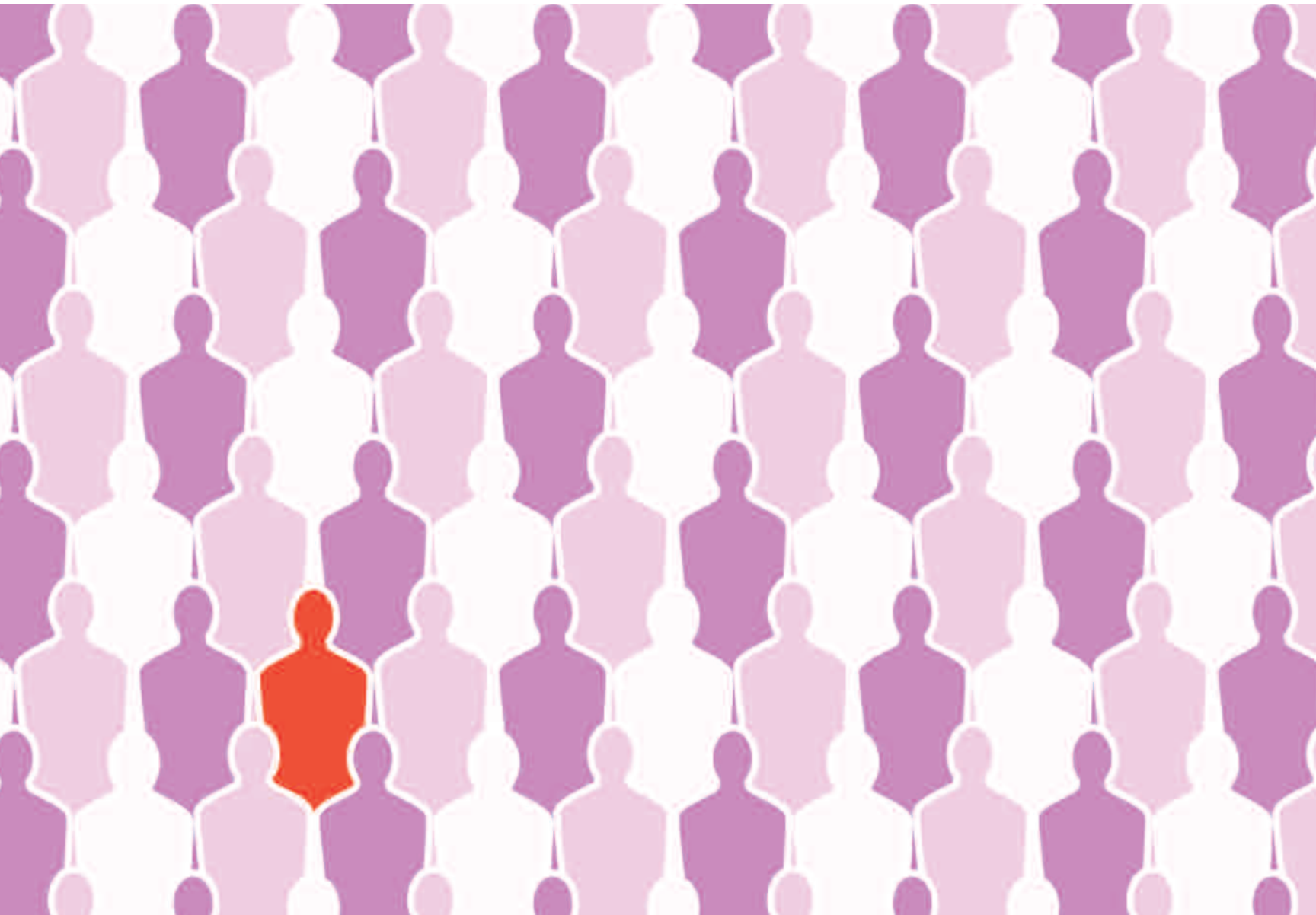


CELIAC DISEASE



Are You the ONE?

By Elaine Monarch

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You've heard of Crohn's disease, cystic fibrosis, multiple sclerosis, and Parkinson's disease—but have you heard of celiac disease?

Celiac disease affects more people than all of these disorders combined. Also known as gluten-sensitive enteropathy or celiac sprue, celiac disease affects one percent of the population worldwide—children and adults, male and female. Yet 97 percent of people with celiac disease go undiagnosed. Celiac disease is one of the most common genetic conditions in the world. It is a multi-symptom, multi-system disorder, activated by eating gluten-proteins found in wheat, rye, barley, and other related grains such as spelt and triticale.

With increased awareness and the subsequent increase in testing for the disease, CD is now known to affect a broader segment of the general population. A study conducted by the University of Maryland's Center for Celiac Research (CFRC), validated in 2004 by the National Institutes of Health Consensus Conference on Celiac Disease, concluded that one out of 133 people in the United States—a total of about 3 million—are at risk for celiac disease.

What Happens with CD?

Historically, the most common symptoms of celiac disease included severe diarrhea, weight loss, abdominal pain and other gastrointestinal symptoms. CD affects not only the gastrointestinal tract, but also the neurologic, endocrine, orthopedic, reproductive, and hematologic systems. Celiac disease may be the result of an evolutionary collision between the

cultivation of wheat and the human immune system.

When individuals with CD ingest gluten, the small intestinal villi (tiny hair-like projections that absorb nutrients) are destroyed. Damaged villi interfere with the body's ability to absorb basic nutrients, i.e., proteins, carbohydrates, fats, vitamins, minerals, and in some cases, water and bile salts. If CD is left untreated, damage to the small bowel may be chronic and life-threatening, leading to associated disorders, both nutritional and immune-related, and an increased risk of intestinal lymphomas and other GI malignancies.

Because the symptoms of CD can be so varied, it can be a difficult diagnosis to make. Many individuals are asymptomatic for years, with the disease becoming active for the first time after surgery, viral infection, severe emotional stress, pregnancy, or childbirth. Symptoms of CD may present themselves any time during the life of an individual who is genetically predisposed and is ingesting gluten. Toddlers and children may exhibit failure to thrive, vomiting, bloated abdomen, and behavioral changes. Classic gastrointestinal symptoms may include abdominal cramping, chronic diarrhea, steatorrhea (fatty stools), and weight loss.

Signs and symptoms in body systems outside the gastrointestinal track may include dental enamel abnormalities, aphthous ulcers, osteopenia or osteoporosis,



bone or joint pain, peripheral neuropathy, fatigue, weakness and lack of energy, infertility, and depression.

CD and FM

A study by one nationwide celiac disease support group indicated that among adults ultimately diagnosed with celiac disease, 9 percent were originally diagnosed with fibromyalgia and 30 percent with IBS. Since many patients with CD have muscle aches, joint pains, GI symptoms, and fatigue, it is understandable that those people might get a label of fibromyalgia.

In addition to the tender points exam, the diagnosis of fibromyalgia is based on a number of symptoms that can be due to other conditions—celiac disease among them. This is further evidence that different so-called “silent” symptoms need to be taken seriously by physicians and thoroughly evaluated before a diagnosis of fibromyalgia (or IBS) is given.

Diagnosing CD

The rate at which celiac disease is diagnosed often depends on the level of your physician's awareness and knowledge of the disease. Research shows that celiacs can see a succession of physicians and specialists over an average period of 11 years before the true source of their illness is accurately diagnosed and treated. Typically, that means 11 years of worsening symptoms, new and potentially dangerous complications, confusion, and anxiety.

There are two steps to diagnosing celiac disease. The first is a blood test that measures the antibodies; the second is the small bowel biopsy.

Certain antibodies are produced by the immune system in response to substances perceived by the body to be threatening, i.e., gluten. Current research indicates that people with CD have higher than normal levels of these antibodies in their blood. If antibody levels are high, it is very likely that celiac disease is present. The diagnosis is confirmed by doing an intestinal biopsy to see if damage has been done to the small intestine—and to rule out the possibility of other conditions. At this time the small bowel biopsy is considered the gold standard for diagnosis of CD for both adults and children. This procedure is performed endoscopically and is usually done on an outpatient basis.

The diagnosed celiac should have medical follow-up to monitor the clinical response to the gluten-free diet, the treatment for those diagnosed with CD.

CD is known to occur in 5-15 percent of the offspring and siblings of the celiac. Recent research results indicate that about one out of 22 first-degree relatives of someone with CD have the disease as well. In 70 percent of identical twins, both twins have the disease. It is therefore recommended that family members (both first and second degree relatives) of an individual diagnosed with CD be tested as well. Because CD is an autoimmune disease, it is also suggested that people living with other autoimmune disorders be screened for CD.

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Genetic testing

Genetic testing can help to determine which family members are extremely unlikely to develop the disease. If family members do have the genes, they should be tested for the antibodies if they develop symptoms or at an appropriate interval, usually every five years.

Genetic testing can be extremely useful to:

1. Eliminate family members who initially have negative blood work from repeated testing for celiac disease
2. Test patients who are already on a gluten-free diet who do not want to be subjected to eating gluten again in order to be tested.

Living the Gluten-free Lifestyle

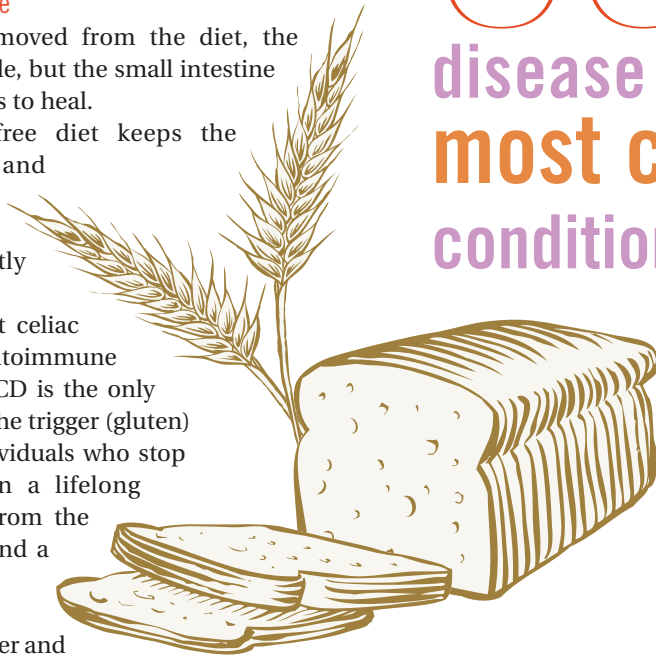
Once gluten has been removed from the diet, the symptoms should start to subside, but the small intestine may take six months to two years to heal.

Adhering to the gluten-free diet keeps the symptoms under control and prevents further complications. It is vital that all gluten—even the tiniest amount—is permanently removed from the diet.

While the bad news is that celiac disease is a lifelong, genetic, autoimmune disease, the good news is that CD is the only autoimmune disease for which the trigger (gluten) is known. Once diagnosed, individuals who stop ingesting gluten and maintain a lifelong gluten-free diet achieve relief from the symptoms of the disease and find a restoration of health and vitality.

Elaine Monarch is the founder and executive director of the Celiac Disease Foundation (CDF), which 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.

For additional information on celiac disease and the gluten-free diet, please contact the Celiac Disease Foundation at (818) 990-2354 or go to www.celiac.org. You may also email cdf@celiac.org.



celiac
disease is one of the
most common genetic
conditions in the world.

SOME CONDITIONS THAT CAN RESULT FROM UNTREATED CD

- o Iron deficiency anemia
- o Osteoporosis
- o Vitamin K deficiency associated with risk for hemorrhaging
- o Vitamin and mineral deficiencies
- o Central and peripheral nervous system disorders (usually due to unsuspected nutrient deficiencies)
- o Pancreatic insufficiency
- o Intestinal lymphomas and other GI malignancies
- o Other food sensitivities
- o Dental enamel defects

OTHER ASSOCIATED AUTOIMMUNE DISORDERS

- o Dermatitis Herpetiformis (DH)
- o Type I insulin-dependent Diabetes Mellitus (5-10 percent of these individuals have CD)
- o Thyroid disease
- o Systemic Lupus Erythematosus
- o IgA nephropathy and IgA deficiency
- o Primary Biliary Cirrhosis

Less Commonly Linked Disorders

- o Chronic Active Hepatitis
- o Scleroderma
- o Myasthenia Gravis
- o Addison's Disease
- o Rheumatoid Arthritis
- o Sjögren's Syndrome
- o Down Syndrome