

ESSENTIALS  
*of* CELIAC  
DISEASE  
*and the*  
GLUTEN-  
FREE DIET



AT THE FOREFRONT  
**UChicago**  
**Medicine**

Celiac  
Disease  
Center

**PUBLISHED BY:**  
UNIVERSITY OF CHICAGO  
CELIAC DISEASE CENTER

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Special thanks to Kim Koeller and GlutenFreePassport.  
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# ESSENTIALS *of* CELIAC DISEASE *and the* GLUTEN-FREE DIET

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# CHAPTER ONE:

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## OVERVIEW OF CELIAC DISEASE

Celiac disease is an inherited autoimmune disorder that affects the digestive processes of the small intestine.



The small intestine is connected to the stomach, and lies just below it. The first two parts of the small intestine— the duodenum and the jejunum—are where celiac disease is commonly found.

The small intestine is lined with tiny, finger-like protrusions called villi. The purpose of the villi is to absorb nutrients from food into the bloodstream. When a person who has celiac disease consumes gluten—which is a protein found in wheat, rye, and barley—his or her immune system responds by attacking the small intestine. Specifically, the villi on the lining of the small intestine flatten out and disappear, inhibiting the absorption of important nutrients into the body. This lack of nutrition severely compromises health and wellbeing. Celiac disease can be associated with other autoimmune disorders and, if undiagnosed and untreated, can lead to a myriad of complications including osteoporosis, infertility, neurological conditions, and, in rare cases, cancer. The only treatment for celiac disease is adherence to a strict, lifelong gluten-free diet.

**RESEARCH HAS DEMONSTRATED  
THAT A SIGNIFICANT  
PERCENTAGE OF CHILDREN  
AND ADULTS WITH POSITIVE  
CELIAC BLOOD TESTS  
HAD EITHER MINIMAL OR  
NO SYMPTOMS WHEN THEY  
WERE TESTED.**

Dermatitis herpetiformis (DH) is another form of celiac disease, that presents with an itchy, blistering skin condition. The rash usually occurs on the elbows, knees, and buttocks. It is generally bilateral, affecting both knees and/or arms. Many people with DH have no digestive symptoms and only about 40% of them have positive antibody blood tests (serology) for celiac disease. However, while these outward signs of the disease may not be present, individuals with DH almost always have the same intestinal damage as people with celiac disease. Normally, a patient suspected of DH would have a skin biopsy rather than an intestinal biopsy. An intestinal biopsy would be performed only in the case of an ambiguous skin biopsy, or a suboptimal clinical response to the gluten-free diet. In addition to following a strict gluten-free diet, DH is also commonly treated with a topical antibiotic medication called Dapsone.

Unless otherwise specified, the information in this book pertains to patients with both celiac disease and dermatitis herpetiformis.

## THE FACTS OF CELIAC DISEASE

Celiac disease affects at least 1% of Americans, or nearly 3 million people in the United States. It is possible to develop celiac disease at any age. While most people are tested for celiac disease as a result of symptoms they experience, some individuals have it without presenting any symptoms. In fact, research has demonstrated that a significant percentage of children and adults with positive celiac blood tests had either minimal or no symptoms when they were tested. Furthermore, there are occasionally patients who carry the gene for celiac disease, have minimal or no symptoms, have negative blood tests, and yet have a positive biopsy. These patients are at equal risk for all of the complications of untreated celiac disease.

# CHAPTER TWO:

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SYMPTOMS, TESTING & DIAGNOSIS

ANTIBODIES

ENDOSCOPIC BIOPSY

GENETICS OF CELIAC DISEASE

Over 200 signs and symptoms of celiac disease have been identified. Many people, including even some medical professionals, think that symptoms occur only in the digestive system.

However, this is incorrect. Symptoms such as infertility (for women), tooth discoloration and anemia are common.

## SYMPTOMS

Young children tend to have more classic signs of celiac disease, including growth problems (failure to thrive) and gastrointestinal problems (chronic diarrhea, constipation, recurring abdominal bloating). In addition, pain, fatigue and irritability are common signs of celiac disease, often seen in children as well as adults. Older children and adults tend to have more extra-intestinal symptoms. Research has demonstrated that only a third of adult patients diagnosed with celiac disease experience diarrhea. Weight loss is also not a common sign. In fact, the most common sign of celiac disease in adults is iron deficiency anemia that does not respond to iron therapy.

Adults and children over the age of three should be tested periodically if they have a close relative with biopsy-confirmed celiac disease.

A close relative is considered to be a parent, sibling, or child. An aunt or uncle, grandparent or cousin with celiac disease may raise an individual's risk for celiac disease somewhat, but not much higher than the risk of the general population.

In children younger than 3 years of age with symptoms, antibody testing may not always be accurate. Young children (below the age of three) with symptoms, especially failure to thrive or persistent diarrhea, should be evaluated by a pediatric gastroenterologist. It can take up to one year for toddlers eating wheat or barley-based cereals to generate an autoimmune response to gluten. This autoimmune response is necessary for the disease to be detected in blood tests.

Anyone who has a related autoimmune disorder or other related condition, regardless of celiac symptoms, should be tested for celiac disease and, if negative, the test should be repeated on a periodic basis.



THIS IS A PARTIAL LIST OF SYMPTOMS AND OTHER CONDITIONS RELATED TO CELIAC DISEASE. OTHERS ARE STILL BEING IDENTIFIED AND CONFIRMED:

**SYMPTOMS :**

› Recurring abdominal bloating and pain	› Delayed puberty
› Chronic diarrhea/constipation	› Pain in the joints
› Vomiting	› Tingling or numbness in the legs
› Liver and biliary tract disorders (transaminitis, fatty liver, primary sclerosing cholangitis, etc.)	› Pale sores inside the mouth
› Weight loss	› A skin rash called dermatitis herpetiformis (DH)
› Pale, foul-smelling stool	› Tooth discoloration or loss of enamel
› Iron-deficiency anemia that does not respond to iron therapy	› Unexplained female infertility, recurrent miscarriage
› Fatigue	› Osteopenia (mild) or osteoporosis
› Failure to thrive or short stature	› Peripheral neuropathy
	› Anxiety and depression



## RELATED DISORDERS :

- › Type 1 diabetes
- › Hashimoto's thyroiditis
- › Graves disease
- › Addison's disease
- › Down syndrome
- › Turner syndrome
- › Williams syndrome
- › Rheumatoid arthritis
- › Multiple sclerosis

In addition, any women who have experienced repeated miscarriages or persistent infertility where a medical cause could not be found should be tested for celiac disease.

## TESTING & DIAGNOSIS

Diagnosis of celiac disease is usually straightforward. A proper diagnosis requires testing for antibodies in the blood, assessing biopsies of the small intestines, and evaluating response to the treatment. Many physicians, however, may not be aware of the disease, how to test for it or how to diagnose it. Until recently, medical schools in the United States inaccurately portrayed both the presentation and the prevalence of celiac disease. Even today, lectures on celiac disease in medical schools are infrequent, and some medical textbooks still contain outdated information. Additionally, because celiac disease often presents with extra-intestinal symptoms, such as fatigue, joint pain, anemia, and infertility, it is sometimes overlooked until other conditions have been ruled out.

## ANTIBODIES

A critical component of the diagnosis of celiac disease is antibody blood testing. People with celiac disease who regularly eat gluten have higher than normal levels of certain antibodies in their blood. Antibodies are produced by the immune system in response to substances that the body perceives to be threatening. Antibodies are the body's soldiers, charged with fighting a specific enemy or harmful substance. However, in the case of an autoimmune disorder such as celiac disease, the enemy is actually something that is harmless for people without the disease—in this case, the proteins in wheat, rye, and barley that are generically known as “gluten.”

### THE THREE RELEVANT ANTIBODIES IN CELIAC DISEASE ARE:

- › Anti-tissue transglutaminase (tTG)
- › Anti-endomysium (EMA)
- › Anti-deamidated gliadin peptides (DGP)

A positive antibody test result suggests that a person might have celiac disease, but it is not conclusive; in most cases, a biopsy of the small intestine is needed to confirm the diagnosis.

To check for celiac disease the doctor will order one or more of the antibody tests indicated above, sometimes collectively referred to as a “celiac panel”. This panel should also include a test called total serum IgA. Total serum IgA is not a celiac test in and of itself. It measures whether the person being tested actually produces IgA in his or her blood in sufficient quantities. Some people have a condition called IgA deficiency, which renders the celiac antibody test result unreliable\*. If a patient is deficient in IgA, the doctor should order another test called tTg-IgG, which measures another antibody related to celiac disease.

Once antibody tests and/or symptoms suggest celiac disease, an intestinal biopsy is necessary to check for damage to the villi. At this point,

the patient needs to visit a gastroenterologist, who is a specialist in the digestive system. While bloodwork can usually be done by a general practitioner, the endoscopic biopsy procedure requires a gastroenterologist.

Even though the blood tests are quite accurate, they may occasionally produce false positive results (when someone who does not have celiac disease receives a positive test result) or, less commonly, false negative results (when a person with celiac disease receives a normal test result). Thus, with rare exceptions (see sidebar p.12), the biopsy of the small intestine is a must to definitively diagnose celiac disease.

### **ENDOSCOPIC BIOPSY**

Biopsy in combination with bloodwork remains the most accurate way to diagnose celiac disease. This is done in a procedure called a biopsy, or endoscopic biopsy. This procedure is always performed by a gastroenterologist, and takes place either in an outpatient surgical suite or a hospital. The procedure lasts less than half an hour, and sedation and/or local anesthesia is generally used. The gastroenterologist needs to establish the diagnosis by obtaining tiny pieces of tissue from the upper small intestine to check for damage to the villi. The physician eases a long, thin tube called an endoscope through the mouth, the esophagus, the stomach and into the small intestine. With the help of a small camera on the tip of the endoscope, the physician finds the duodenum, at the top of the small intestine, and inserts the tube there. As the tube makes its way to the small intestine, the camera sends a video image to a monitor in the procedure room. This helps the physician visually assess any evident abnormalities such as ulcers or gastritis.

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*\*Celiac patients who happen to be IgA-deficient (i.e. have a level of total IgA less than 20 mg/dl) would show a normal result of TTG and EMA. Under these circumstances, the test that would reveal celiac disease has to be a TTG-IgG, EMA-IgG or DGP (“Deamidated Gliadin Peptides”)-IgG. It is important to note that IgA-deficiency does not pose, in general, any particular health issues.*

## CELIAC SEROLOGY

ANTI-TISSUE TRANS- GLUTAMINASE (TTG-IGA)	The tTG-IgA test is the most common and most sensitive celiac screening test available. Some 98% of people with celiac disease have a positive tTG test. While the tTG test is very sensitive, it can occasionally produce <b>false positive</b> results. People with Type 1 diabetes, Hashimoto’s thyroiditis, and autoimmune liver conditions are more likely to have elevated tTG without having celiac disease. This screening test can also produce <b>false negative</b> results, if the patient does not have enough IgA to measure (this harmless condition is known as IgA-deficiency.*)
ANTI- ENDOMYSIAL ANTIBODY TEST (EMA-IGA)	This tests specifically for celiac disease. It is estimated that a person with an elevated level of EMA has an almost 100% chance of having celiac disease. However, this test is not as sensitive as the tTG-IgA test—about 5% to 10% of people with celiac disease in fact do not have a positive EMA test.
TOTAL SERUM IGA	This tests for IgA deficiency, not for celiac disease itself
HLA-DQ2 AND HLA-DQ8	Gene tests for celiac disease, to determine whether the patient carries a gene. This test is not affected by diet (gluten or gluten-free). If negative, these gene tests are very useful to confidently rule out celiac disease for life.

\* See note, p. 11

In the small intestine, the physician uses the camera to examine most of the duodenum, the area affected by celiac disease. However, in many celiac patients, the duodenum appears normal at the time of biopsy. This is why the surgical removal of tissue is so important—it is only by examining the cells under a microscope that a definitive diagnosis of celiac disease can be made.

To procure tissue for the biopsy, the physician inserts a tiny surgical instrument through the endoscope tube. The physician will take five to six biopsies by grasping tiny sections of the small intestine and gently slicing them away from the walls of the intestine. There are no nerve endings in the lining of the intestine, so this procedure is painless. Afterward, some patients experience a sore throat, but most have no memory of the procedure.

Multiple tissue samples are vital for an accurate diagnosis—celiac disease can cause patchy lesions in the duodenum, which can be missed if only one or two samples are taken. The tissue is prepared on slides and sent to an experienced pathologist, who will examine them under a microscope and determine whether they show signs of celiac disease or another malady.

The biopsy procedure is unequivocally the most reliable way to ascertain the diagnosis. However, there are some cases where the experienced physician may decide to forgo this procedure. This may occur when a child who has symptoms consistent with celiac disease also has extremely elevated celiac autoantibodies (known as tTG) and autoantibodies (known as EMA) that are clearly positive, along with a positive genetic test. In all other circumstances, the biopsy is necessary for a final diagnosis.

Many parents express concern about the biopsy procedure. While

## DIAGNOSIS WITHOUT A BIOPSY:

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While the vast majority of cases of celiac disease follow the normal course of diagnosis, antibody testing and a biopsy of the small intestine, there are some cases that can be definitely diagnosed without the biopsy. In 2012, the European Society for the Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN)

issued guidelines for doing just that. The guidelines say, in summary, that in the pediatric population, if a patient presents with classic symptoms of celiac disease, the doctor can issue a diagnosis of celiac disease if the following protocol is met:

- › The TTG-IgA comes back highly elevated (greater than 10 times normal);
- › The EMA comes back clearly positive;
- › The patient is positive for at least one of the two genes correlated with celiac ease (DQ 2 or DQ 8);
- › The patient has a positive response to the gluten-free diet.

These guidelines apply to children; in fact, the American College of Gastroenterology published their most recent guidelines in 2013, and while they overlap with the ESPGHAN recommendations in all other aspects, they still place the biopsy as a necessary diagnostic step.

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all medical procedures have risks, there are several important facts to consider: First, the procedure takes just 10 to 15 minutes, during which the child is under general anesthesia and is closely monitored by a team of anesthesiologists and a gastroenterologist. Second, research shows that children diagnosed with celiac disease before age four reduce their risk of developing additional autoimmune disorders. This advantage is significant, as children who are diagnosed between the ages of 4 and 12 have a 17% risk. From 12-20 years of age the risk goes up to 27%. Patients diagnosed after age of 20 have a 34% chance of developing another autoimmune disorder.

Finally, the longer a child is on a gluten-free diet, the more difficult it becomes to correctly diagnose celiac disease. Clinical experience also shows that children and adults who have not had a biopsy as part of their diagnosis for celiac disease tend to take the diet less seriously, which can cause future complications.

### **GLUTEN REQUIRED**

Antibody tests and biopsies are accurate only when a patient is on a diet that contains gluten. Anyone who suspects that he or she might have celiac disease should **not** start a gluten-free diet before being evaluated. Any change in the diet, even for just a month or two, can render the diagnostic tests unreliable.

If gluten has been removed from the diet prior to blood tests and/or biopsy it is important to notify the physician so that a plan to reintroduce gluten in sufficient quantities, for a sufficient amount of time, can be made before moving forward with diagnosis. The re-introduction of gluten is sometimes referred to as a gluten challenge. A gluten challenge can range from a couple of weeks to a few months, depending on the situation.

### **SKIN BIOPSY FOR DERMATITIS HERPETIFORMIS**

DH is diagnosed by a skin biopsy, which involves removing a tiny piece of skin near the rash and testing it for the IgA antibody. The biopsy



must be taken when the rash is active. DH is treated with a gluten-free diet and a topical antibiotic medication called Dapsone to control the rash. Drug treatment is short term, usually until the gluten-free diet starts to relieve symptoms. It is not necessary to perform an intestinal biopsy to establish the diagnosis of celiac disease in a patient with DH; the skin biopsy is definitive.

## GENETICS OF CELIAC DISEASE

The gene test for celiac disease does not diagnose celiac disease. Rather, if the result is positive, it places individuals into an at-risk group for celiac disease. People who carry a gene for celiac disease who also have a first degree relative with it should be tested every three years, or sooner if symptoms develop. Those without a diagnosed close relative can be checked if and when symptoms develop. When the genetic predisposition for celiac disease was first detected, researchers noted that having a relevant gene is required for the disease to develop, but it is not the only factor. In fact, up to one-third of the U.S. population may have the genes necessary to develop celiac disease. These genes are located on the HLA-class II complex on Chromosome 6 and are called DQ2 and DQ8.

Unlike antibody testing, gene testing for celiac disease measures the presence or absence of one or both of the genes that are necessary to develop celiac disease. The HLA gene test for celiac disease can be performed at any time after birth (and even on cord blood at birth). People are born either with or without these genes, and that does not change over time. An individual with either HLA DQ2 or HLA DQ8 can develop celiac disease at any time.

Every case of celiac disease studied has been found to show these genes; therefore, someone with a negative gene test will not ever develop celiac disease. The HLA test is not affected by diet. Thus, for a person who is already on a gluten-free diet and who is reluctant to go through a gluten challenge, having an HLA gene test can help rule out celiac disease. It

is impossible for someone with a negative gene test to develop celiac disease.

The HLA gene test is also useful for people with celiac disease in their families, who are at higher risk for the disease. When an individual is diagnosed with celiac disease, the entire family should be tested for it, because celiac disease does run in families. The general population has a 1 in 133 chance of developing celiac disease, but once a family member is diagnosed, those statistics change significantly. First-degree relatives (parent, child, sibling) have a 1 in 22 chance of developing celiac disease, and second-degree relatives (aunt, uncle, grandparent), have a 1 in 39 chance. A first or second degree relative of a celiac patient can have a genetic test. If it is negative, that person will not need further screening. People who test negative for the gene do not need regular antibody screening. Those who test positive, however, would need to undergo regular antibody blood tests for celiac disease every three years or so for the remainder of their lives. This is especially helpful for children of an adult with celiac disease, so that the parents can know which children in the family need close monitoring.

### **INHERITING THE GENES**

The genes for celiac disease are passed on differently than the way many genetic traits are inherited. These genes do not behave with dominant or recessive traits, to form sets to determine one's hair color, height, and other characteristics. A child who inherits either celiac gene from either parent can develop celiac disease. If one inherits both genes from either parent, one has a greater risk of developing the disease. At the same time, even though the DQ2 and DQ8 genes are inherited and are necessary to develop celiac disease, having them is no guarantee that the disease will occur, even when the genes are inherited from both parents. It may be useful to know that only 1 in 20 of the individuals who have either gene develops celiac disease in the course of his or her life; 19 out of 20 do not.

Genetic testing is widely available. Most of the major diagnostic labs in the United States have the capability to run HLA testing for celiac disease. Kimball Genetics, a division of LabCorp, also offers the genetic test using a cheek swab rather than a blood sample. More and more insurance companies are covering the cost for the test, especially if the individual being tested has a risk factor for celiac disease.

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# CHAPTER THREE:

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TREATMENT OF CELIAC DISEASE  
BASICS OF THE GLUTEN-FREE DIET  
FOLLOW-UP CARE  
THE FUTURE

Once a diagnosis of celiac disease has been confirmed, the patient needs to begin following the gluten-free diet, eliminating all foods that contain even trace amounts of gluten.



## TREATMENT OF CELIAC DISEASE

Currently, celiac disease does not have a pharmaceutical treatment option—the only treatment for it is the gluten-free diet. For most people, this diet will ameliorate symptoms, allow intestinal damage to heal, and prevent further harm. Improvements usually begin within weeks of starting the diet. The vast majority of children experience full recovery of their intestinal lining, but research has shown that many adults do not heal completely, even though symptoms may improve.

The gluten-free diet is a lifelong requirement for those with celiac disease. Any gluten, no matter how small an amount, can damage the small intestine and lead to complications. This is true for anyone with the disease, including patients without noticeable symptoms. Depending on a person's age at diagnosis, some issues, such as delayed growth and tooth discoloration, may not improve on the gluten-free diet.

A gluten-free diet means avoiding all foods that contain wheat, rye, and barley. In addition, unprocessed meat, fish, fruits, and vegetables do not contain gluten, unless they are marinated with or cooked with gluten-containing ingredients.

The gluten-free diet requires one to rethink all of one's customs and habits related to eating. Those with celiac disease have to be extremely careful about what they buy for lunch at school or work, eat at cocktail parties, or grab from the refrigerator for a snack. Eating out can be a challenge as one learns to scrutinize menus and question waiters or chefs about possible hidden sources of gluten and potential issues of cross-contact in the kitchen. Eventually it becomes easier to identify potential sources of gluten and to recognize which foods are safe and which are off limits.

Dietitians are healthcare professionals specializing in food and nutrition. A dietitian, especially one with knowledge of the gluten-free diet,

can help newly diagnosed patients learn how to change and adjust to the diet. Support groups, both online and in person, can also be helpful as patients and their families learn to adjust to a new way of life. If the diet is still difficult after several months or if symptoms persist, it is important to consult the doctor and dietitian. A thorough review of the diet from an outside perspective will help identify hidden sources of gluten.

### **BASICS OF THE GLUTEN-FREE DIET**

The gluten-free diet is a lifelong requirement. Eating any gluten-containing food, no matter how small an amount, can damage the small intestine, especially if it happens consistently. It can take months for antibody levels (indicating intestinal damage) to normalize after a person with celiac disease has started the diet.

A gluten-free diet requires a completely new approach to eating that affects a person's entire life. It means avoiding all foods that contain wheat (including spelt, triticale and kamut), barley and rye, as well as ingredients derived from these grains. For example, malt is derived from barley, so any products that list malt in any form should not be consumed by those with celiac disease. Despite these restrictions, people with celiac disease can eat a well balanced diet with a variety of foods, including gluten-free bread and pasta made from alternative types of flour. For example, instead of wheat flour, baked goods can be made with potato, rice, soy, nut or bean flour. Unprocessed meat, fish, fruits and vegetables do not contain gluten, so people with celiac disease can eat these foods, as long as they are mindful of marinades or sauces with gluten. Eating out can be a challenge, but with practice, the person with celiac disease will learn to scrutinize menus and ask the right questions.

A dietitian can help people learn about their new diet. It is important to find a dietitian who specializes in celiac disease. The American Dietetic Association has a listing of dietitians at [EatRight.org](https://www.eatright.org), and doctors can provide referrals as well.

The first step in managing the gluten-free diet is to understand which foods contain wheat, rye and barley so they can be eliminated from the diet and intestinal healing can begin. It may seem overwhelming at first, as wheat, rye and barley are common ingredients. However, there are many foods that are naturally gluten free. Fresh foods, without any processing or additives, from the fruit, vegetables, dairy products and meat food groups are all NATURALLY GLUTEN FREE. That is four out of five food groups!

**LABELING AND CERTIFICATION:  
THE U.S. FOOD ALLERGEN LABELING AND CONSUMER  
PROTECTION ACT**

The Food Allergen Labeling and Consumer Protection Act, or FALCPA, became effective in January, 2006. Its purpose is to list in a clear way the eight major allergens in food product ingredient lists. One of those eight allergens is wheat, so if wheat is used in any way, either as a pure ingredient or in a derivative form in a particular food product, it will be listed in the ingredients. Rye and barley are not among the eight major allergens. However, rye and barley have few derivatives, so if the ingredients do not list rye and barley (or malt), the consumer can be quite sure they are not in there.

With FALCPA, the U.S. Food and Drug Administration (FDA) proposed to define the term “gluten free” for voluntary use in the labeling of foods. In doing so, the FDA has also adopted the standard of 20 parts per million (ppm) for the term gluten free. This ruling requires that a product contain less than 20 ppm of gluten in order to be considered gluten free. The vast majority of physicians and scientists worldwide agree that 20 ppm is a safe threshold. Even the most sensitive celiac patient would have to eat—in one day— more than two pounds of a food that contains 20 ppm of gluten per serving to exceed this threshold.

Since 2014, the FDA has required that any processed food that is labeled gluten free meet the 20 ppm standard. Avoiding gluten completely is extremely difficult, if not impossible. Celiac patients are inevitably exposed to products containing trace amounts of gluten. Gluten intake is cumulative. The safe threshold for gluten intake in a 24-hour period varies among patients between 10 and 50 mg. Research in fact shows that while no celiac patient will react to less than 10 mg of gluten ingested per day, most will have a reaction (either detected by a biopsy only and/or clinical) to gluten when they ingest 50 mg or more per day. Translated into practical terms, that means an amount as small as 1/64 of a teaspoon of wheat flour (that contains about 10 mg of gluten) could be damaging for the most sensitive patients. The University of Chicago Celiac Disease Center concurs that a 20 ppm gluten-free standard is a safe threshold.

Because it is voluntary, the term “gluten free” does not need to be on every product available to consumers. If the product is labeled as gluten free, the company should be willing to stand behind that claim. Some products may not be labeled “gluten free” but also do not contain gluten in the ingredient list; this does not mean they are safe products. In these cases it is best to contact the manufacturer to determine if gluten actually may be in the product as a result of cross-contamination.

If a food product bears the claim “gluten free” in its labeling and fails to meet the conditions above, it will be deemed misbranded. However, the FDA does not actually test products. It leaves testing to the companies themselves, so consumers still need to be cautious. The ruling also states that if a product is naturally gluten free, it must note that in its claim as well. For example, if a company wants to label its milk “gluten free”, it would also have to state that all milk is gluten free.

A food product that contains an undeclared allergen may be subject to recall. Additionally, if a food product is found to be improperly labeled, it may be subject to seizure and removed from the market place.



## INDEPENDENT CERTIFICATION

Some manufacturers take the additional step of certifying their products as gluten free using an independent organization. The Gluten-Free Certification Organization ([GFCO.org](https://www.gfco.org)) has the most rigorous certification process available in the United States.

## FOLLOW-UP CARE

The purpose of follow-up testing after diagnosis is to ensure that antibody levels are returning to normal. This is considered to be the best proxy indication of intestinal healing, in the absence of any other reliable non-invasive marker. If the antibodies decline as expected and symptoms improve, it is rarely necessary to do a repeat intestinal biopsy. These follow-up tests also help the doctor evaluate the extent to which a celiac patient has been compliant with the gluten-free diet. Antibody levels take a long time (sometimes more than a year) to normalize after a person has stopped eating gluten. Antibody levels measured periodically—along with other tests that may be useful in individual cases—are an important part of the doctor's assessment of the improvement of the intestinal damage.

## FOLLOW UP TESTS

Guidelines on the diagnosis and treatment of celiac disease from the North American and European Societies for Pediatric Gastroenterology, Hepatology and Nutrition advise that tTG-IgA be used for follow-up care. The University of Chicago Celiac Disease Center also recommends the newer tests (DGP-IgA and DGP-IgG), because the tTG test, used widely for screening, can sometimes be inaccurate in people with autoimmune disorders such as Type 1 diabetes. Interpreting the tTG or DGP result is straightforward—a celiac patient on the gluten-free diet for at least several months should have a negative test, or at least a result well below the initial result pre-diagnosis. The DGP antibodies appear to be more responsive to a strict gluten-free diet, so their numbers should be within the normal range, indicating absence of a meaningful antibody response to gluten. If they remain abnormal, this can indicate

that the patient is still ingesting some gluten, or is not responding as well as hoped to the gluten-free diet.

The University of Chicago Celiac Disease Center recommends that new celiac patients receive follow-up testing three to six months after diagnosis, and after one year on the gluten-free diet. After that, a celiac patient should receive follow-up testing on an annual basis, to ensure compliance with the diet.

While patients are anxious to see a negative test right after beginning the gluten-free diet, a normal value may appear only after a year or more on the diet, especially if the initial value was very elevated. As long as the numbers are in steady decline, the patient is progressing.

## THE FUTURE

While the gluten-free diet can be challenging, these are exciting times for those with celiac disease. Research is active on several fronts, including the development of treatment options that go beyond the diet and for research toward a cure.

Among the most promising initiatives:

- › Enzyme pills that, when ingested along with meals containing some gluten, would break it down (thus, making the gluten nontoxic) before it reaches the small intestine
- › Pharmaceutical drugs to quench the inflammatory response of the intestine to gluten
- › A cure, or therapeutic vaccines, that would be able to restore the body's tolerance to gluten

## WHEN PROBLEMS PERSIST

A common issue with celiac patients who are on a strict gluten-free diet is that sometimes the symptoms they had before diagnosis do not seem to resolve, or at least not completely. In general, this problem is caused

by one of the following circumstances: 1) there is still gluten in the diet; 2) the symptoms are not due to celiac disease; or 3) the symptoms are due to celiac disease despite adhering to a strict gluten-free diet (in some instances symptoms may persist even when following a gluten-free diet).

In the first instance, it is imperative that, in addition to the follow up blood tests (see above), a careful dietetic review be done. It is rare, but possible, for the tests to be normal even when a small amount of gluten may have unknowingly been consumed.

In the second instance, it is common for the symptoms to be due to another cause, rather than celiac disease. For example, people with irritable bowel syndrome (IBS) in addition to celiac disease will have gastro-intestinal symptoms that persist. Thus, it is extremely important to find the true cause(s) for such symptoms.

Finally, in the third instance, some patients develop health issues that originate because of celiac disease but do not resolve on a gluten-free diet. For instance, patients with peripheral neuropathy related to celiac disease may continue to have peripheral neuropathy even on a gluten-free diet. Similarly, depending on a person's age at diagnosis, some problems, such as delayed growth and tooth discoloration, may not improve. Gastroenterological symptoms that persist, including extreme weight loss and diarrhea, despite following the diet could indicate a very rare condition called refractory celiac disease.

From a practical standpoint, it is important to first make sure that the diet is completely gluten-free; then the doctor can determine if symptoms could be due to other causes and address them appropriately. Sometimes the doctor may want to repeat the biopsy to be sure that celiac disease is in remission.

## FOLLOW-UP OF CELIAC PATIENTS

	AT DIAGNOSIS	AT 3-6 MONTHS	AT 1 YEAR	YEARLY
TTG-IgA	●	●	●	●
CBC	●	●	●	●
Fe studies	●			
TSH+T4	●	●	●	●
Vitamin D	●			
Dietitian Review	●	●	●	●

IN OUR CENTER WE ALSO ROUTINELY ADD EMA AT INITIAL DIAGNOSIS ONLY; AND DGP-IGG AS A USEFUL TOOL FOR FOLLOW-UP AT ALL SUBSEQUENT TIME INTERVALS.

*Snyder J et al., Pediatrics September 2016*

*Evidence-Informed Expert Recommendations for the Management of Celiac Disease in Children*

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# CHAPTER FOUR:

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MANAGING EVERYDAY LIFE  
GROCERY SHOPPING  
EATING OUT

The gluten-free diet seems overwhelming at first. But with time and patience, it quickly becomes easier, and will eventually be second nature to those with celiac disease.

## MANAGING EVERYDAY LIFE

When there are other gluten-containing foods in the household, it is very important that the person with celiac disease does not inadvertently ingest any gluten from cross-contact.

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### RECOMMENDATIONS TO ELIMINATE CROSS-CONTACT:

- › A separate toaster should be used for gluten-free products. Even a crumb is a source of gluten, which can cause harm to a person with celiac disease.
- › A separate colander (strainer) should be used with gluten-free pasta because the small crevices are a good hiding place for the glutinous substance of regular pasta. Other cooking utensils, such as pots and pans, should be scrubbed thoroughly after each use and before cooking gluten-free products.
- › A bread machine may be a good purchase for families who want to make their own gluten-free bread. The bread machine should be used with gluten-free bread mixes only.
- › Sponges are not only a large source of bacteria, but also are very likely to spread gluten around the kitchen. Use disposable paper towels and disinfect frequently to ensure the surfaces are clean and free of gluten.
- › Purchase and mark separate peanut butter, jam, mayonnaise, butter or other spreadable condiments which can be contaminated with gluten through shared silverware.
- › Be mindful of old coated pans with deep crevices. Parchment paper or tinfoil can help avoid cross-contact on sheet pans.
- › Be aware of wooden cutting boards, rolling pins, and utensils previously used for gluten containing items. These items do not clean well and may carry gluten in the cuts and porous surface. Purchase new for gluten-free use.

## BEFORE HEADING TO THE STORE, MAKE A LIST OF SAFE FOODS.

### GROCERY SHOPPING

The first trip to the grocery store after a diagnosis of celiac disease may be difficult. It is good to go prepared, ideally with a supportive family member or friend, who can help with reading ingredients. Before heading to the store, make a list of safe foods:

#### FRUITS AND VEGETABLES

All!

#### DAIRY PRODUCTS

- › Eggs, egg substitutes
- › Milk (unflavored), butter
- › Cream cheese, cottage cheese
- › Swiss, cheddar, mozzarella
- › Yogurt or kefir

#### MEAT AND ALTERNATIVES

- › Fresh poultry (take caution with self-basting types)
- › Fresh fish/shellfish
- › Fresh beef, pork, lamb, venison
- › Beans, lentils, peas, nuts, seeds

#### MISCELLANEOUS (NOTE: CHECK INGREDIENTS JUST TO BE SURE)

- › Nut butters (peanut, almond, sunflower seed, cashew)
- › Jelly, jams, marmalade
- › Ketchup, mustard, mayonnaise
- › Vinegars: balsamic, red wine, white wine, apple cider, champagne
- › Olive oil, grapeseed oil, coconut oil, canola oil

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**STICK TO THE LIST!** It's easy to become overwhelmed (and distressed) when considering options. It takes time to read food ingredient labels, so if you prepare ahead, a trip to the grocery store will be less burdensome.

## **POSSIBLE PITFALLS AT THE GROCERY STORE:**

### **PRE-SLICED DELI MEATS:**

It is best to purchase pre-sliced packaged gluten-free deli meats and cheeses and to check all ingredients carefully. Some deli items may contain marinades and seasonings with wheat and slices can be contaminated by gluten-containing products.

**BULK BINS:** These storage containers are difficult to clean and are at risk for cross contact. Buy only pre-packaged flour, dried beans, nuts and cereals. Avoid products in bulk bins.

### **GLUTEN-FREE CONVENIENCE FOODS**

After filling your cart with naturally gluten-free choices, it is time to select gluten-free alternatives to your regular breads, cereals and snack foods. There is a wide variety of gluten-free options to choose from. Prices tend to be higher, so you may want to buy small quantities at first, until you know what you like.

### **BREAKFAST IDEAS**

- › Gluten-free cereal mixed with fruit and milk (add some ground flax seed for additional fiber)
- › Yogurt mixed with fresh fruit and nuts
- › Gluten-free bread, bagel or muffin topped with cream cheese, peanut butter, preserves or honey
- › Homemade French toast prepared with gluten-free bread, made with egg and topped with gluten-free syrup and fruit
- › Fruit smoothie made with yogurt and fresh or frozen fruit (check ingredients on frozen packaging)
- › Cooked cereal mixed with chopped dried fruit such as raisins or dates, mixed with brown sugar or cinnamon
- › Eggs and omelets



## **LUNCH IDEAS**

- › Sandwiches on gluten-free bread (choose ones with more than three grams of fiber per slice) topped with vegetables, gluten-free lunch meat
- › Homemade pizza with a gluten-free crust topped with gluten-free pizza sauce, cheese and fresh vegetables
- › Leftovers (casseroles, pasta, meat, potatoes, chicken, rice, quinoa)
- › Wraps made with lettuce or corn tortillas stuffed with rice noodles, meat, vegetables or cooked rice
- › Rice cakes topped with peanut butter, banana or cheese
- › Baked potatoes topped with cheese, vegetables and chili
- › Gluten-free hot dog with gluten-free bun
- › Gluten-free crackers, hummus, raw vegetables and fresh fruit

## **DINNER IDEAS**

- › Gluten-free lasagna
- › Meatloaf made with lean turkey or beef, gluten-free bread crumbs, egg and herbs/spices
- › Barbecue chicken, beef, pork, seafood, fish with rice pilaf, quinoa or buckwheat salad
- › Gluten-free pizza
- › Gluten-free tacos made with corn tortillas
- › Oriental stir fry made with fresh vegetables, gluten-free soy sauce, served over rice

## **SNACK IDEAS**

- › Yogurt and nuts
- › Gluten-free pretzels with peanut butter or cheese
- › Fresh, dried, or canned fruit
- › Popcorn
- › Fresh vegetables and gluten-free dip
- › Gluten-free snack bars
- › Homemade gluten-free trail mix (gluten-free cereal, raisins, nuts and gluten-free chocolate candies)
- › Fruit and nuts

## **SERVING SUGGESTIONS & TIPS FOR HEALTHY EATING** **BREADS, CEREAL, RICE AND PASTA**

(5-6 SERVINGS, DEPENDING ON AGE AND WEIGHT)

- › One slice brown rice bread
- › 1/3 cup cooked quinoa, buckwheat or rice
- › 1/3 to one cup cooked cereal (depending on the brand)
- › One cup ready-to-eat gluten-free cereal

Look at the Nutrition Facts Food Labeling on foods to determine the fiber content of the product. A good choice would contain more than three grams fiber per serving. Choose grains such as quinoa or buckwheat more often than foods made with rice flour; these grains contain more fiber and protein than products made with white rice.

## **VEGETABLES**

(2.5 CUPS PER DAY)

- › One cup raw leafy vegetables
- › One cup cooked or chopped raw vegetables
- › One cup vegetable juice

Choose dark green leafy vegetables (romaine or baby spinach) instead of lighter colored varieties (iceberg). Cook vegetables for a short amount of time in an inch of water in a covered pot to retain nutrients – vegetables should still have a bite to them.

## **FRUIT**

(2 CUPS PER DAY)

- › One cup fresh, frozen or canned fruit
- › One medium sized apple, orange, pear
- › ¼ cup dried fruit
- › ½ cup juice (4 oz)

Fresh fruit is ideal for snacks. If you eat canned fruit, choose fruit in its own juice, rather than in heavy syrup. After a trip to the grocery store, wash and cut up produce right away so it is ready to eat and easily accessible from the refrigerator.

## **MILK, YOGURT, CHEESE & OTHER DAIRY PRODUCTS**

(3 SERVINGS PER DAY)

- › One cup milk  
(8 ounces)
- › Six ounces yogurt
- › One ounce cheese
- › Four ounces cottage cheese

Choose low-fat dairy products. If dairy products are not tolerated well, try lactose-free milk or Lactaid tablets when eating dairy products. If you are unable to consume milk or alternative dairy products, talk to your dietitian about taking calcium supplements.

## **MEAT, POULTRY, FISH, BEANS, EGGS AND NUTS**

(2-3 SERVINGS PER DAY)

- › 3-4 ounces lean meat, poultry or fish
- › One cup cooked legumes (beans, peas, lentils)
- › 1/3 cup tofu
- › Two tablespoons peanut butter
- › One egg = One ounce lean meat

Choose lean meats. Trim all visible fat from meats and remove the skin from poultry. Limit high fat processed meats such as sausages, bacon, bologna, salami and cold cuts.

**THIS IS JUST A SMALL SAMPLING OF THE MANY  
NATURALLY GLUTEN-FREE ITEMS YOU CAN  
PURCHASE AT YOUR GROCERY STORE.**

## EATING OUT

Many newly diagnosed celiac patients feel that they will never be able to enjoy a restaurant meal again. Indeed, eating in restaurants can be a challenge, especially at first, but it is by no means impossible. Here are a few suggestions to help make the process go smoothly:

- › Search online for gluten-free-friendly restaurants.
- › Check out menus on restaurant websites to identify possible options.
- › Call the restaurant in advance, preferably not during the lunch or dinner rush, to speak with the manager and explain your needs.
- › When you arrive, speak with your server, hostess and/or chef to ask about the specific options you've identified.
- › For fast food places, you'll need to check whether options can be cooked separately, to reduce cross contamination—for example, you would not want to have a burger if buns are toasting on the same griddle.
- › For any products that are prepared in a fryer, you'll need to verify whether products with gluten are fried in the same oil. Gluten-free products require a dedicated fryer.

## SCHOOLS & UNIVERSITIES

The key to a safe diet at school is communication. Note that these conversations may be ongoing, or may have to be repeated at the beginning of each school year, and if mid-year personnel changes during the year.

- › Talk to teachers and the school nurse right away, and explain your child's needs, as well as potential consequences if the diet isn't followed
- › Make sure that there are extra non-perishable snacks in the classroom and the nurse's office, in case of an impromptu celebration or event
- › Communicate with other parents, and ask them to alert you if a birthday or special event comes up, so that you can send your child in with an appropriate treat
- › If a school lunch is served, meet with the kitchen staff to ensure a safe alternative every day
- › Make sure your child understands the diet and can advocate for him or herself as needed

## COLLEGE BOUND

For young adults going off to college, communication is extremely important. Speak with the dining services director and the business office to ensure that the school can offer a gluten-free meal plan or other arrangements so that the student can stay healthy.

## SOCIAL EVENTS

Social events, such as dinner parties, weddings, etc., may require some extra effort on the part of both the host and the guest. We recommend contacting the host in advance, and politely explaining the situation. It is always helpful to offer to alleviate the burden by bringing food. With a catered event, request a special meal. Many caterers are well aware of food allergies and special diets. However, we always recommend carrying a snack as well, and perhaps eating something beforehand just in case.

## TRAVEL

Like eating out, traveling does not have to be abandoned after a diagnosis of celiac disease. It requires some advance research and possibly some compromise, but it is not impossible. Again, here are some tips to help you get started:

- › Research gluten-free options at your destination. If you are traveling to a foreign country, try to educate yourself about the local cuisine.
- › Many European and South American countries have gluten-free labeling. Educate yourself on the different symbols used to identify gluten-free options.
- › Most airlines offer gluten-free meals. However, they must be requested well in advance. Regardless, bringing safe snacks, especially on long flights, is always prudent.
- › If you are traveling to a non-English speaking country, bring a translated card with you that explains your needs. There are several such options available online.
- › Bring snacks such as gluten-free bars with you, and be prepared to compromise, with fruit, salad, etc.
- › Find a grocery store at your destination to replenish your snacks or buy food that you can prepare yourself.
- › Make sure you have plenty of snacks available for car and plane travel.

# CHAPTER FIVE:

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WEIGHT GAIN  
MEDICATIONS AND VACCINES  
TESTING FAMILY MEMBERS  
MYTH BUSTERS  
MOVING FORWARD

There are some additional issues celiac patients need to stay on top of, such as potential undesirable weight gain and gluten in medications.



## WEIGHT GAIN

Once the gut starts to heal, calories and nutrients will be absorbed efficiently. Weight gain is typical for patients after diagnosis. Weight gain is certainly desirable in those patients who have experienced weight loss, diarrhea and malabsorption prior to diagnosis. Many underweight celiac patients have become accustomed to eating very large portion sizes, because they absorb so little from their food. While these patients need to gain weight, they also will need to adjust their portion sizes to accommodate for both increasing absorption and the tendency of gluten-free foods to have more calories, fat and sugar than comparable gluten-comparable foods. The best antidote to unwanted weight gain is to eat as many fresh and unprocessed naturally gluten-free foods as possible, and to consume manufactured and processed foods sparingly.

There are also many patients who are already overweight at diagnosis. It is not uncommon for celiac patients to be overweight; in fact, one study showed that an estimated 22-32% of individuals with celiac disease in the U.S. will initially present as overweight or obese despite some degree of malabsorption. The weight gain that usually comes after diagnosis can be a problem for these patients. It is especially important for them to be aware of the pitfalls of calorie-laden gluten-free substitutes for breads, baked goods and other gluten-containing foods. Naturally gluten-free foods, such as fruit, vegetables, lean meats, fish, beans and nuts, are usually better options from a nutritional and caloric standpoint.

## MEDICATIONS AND VACCINES

Currently, the FDA does not regulate gluten in medications and generic drugs. If gluten is in a drug, it is typically in the filler. Drug companies change the source and type of filler regularly. For the most up-to-date resource on this topic, visit [glutenfreedrugs.com](http://glutenfreedrugs.com), a listing managed by a reputable pharmacist with a special interest in celiac disease.

Vaccines are safe for those with celiac disease, and children with the disease should be vaccinated on a normal schedule in consultation with their pediatrician.

Intravenous medications, such as anesthesia during surgery, are not of concern to those with celiac, as they do not pass through the digestive system.

## TESTING FAMILY MEMBERS

It is important to inform close relatives that they too are at risk for celiac disease. First-degree relatives (parents, siblings and children) are at higher risk for celiac disease and should be tested for it periodically. First-degree relatives should undergo antibody testing every three years, or more frequently if symptoms develop. Alternatively, because celiac disease is a genetic condition, a relative could have a gene test to rule out the disease. If the gene test is negative, that person cannot ever develop celiac disease and thus does not require further antibody testing.

Once you are diagnosed with celiac disease, you will need to have conversations with some of your close friends and family. This is especially important in the cases of children who are diagnosed, who spend time with friends and relatives outside the presence of their parents.

It is important to inform people about the diagnosis, while at the same time, maintaining a neutral tone and not asking for too much. We suggest letting people know about the importance of maintaining the gluten-free diet and avoiding cross contamination, accompanied by some version of the following language:

*Please respect the importance of preparing food in this way. While it may be a bit inconvenient at first, it is important to continue to include celiac patients in family and social functions without judgment or ostracism, the same way a patient with any other disease or chronic condition would be welcomed. Any reaction to the contrary can exacerbate feelings of depression and isolation that are common with this disease.*



## MYTH BUSTERS

There are numerous myths about celiac disease and the gluten-free diet. Here are some of the most common ones:

### GOING GLUTEN FREE IS HARMLESS.

WRONG: Contrary to popular belief, the gluten-free diet is not the healthiest for everyone. We do not recommend it for those who do not have celiac disease. It can cause constipation from lack of fiber and also limits the intake of vitamins and minerals. The problem is that many people switch to manufactured gluten-free products, which are refined, highly processed and lack nutrition.

### CELIAC DISEASE ONLY AFFECTS THE GI TRACT.

WRONG: Some of the typical symptoms are GI-related, such as bloating, constipation and gas, but an array of other symptoms also occurs. These non-GI symptoms are just as prevalent, if not more so, than the typical symptoms. They include anemia, recurring headaches, arthritis and osteoporosis. Some people have no symptoms at all, yet the internal damage from active celiac disease is present, along with the potential for serious complications.

### CELIAC DISEASE IS A FOOD ALLERGY.


WRONG: Celiac disease is not an allergy. It is an autoimmune disease in which the body produces antibodies and immune cells that attack and destroy the epithelium, or cell lining, of the small intestine. Celiac is a chronic, incurable disease and the only current treatment for it is a life-long, strict gluten-free diet.

### GLUTEN IS ONLY IN FOOD.

WRONG: Gluten can be found a lot of unexpected places other than food. Medicine, toothpaste and cosmetics can contain gluten. Celiac patients can use topical products containing gluten. However, they must be very careful not to ingest any such products.

## MOVING FORWARD

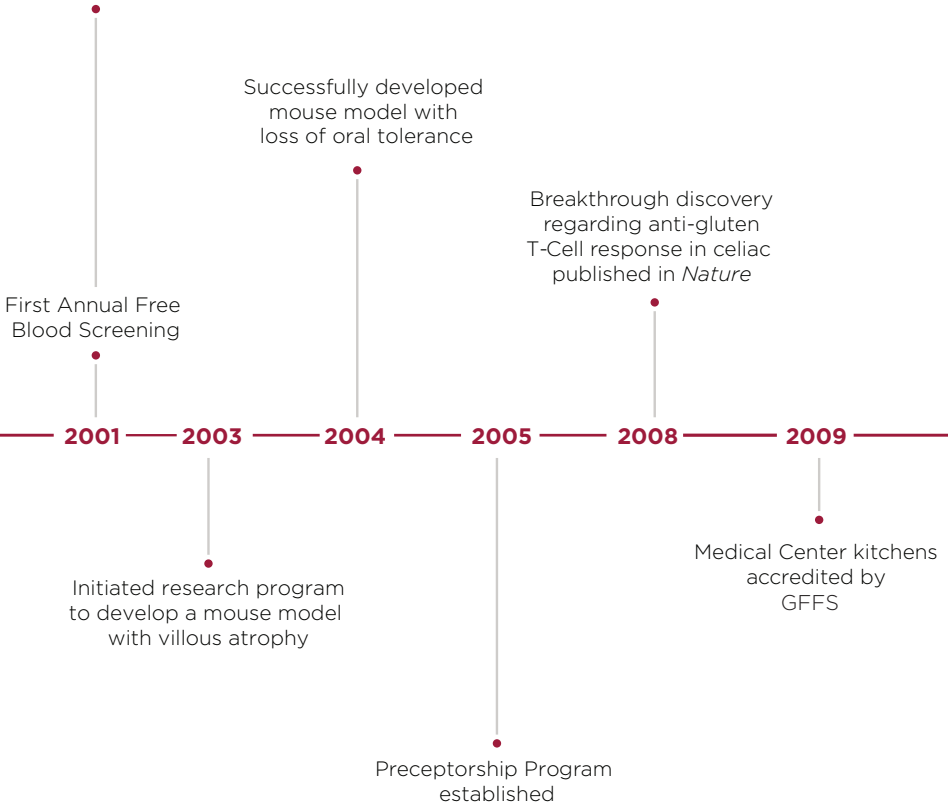
Celiac disease is certainly a major inconvenience, and when not properly identified and treated, can be a major health risk. However, it is very rarely a fatal condition, and with some effort and adjustments in expectations, can be managed effectively. While changing one's diet seems daunting at first, it will become easier as time goes by. It is important to keep in mind that the vast majority of foods are naturally gluten free, and many wonderful alternatives to gluten-containing foods exist today. Focus on the options you have, rather than what you need to leave by the wayside, and you will become healthier and feel better every day.



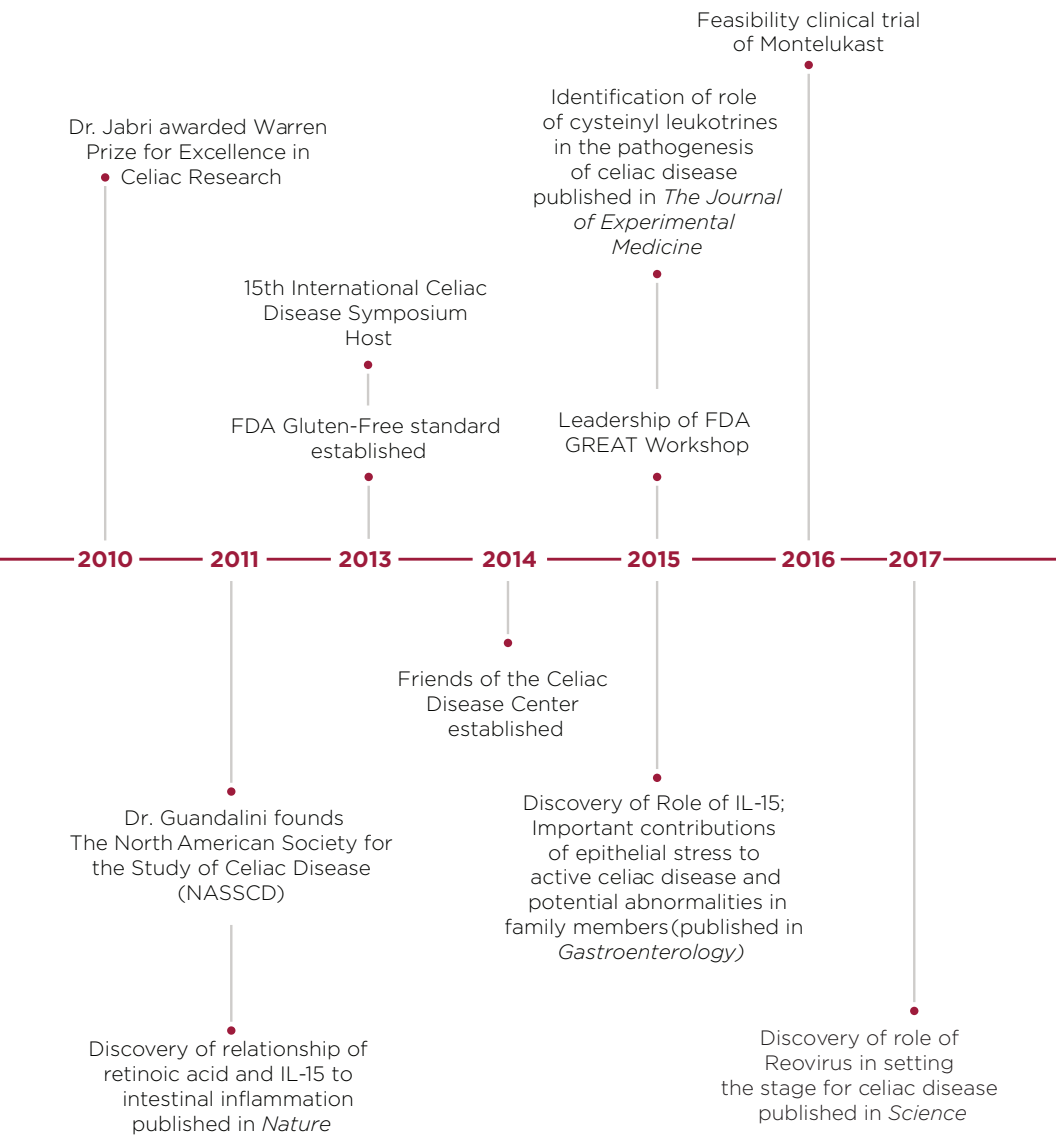
Further information on dealing with friends and family is available under the Fact sheet section of our website,

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# A Cure for Celiac Disease is possible ...

We are making it happen.



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Disease  
Center

The goal of The University of Chicago  
Celiac Disease Center  
is simple and straightforward:  
to find a cure for celiac disease.  
While the goal is simple to state,  
making it happen is more challenging.  
Achieving this goal requires coordinated  
effort, intensive research,  
and adequate funding.

For more information, please visit  
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