, the basic skill families need to develop is comfort with reading medication labels and contacting pharmaceutical companies. Families need to learn that a medication label may not provide enough information to clarify the GF status of a medication.

The establishment of a collaborative relationship with a pharmacist or HCP is essential to success. However, even with the most aggressive inquiries, the success of identifying the GF status of medications depends on the manufacturer's ability and willingness to identify the source of all ingredients and the ability of the patient and pharmacist to ask the correct questions. Additionally, suppliers may change periodically, so families will need to intermittently verify the GF status of any medication. Families need to practice one basic skill—read labels with caution:

- Be cautious of a product when:
  - The label lists a new or improved formulation
  - There is a change in the appearance of the medication
  - There is a change in how the medication is delivered (capsule, tablet, liquid)

Any of these situations could indicate a change in the manufacture of the medication formulation and therefore a possible change in the pre-existing GF status (13). Families often ask the HCP what information they need to prepare before calling a pharmaceutical company. Below is a list of background information needed for successful communication with a drug manufacturer.

1. Review the list of possible gluten sources in medication ingredients (Table 6)
2. Review the product label:
  - a. Provide the Lot number and /or Batch number. This helps identify the specific product production history
  - b. Create a list of questions:
    1. Ask the manufacturer to verify the GF status of each ingredient including fillers, colorings and powders
    2. Inquire about the source of suspected hidden gluten—Table 6, i.e., unidentified source of starch
    3. Inquire if the drug's formulation or processing has changed since this GF information was identified.
    4. Inquire if any of the manufacturers supplying inactive ingredients have changed since the GF information was identified
    5. Inquire about the possibility of cross contamination during production and processing

Success of the family's inquiry into the GF status of a medication relies on their knowledge and their ability to interpret labels and evaluate manufacturer's feedback.

## REMEMBER

1. Safe dextrin sources—dextrose (from corn) and dextrans (from corn or potato starch).
2. Table 6 Ingredients apply to any form of medication which can be ingested in the body, whether orally or rectally or nasally.

## EDUCATION

Literature supports the role of patient education in the management of chronic disease (5,18,19). CD is no exception. A team approach, including a registered dietitian is crucial to overcoming the challenge of living GF. HCPs must identify the patient's level of acceptance and explain the treatment regime in relationship to lifestyle. The family's ability to eliminate all gluten, both obvious and hidden, is dependent on their knowledge, relationship with HCP team members and support from celiac groups. Treatment needs to be tailored to the needs of each child and family. This includes identifying barriers to compliance. This may

**Table 6**  
**Possible gluten sources in medications.**  
Adapted from 13,15,16,17

**Unspecified starch:**

- Pregelatinized, sodium starch glycolate
  - Source may be from any starch source
- Whole grain or grain flour
  - Source may be a gluten grain
- Dextrates and dextrans
  - Any source of starch can be used in their processing
- Dextrimaltose or caramel coloring
  - Barley malt may be used in their processing
- Maltodextrin, dextrates, dextrans
  - May come from wheat or barley
- Starch derivatives
  - Starch source is usually corn or potato
  - Other gluten starches may be used
  - The safe starches for celiac patients used in medication are corn, rice, potato and tapioca

Note: these ingredients apply in any form of medication which can be introduced in the body, whether oral or rectal.

involve coping skills and practical issues such as cost, taste or availability of GF food. At the time of diagnosis, families have reported feeling overwhelmed with the amount of information they need to process. In addition to providing GF information, the HCP must assess if a need exists for psychological support other than what is offered through support groups.

## CONCLUSION

In summary, successful GF living results from an effective partnership between the family and a multidisciplinary healthcare team. Each family progresses toward the acceptance of CD at their own pace. From the initial diagnosis and nutritional education, through consistent follow-up, the family achieves a greater level of understanding. However, medical and nutritional monitoring alone often is not enough. Support groups augment disease education by providing the assistance and encouragement families require to surmount daily obstacles

created by CD. HCPs should assess the family's coping skills and offer referrals for emotional support if needed. Access to support groups assists families to eliminate gluten in all forms, offer practical information about community resources and parent/peer support.

Our hope is that this article has provided the groundwork to help guide HCP and families in identifying sources of gluten, both obvious and hidden. This knowledge, coupled with consistent HCP follow-up and encouraging involvement with celiac support groups are critical steps toward establishing and maintaining compliance with a GF lifestyle. The future holds the potential to provide CD education to every person with CD, regardless of their age or geographic location. This can be achieved only through the partnership between HCPs and families. Current teaching approaches need to be evaluated, obstacles identified and new approaches created. All families affected with CD deserve access to CD information and support groups. Only through unrestricted access to CD information will the goal of GF living be achieved. Remember, true success is measured by the family's ability to seamlessly incorporate GF living principles into their lives. ■

## Web Sites

### General Sites

[www.celiaccentral.org](http://www.celiaccentral.org)  
[www.NASPGHANN.org](http://www.NASPGHANN.org)  
[www.glutenfreeliving.com](http://www.glutenfreeliving.com)

### Medications

[www.glutenfreedrugs.com](http://www.glutenfreedrugs.com)  
[www.glutenfreemedications.com](http://www.glutenfreemedications.com)  
[www.celiacmeds.com](http://www.celiacmeds.com)  
[www.about.com:celiac](http://www.about.com:celiac)  
[www.ashp.org](http://www.ashp.org)  
[www.celiaccentral.org](http://www.celiaccentral.org)  
[www.clanthompson.com](http://www.clanthompson.com)

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