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 13251 Ventura Blvd., Suite 1, Studio City, CA 91604-1838
 (818) 990-2354 • FAX (818) 990-2379

CELIAC DISEASE FOUNDATION is a recognized 501 (c) (3) nonprofit organization. All proceeds are tax-deductible to the extent allowed by law. TTP:408
 Funds received by CDF are used to provide information and education on screening and treatment programs and projects to heighten awareness and improve the well being of those diagnosed with CD/DH.

TREATMENT

Because CD/DH is a chronic disorder, the only treatment is the lifelong adherence to the gluten-free diet. When gluten is removed from the diet, the small intestine will start to heal and overall health improves. Medication is not normally required. Consult your physician regarding specific nutritional supplements to correct any deficiencies. The diagnosed celiac should have medical follow-up to monitor the clinical response to the gluten-free diet.

Dietary compliance increases the quality of life and decreases the likelihood of osteoporosis, intestinal lymphoma and other associated illnesses.

Because osteoporosis is common and may be profound in patients with newly diagnosed CD, bone density should be measured at or shortly after diagnosis.

Adapting to the gluten-free diet requires some lifestyle changes. It is essential to read labels and learn how to identify foods that are appropriate for the gluten-free diet and do not contain toxin gluten.

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 This pamphlet is intended to provide basic information about Celiac Disease/ Dermatitis Herpetiformis. Information contained herein has been approved by the CDF Medical Advisory Board. It is not intended to provide, nor does it constitute medical advice. Dietary changes based on information in this brochure should not be initiated without first consulting a physician.
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All names and personal information given to Celiac Disease Foundation will be kept confidential. Celiac Disease Foundation will not sell, rent or share personal information with any outside organization, individual or entity. The information may be used for internal purposes only to track statistical and demographic data to help us improve our services.

Visit the CDF website www.celiac.org or call the office for additional diagnostic and dietary information, as well as resources for food products, recipes and coping strategies.

This pamphlet is also available in Spanish.

MEMBERSHIP

Benefits of CDF Membership include:

- ❖ **Guidelines for a Gluten-Free Lifestyle**, a comprehensive handbook for living gluten-free which includes: a disease synopsis, nutritional guidelines, list of allowed additives and questionable ingredients, as well as samples of gluten-free menus
- ❖ **Quarterly Newsletters**, which include articles on current research, updates on food labeling, health and nutrition information, gluten-free friendly restaurants, product news, recipes and the latest gluten-free food products
- ❖ Advance notice of special events and meetings
- ❖ Member Discount for Annual Conference
- ❖ Gluten-Free resource list
- ❖ Email updates

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Celiac Disease Foundation is a member of:

- ◆ American Celiac Disease Alliance
- ◆ National Institutes of Health Celiac Disease Awareness Campaign
- ◆ National Digestive Diseases Information Clearinghouse
- ◆ National Coalition of Autoimmune Patient Groups

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Celiac Disease Foundation is grateful to the Friends and Family of Ariana Martino whose donations made this publication possible.

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CELIAC DISEASE

Celiac Disease (CD) is a lifelong, digestive disorder affecting children and adults. When people with CD eat foods that contain **gluten**, it creates an immune-mediated toxic reaction that causes damage to the small intestine and does not allow food to be properly absorbed. Even small amounts of **gluten** in foods can affect those with CD and cause health problems. Damage can occur to the small bowel even when there are no symptoms present.

Gluten is the common name for the proteins in specific grains that are harmful to persons with celiac disease. These proteins are found in **ALL** forms of **wheat** (including durum, semolina, spelt, kamut, einkorn and faro) and related grains **rye, barley** and **triticale** and **MUST** be eliminated.



Celiac Disease Foundation

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WHAT HAPPENS WITH CELIAC DISEASE

Celiac Disease (CD) is unique in that a specific food component, **gluten**, has been identified as the trigger. When individuals with CD eat gluten, the **villi**, tiny hair-like projections in the small intestine that absorb nutrients from food, are damaged. This is due to a toxic reaction to gluten. Damaged villi do not effectively absorb basic nutrients – proteins, carbohydrates, fats, vitamins, minerals and, in some cases, water and bile salts. If CD is left untreated, damage to the small bowel can be chronic and life threatening. This leads to malabsorption which can result in an increased risk of associated disorders – both nutritional and immune related.

SOME LONG-TERM CONDITIONS THAT CAN RESULT FROM UNTREATED CD

- ◆ Iron deficiency anemia
- ◆ Early onset osteoporosis or osteopenia
- ◆ Vitamin K deficiency associated with risk for hemorrhaging
- ◆ Vitamin and mineral deficiencies
- ◆ Central and peripheral nervous system disorders - usually due to unsuspected nutrient deficiencies
- ◆ Pancreatic insufficiency
- ◆ Intestinal lymphomas and other GI cancers (malignancies)
- ◆ Neurological manifestations
- ◆ Gall bladder malfunction

ASSOCIATED AUTOIMMUNE DISORDERS

- ◆ Dermatitis Herpetiformis (DH)
- ◆ Insulin-dependent Type 1 Diabetes Mellitus
- ◆ Thyroid Disease – Hashimoto’s Thyroiditis
- ◆ Systemic Lupus Erythematosus
- ◆ Autoimmune liver diseases

LESS COMMONLY LINKED TO CD

Addison’s Disease, Chronic Active Hepatitis, Down Syndrome, Rheumatoid Arthritis, Turner Syndrome, Williams Syndrome, Sjögren’s Syndrome, Fibromyalgia, Alopecia Areata and Scleroderma.

SYMPTOMS

Celiac Disease can appear at any time in a person’s life. In adults, the disease can be triggered for the first time after surgery, viral infection, severe emotional stress, pregnancy or childbirth. CD is a multi-system, multi-symptom disorder. Gastrointestinal (GI) symptoms are extremely varied and can often mimic other bowel disorders.

Infants, toddlers and young children with CD may often exhibit growth failure, vomiting, bloated abdomen, behavioral changes and failure to thrive.

CLASSIC SYMPTOMS MAY INCLUDE

- ◆ Abdominal cramping, intestinal gas
- ◆ Distention and bloating
- ◆ Chronic diarrhea or constipation (or both)
- ◆ Steatorrhea – fatty stools
- ◆ Anemia – unexplained, due to folic acid, B12 or Iron deficiency (or all)
- ◆ Weight loss with large appetite or weight gain

OTHER SYMPTOMS

- ◆ Dental enamel defects
- ◆ Osteopenia, osteoporosis
- ◆ Bone or joint pain
- ◆ Fatigue, weakness and lack of energy
- ◆ Infertility – male/female
- ◆ Pregnancy related problems
- ◆ Depression
- ◆ Aphthous ulcers
- ◆ Delayed puberty

Dermatitis Herpetiformis (DH) is the skin manifestation of celiac disease characterized by blistering, intensely itchy skin. The rash has a symmetrical distribution and is most frequently found on the face, elbows, knees and buttocks. DH patients can have intestinal damage without obvious GI symptoms.

Dermatitis Herpetiformis (DH) is diagnosed by a biopsy of a skin lesion and staining for IgA in the tissues. More than 85% of DH patients have small bowel sensitivity to gluten. Everyone with DH needs to follow a gluten-free diet.

THE CAUSE

The cause of Celiac Disease, also known as gluten sensitive enteropathy (GSE), is still a mystery. One out of 133 people in the United States is affected with celiac disease. CD occurs in 5-15% of the offspring and siblings of a person with celiac disease. In 70% of identical twin pairs, both twins have the disease. It is strongly suggested that family members of a diagnosed celiac be tested, even if asymptomatic. Family members who have an autoimmune disease are at a 25% increased risk of having celiac disease.

Celiac Disease is **not** a food allergy - it is an autoimmune disease. Food allergies, including wheat allergy, are conditions that people can grow out of. This is not the case with Celiac Disease.

DIAGNOSIS

A person seeking preliminary diagnosis **MUST** be eating gluten. Specific antibody blood tests help identify the presence of CD and are the initial step in screening and should include the following tests:

- ◆ Endomysial antibody (EMA-IgA)
- ◆ Tissue transglutaminase antibody (tTG - IgA/IgG)
- ◆ Anti-gliadin antibody (AGA-IgG, AGA-IgA)
- ◆ Total serum IgA

The exception is children under the age of 2 years in which tTG and EMA may not be present. Consult your physician.

It is essential that patients with positive antibody tests, and those with an IgA deficiency have a small bowel biopsy (which is performed endoscopically) to confirm the diagnosis and assess the degree of damage to the villi in the intestinal lining.

Blood tests can only screen for RISK of celiac disease and cannot confirm it. When blood tests and biopsy are inconclusive, testing for specific HLA (human leukocyte antigen) DQ2/DQ8 genes associated with celiac disease may be helpful. As an autoimmune disease, CD is the result of the interaction between genes and the environment (gluten). All the necessary genes to develop CD are not known; however, HLA DQ2 and/or DQ8 are absolutely necessary to develop CD. Since one-third of the population also have these genes, the presence of DQ2 or DQ8 does not imply that the person will develop CD, rather, that they have a genetic compatibility with CD.

Genetic testing does not diagnose celiac disease – the absence of DQ2/DQ8 almost always rules it out. Patients should always consult with a physician to ensure proper diagnosis.

WHO IS CDF

Celiac Disease Foundation (CDF) is a highly-regarded national organization that has been raising awareness of celiac disease since 1990. CDF strives to promote awareness and build a supportive community for patients, families and healthcare professionals. CDF is actively involved in advocating for patient concerns and networking with other national and international organizations.

MISSION STATEMENT

Celiac Disease Foundation is a nonprofit, public benefit corporation dedicated to providing services and support regarding Celiac Disease and Dermatitis Herpetiformis through programs of awareness, education, advocacy and research.

WHAT CDF DOES

- ❖ CDF develops and distributes current evidence-based information about CD/DH and the gluten-free lifestyle
- ❖ CDF informs, assists and supports people with CD/DH and their families to help them understand and cope with the condition creating an improved quality of life and better health maintenance.
- ❖ CDF emphasizes the importance of identifying the undiagnosed population and the population at risk through our awareness campaigns, “**Are You The One?**” and “**Is Your Patient The One?**”
- ❖ CDF strives to raise awareness of CD/DH on a national level by networking with government agencies, healthcare professionals, patients, families, the media and general public in order to increase the rate of diagnosis
- ❖ CDF encourages food and drug manufacturers and the food service industry to meet gluten-free dietary needs
- ❖ CDF advocates for and encourages Celiac Disease research