



پاکستانی سیلیک سوسائٹی  
Pakistani Celiac Society  
[www.celiac.com.pk](http://www.celiac.com.pk)

All About Gluten-Free Lifestyle گلوٹن کے بغیر روزمرہ زندگی

# NEWSLETTER

## Summer 2010

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*Paediatric Gastroenterologist*

### MISSION STATEMENT

The Pakistani Celiac Society is a national, volunteer, non-profit organization dedicated to provide support and services to individuals and families with celiac disease and dermatitis herpetiformis through programmes of awareness, advocacy and education.

### What is New?

### Understanding the Meaning of "Gluten-Free"

A gluten-free diet provides a very effective treatment for celiac disease. In fact, this is the only treatment available for this disorder at present. For it to be effective, the diet must be followed strictly with no exceptions. This issue of the Newsletter is dedicated to understanding what a gluten-free diet entails and the issues of cross contamination.

A gluten-free diet should not contain any wheat, barley, rye or triticale (a cross between wheat and rye). All other grains and food products are safe. Oats need to be used with caution. Pure and uncontaminated oats in limited quantities are safe for consumption by most people with celiac disease. However, pure oats are not available in our country at this time. Therefore, oats (*dalya*) should be avoided as they are likely contaminated with gluten-containing grains.

In preparation of gluten-free food products there is a risk of contamination with wheat rye or barley. That brings up the question of what amount of gluten is acceptable in a "gluten-free" diet. Research has shown that a gluten content of food less than 20 parts per million (ppm), or 20 mg/kg is safe

for most individuals with celiac disease. The safety will also depend on the total amount of food eaten per day.

The Codex Alimentarius Commission is an international body of the Food and Agriculture Organization of the United Nations (FAO UN) and the World Health Organization (WHO). It is responsible for setting standards for regulating foods allergens. In 2008, the Codex Commission revised its standard for foods to be considered "gluten-free" for international trade. This is referred to as Codex Stan 118-1979. The highlights of this latest standard include the following:

- Gluten-free foods do not contain wheat, rye, barley, oats or their crossbred varieties and the gluten level does not exceed 20 ppm (parts per million i.e. 20 mg/kg) in total, based on the food as sold or distributed to the consumer.  
and/or
- Gluten-free foods may contain one or more ingredients from wheat, rye, barley, oats or their crossbred varieties which have been specially processed to remove gluten and the gluten level does not exceed 20 mg/kg (20 ppm) in total, based on the food as sold or distributed to the consumer.
- The allowance of pure, uncontaminated oats may be determined at the national level.

If a product is labeled "gluten-free", it must meet the above standard of less than 20 ppm of gluten. This standardized definition of gluten-free is being applied in the USA, Europe and other countries and will help create uniformity for international trade.

## LOW Gluten or NO Gluten

Patients starting a gluten-free diet soon realize its complexity and challenges. Major issues are availability and cost. Wheat (*atta*) is one of the most common ingredient of our diet and eliminating it completely from everyday eating is extremely difficult. There are few options available. Rice is expensive, especially for long-term use. Corn (*makai*) and millet (*bajra*) are other alternates. However, the flour made from these grains is often ground in the same factories preparing wheat flour and cross contamination is a strong possibility.

People on a gluten-free diet need to know that a low or a reduced gluten diet is not the same as gluten-free. The following example will help illustrate this point.

As little as 50 mg of gluten if taken daily for a few months can cause damage to the intestines. An average slice of bread contains approximately 3.5 gm of gluten which amounts to about 70 times this 50 mg threshold limit for intestinal damage. This means that an amount as little as 1/70<sup>th</sup> of a slice of bread may lead to problems. This is a tiny amount.

A gluten-free diet is fully effective only if it is strictly gluten-free.

## Risks of Not Following a Gluten-Free Diet

**What might happen if a patient with celiac disease continues to ingest gluten?**

There are several risks to the patient. Some patients may not feel anything. Others may get a variety of symptoms. In a patient who does not get symptoms it does not mean that there is no damage happening to the intestine. The following are the three major groups of complications that might occur in patient who continue to take gluten in their diet.

### (1). Malignancy

Malignancy (cancer) is one of the most serious complications of celiac disease. The risk of developing cancer is significantly higher in patients with celiac disease than the general population and more so in patient who do not follow a strict gluten-free diet. A variety of cancers can occur, the most common type being *non-Hodgkin's lymphoma*. Lymphoma is a malignancy of the cells and organs of the immune system. This can involve the intestines, lymph glands or other organs of the body. Other types of malignancies in celiac disease include those of the thyroid, esophagus and *adenocarcinoma* of the small intestine.

Patients with celiac disease who are not following a gluten-free diet should be aware of this serious risk.

### (2) Autoimmune Disorders

Patients with celiac disease also have a higher risk of developing other autoimmune disorders, most commonly thyroid disease and type 1 diabetes (insulin dependent). There is some evidence that continued exposure to gluten may increase the

risk of developing these disorders in patients with celiac disease.

### (3) Nutritional Deficiencies

If the intestine gets damage, the body is unable to absorb nutrients. A variety of nutritional deficiencies can occur. The most ones are anemia (lack of blood) due to deficiency of iron and/or folate and osteoporosis (weak bones) due to low calcium and vitamin D.

## "Gluten-Free" Wheat Flour

**Is there a flour that is derived from wheat and is gluten-free?**

The answer is NO. Gluten is the major protein in wheat and to our knowledge there has not been a flour developed anywhere in the world that is gluten-free. Even the non-protein ingredients like wheat starch (a carbohydrate) which is derived from wheat carries a risk of gluten contamination.

It has been noticed that a manufacturer in Pakistan is selling a flour made from wheat that is labeled on the bag as "Gluten-Free". The claim is that the product was tested in a laboratory and was found to have no gluten in it. The Pakistani Celiac Society has contacted the relevant testing agency for an explanation but no reply has been received yet. Testing for gluten is complex and as far as we know not available easily in Pakistan.

While this issue is being investigated, we advise the members to exercise caution and not use this flour or any wheat flour claimed to be "gluten-free". The chemistry of gluten is extremely complex. There is a lot of research going on in this area in the agriculture and food industry around the world. It does not seem possible that an *atta* factory in Pakistan has developed the technology to make "gluten-free" wheat flour.

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## Joining Hands



**Membership of Pakistani Celiac Society is open to all patients with celiac disease and those who are interested in this field**

**Join our free membership on-line at**

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