

Who is CDF

Celiac Disease Foundation is a highly-regarded national organization recognized throughout the world. CDF strives to promote awareness and build a supportive community for patients, families and health care professionals. CDF is actively involved in advocating for patient concerns and networking with other national and international organizations.

CDF Mission Statement

Celiac Disease Foundation is a non-profit, 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 enabling an improved quality of life and better health maintenance
- ◆ CDF works to raise awareness of CD/DH on a national level by working with government agencies, health care professionals, patients, families, the media, and the general public in order to increase diagnosis
- ◆ CDF encourages food and drug manufacturers and the food service industry to better meet gluten-free dietary needs
- ◆ CDF advocates for, and encourages, Celiac Disease research

Membership

- ◆ Benefits of membership include the comprehensive handbook, Guidelines For A Gluten-Free Lifestyle, Quick Start Diet Guide and quarterly CDF Newsletters. Materials contain timely information on CD/DH, treatment, nutrition, food and drug updates, support articles, recipes and food sources
- ◆ Information, education and referral services
- ◆ Annual Educational Conference with vendor faire
- ◆ Special events and workshops
- ◆ CDF *Connections/Chapters* provide support opportunities for the celiac and their families and play a vital role in their communities in generating awareness.

Treatment

The only treatment for CD/DH is the **lifelong** adherence to a 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. Because osteoporosis is common and may be profound in patients with newly diagnosed CD, bone density should be measured at or shortly after diagnosis. Consult your physician regarding specific nutritional supplementation 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.

Adapting to the gluten-free diet requires some lifestyle changes. It is essential to read labels which are often imprecise, and to learn how to identify ingredients that may contain hidden gluten.

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.

Consult the CDF web site: 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.

All names and personal information given to Celiac Disease Foundation will be kept confidential. Celiac Disease Foundation will not sell, rent or share your 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.



Celiac Disease Foundation is a member of:

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

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CELIAC DISEASE

A **lifelong** autoimmune intestinal disorder found in individuals who are genetically susceptible. Damage to the mucosal surface of the small intestine is caused by an immunologically toxic reaction to the ingestion of gluten and interferes with the absorption of nutrients. Celiac Disease (CD) is unique in that a specific food component, **gluten**, has been identified as the trigger. **Gluten** is the common name for the offending proteins in specific cereal 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.



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WHAT HAPPENS WITH CELIAC DISEASE

When individuals with CD ingest gluten, the villi, tiny hair-like projections in the small intestine that absorb nutrients from food, are damaged. This is due to an immunological 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, causing an increased risk of associated disorders — both nutritional and immune related.

SOME LONG-TERM CONDITIONS THAT CAN RESULT FROM UNTREATED CD:

- ◆ Iron deficiency anemia
- ◆ Osteoporosis
- ◆ 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
- ◆ Lactose intolerance
- ◆ Neurological manifestations

OTHER ASSOCIATED AUTOIMMUNE DISORDERS

- ◆ Dermatitis Herpetiformis (DH)
- ◆ Insulin-dependent Type I Diabetes Mellitus
- ◆ Thyroid Disease
- ◆ Systemic Lupus Erythematosus
- ◆ 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 may appear at any time in a person's life. 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. Symptoms are extremely varied and can often mimic other bowel disorders. Infants, toddlers, and children often exhibit growth failure, vomiting, bloated abdomen and behavioral changes.

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
- ◆ depression
- ◆ Aphthous ulcers

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 gastrointestinal damage without perceptible symptoms.

CAUSE

The cause of Celiac Disease, also known as celiac sprue, or gluten sensitive enteropathy (GSE), is unknown. Research indicates that CD is strongly associated with a group of genes on Chromosome 6.

These genes (HLA class II) are involved in the regulation of the body's immune response to the gluten protein fractions.

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 be tested, even if asymptomatic. Family members who have an autoimmune disease are at a 25% increased risk of having celiac disease.

DIAGNOSIS

A person seeking preliminary diagnosis must be consuming gluten. Specific antibody blood tests help identify the presence of CD and are the initial step in screening and should include: IgA endomysial antibodies (EMA), IgA tissue transglutaminase (tTG), IgG tissue transglutaminase and Total IgA antibodies. It is essential that patients with positive antibody tests, and those with an IgA deficiency, have a small bowel biopsy to confirm the diagnosis and assess the degree of mucosal damage, which is performed endoscopically.

When serology and biopsy are inconclusive, testing for specific HLA (human leukocyte antigen) genes associated with celiac disease may be helpful in screening for CD. If these genes are NOT present, it is unlikely that the individual will develop CD. A positive HLA or genetic test, however, does not mean that the individual has the condition, as these genes are common in the general population. Patients should consult with an experienced physician to ensure proper diagnosis.

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.

I support the CELIAC DISEASE FOUNDATION

Yes, I would like to become a member. Enclosed is my \$35 tax-deductible annual membership. \$ _____

Yes, I am renewing my membership. Enclosed is my \$35 tax-deductible annual renewal. \$ _____

I am a Healthcare Professional – Specialty _____

Additional Contribution: Benefactor \$1000 Sponsor \$500 Associate \$250 Friend \$100 Donor \$50 Other _____ \$ _____

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CELIAC DISEASE FOUNDATION is a recognized 501 (c) (3) non-profit organization. All proceeds are tax-deductible to the extent allowed by law. 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.