

# What on Earth is a Celiac?



*By*  
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## PREFACE

**April 1, 2003. The attacks begin.**

I have no recollection of what I had eaten on the day of April 1st, but before turning in for the night, I felt a strange sensation in my abdomen, like a bicycle pump pushing air into the region of my stomach...or somewhere in that approximate area. A gnawing pain and lots of bloating accompanied this pressure. However, *nothing* could have prepared me for what occurred around 3 A.M.

A sensation in my gut awakened me: cramping, spasms, accompanied by extreme pain. By this time, I was also making frequent trips to the bathroom with diarrhea. Next came the nausea and finally vomiting. This would continue for an hour or two, until I would go into shock with uncontrollable shivering. It seemed that my body would eliminate everything it possibly could, until nothing remained. The whole process would cease only when it seemed there was nothing more in my bowels to purge.

Night after night I experienced these "attacks." I *feared* going to sleep, knowing that I would awaken in physical hell. This experience went on for over two weeks. I continued to lose weight at an alarming rate. My primary care physician handed me "the purple pill" for stomach acid and suggested I get to a gastroenterologist. No one thought of prescribing an anti-spasmodic for the terrible pain. And specialists in my small rural town could not see me for 6 months. No attempts were made by my primary care physician to expedite this process, even with my daily phone calls to his office. (He has since closed his practice.) I began making numerous calls to Phoenix area gastroenterologists who were two hours away. Some had waiting periods for new patients of up to a year! The "attacks" still continued. It seemed no one could help me.

Eventually I arrived at the emergency room of our regional hospital, expecting to be admitted to the hospital. But by the time I arrived at ER and was seen, several hours had passed...and so had the episode. All results of testing done at the hospital were normal. I was patted on the head, given an antacid and sent home. I had told the attending physician that I "wasn't going anywhere" until they figured out what was going on. It seemed that no one was taking me seriously!

Still suffering, but with the help of a friend who lived in the Scottsdale area, I was finally able to get an appointment with a former Mayo Clinic gastroenterologist, who had just opened his private practice. He ordered and I completed the upper and lower bowel scopes. About ten days later, he informed me that, upon biopsy during the endoscopy, damage to the small intestine was seen. The villi in the lining of the small intestine were flattened. Initial diagnosis: Celiac Sprue, a "very rare" autoimmune disease that causes malabsorption of nutrients in the body

and is initiated by eating grains containing gluten. He suggested that I avoid gluten and observe the results.

Eager to do anything to feel better, I immediately took his advice. I eliminated gluten and almost instantly got better. The "attacks" ceased! To back up his findings, the doctor ordered additional blood work...and the results came back negative. Because of the results of this blood work, (I have since found that the antigen anti-body blood work is frequently unreliable) he seemed confused as to whether or not the disease that I was dealing with was actually Celiac Sprue. He asked me to return to my normal diet containing grains and gluten. I did...and the results were disastrous. My symptoms increased so dramatically after adding gluten back to my diet that I stopped all gluten a *second* time. From that day on, the positive results of a non-gluten lifestyle have demanded strict dietary change and I have refrained from knowingly eating any foods that contained gluten in any form.

Except for discovering the disease and telling me what Celiac Sprue was, I found the specialist to be of little help after the initial visit. The doctor sent me to a health food store, telling me *they* would be able to help me with my new diet. I was given no other information by this physician. Basically, he brushed me aside, became annoyed when I asked additional questions, and did not return my phone calls.

I was on my own.

The attacks had ceased, yet I continued feeling very exhausted and extremely sensitive to many *other things* in my diet. I wanted to know why I continued to feel so horrible, long after the larger issue of the attacks had ended. I was now experiencing headaches and fatigue from dairy products, fatty foods, and sugar, experiencing numerous bouts with the flu and colds, battled pink eye, canker sores in my mouth and achy, throbbing lymph nodes. Peculiar reactions to topical applications of wheat-containing hair care products and face creams emerged, with rashes and prickly heat headaches. Next came allergic reactions to my jewelry. Hundreds of dollars invested in the hair care products and jewelry that had to be given away! Frankly, it was one thing after another. It became difficult to work at my job. I was exhausted and my eyes were constantly inflamed and bloodshot. My job required that I be away from my home or office at meal times, and it was like walking through a land mine daily to figure out where and what to eat, now that I was attempting to eat gluten-free. I began to bring my meals with me, but even that was a very distressing and time-consuming challenge. I felt confused, vulnerable and alone.

*It is important to note that this is how my scenario played out with Celiac Disease. As you will find as you read on with this information, symptoms vary significantly from individual to individual, and my experience may not necessarily be your experience. This was my extreme, but there were numerous struggles with my general health and, what I will refer to as, overall autoimmune challenges throughout the course of my life that led up to the culmination of the events of April of 2003.*

Battling *secondary autoimmune disease* continued to be a significant aspect of my daily life and no physician seemed able to answer *any* of my questions. I was treated as if I were a hypochondriac. "*Stop eating the grains and you'll be fine; aren't you the lucky one!*" Few physicians will do more than just give you a pat on the head and push you out their office door!

And I was to learn more about the *global picture* of Celiac Disease as days, weeks, then months, and even years passed. How other autoimmune disease is frequently seen hand in hand with this illness, particularly if the patient has gone for much of their life undiagnosed. So, for me, what I believed was to be *the end* of all the peculiar maladies, was only just the beginning.

## INTRODUCTION

*Reader's Digest* magazine published a list in recent years of the top ten most under diagnosed diseases in this country. In the article entitled "10 Diseases Doctors Miss," the ten diseases mentioned were: hepatitis C, lupus, **Celiac Disease**, hemochromatosis, aneurysm, Lyme Disease, hypothyroidism, polycystic ovary syndrome, chlamydia, and sleep apnea.<sup>1</sup>

Almost simultaneously, articles emerged from both *The Wall Street Journal* (June 2003) and *The Washington Post* (February 2003), most likely based on a study published in the February 10, 2003 edition of *The Archives of Internal Medicine*.<sup>2</sup>

"Here's a disease for which there are good tools for diagnosis, an effective remedy and the potential of relieving a large population of people from a lot of misery and discomfort, and yet the disease is being grossly diagnosed."<sup>3</sup>

"It's now clear that the text book description of this once-obscure ailment is woefully incomplete and describes only a minority of cases. Below the tip of the so-called celiac iceberg is a diverse world of illness that may include thousands of people suffering from various, seemingly unrelated conditions, such as anemia, osteoporosis, infertility, irritable bowel syndrome and chronic fatigue."<sup>4</sup>

Researchers directing the study screened more than 13,000 people in 32 states." We now believe that more than 1.5 million Americans suffer from Celiac Disease, making it twice as common as Crohn's disease, ulcerative colitis and cystic fibrosis combined," says Alessio Fasano, M.D., the study's principal investigator and professor of pediatrics, medicine and physiology at the University of Maryland School of Medicine. This new study, which is the largest multi-center study ever on the prevalence of Celiac Disease in the U.S., took place over five years and included blood samples from 13,145 people, including adults and children. Suddenly, the long accepted thinking that Celiac Disease was rare has literally *exploded* off of the medical horizon.

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<sup>1</sup> *Reader's Digest*, February, 2004, USA.

<sup>2</sup> *Archives of Internal Medicine*, 2003, USA.

<sup>3</sup> *The Wall Street Journal*, June 19, 2003.

<sup>4</sup> *The Washington Post*, February 11, 2003.

There has *previously* been a lot of mixed data about the frequency that this disease exists in our society, but some data suggests that in Europe, Celiac Disease is seen as often as 1 in 250 people or more. Children are routinely checked for Celiac Disease as a matter of course.

Celiac Disease is the most common genetic disease in Europe. This disease is most typically seen in Northern European populations, with the highest incidence in people of Irish descent. This being said, then doesn't it stand to reason that there would be just as strong a prevalence of Celiac Disease in *this* country?

Until very recently, data in the USA suggested that Celiac Disease occurred only in 1 in 4700 people (based on the frequency of diagnosis). This was considered a *very rare* disease. However, the newest information *does* indicate that statistics in this country are probably more parallel to those in Europe. The recent landmark study in the *Archives of Internal Medicine* (2003) showed that Celiac Disease is "*a common inherited autoimmune disorder*" in the United States, striking 1 in 133 to 500 (up to 3 million) Americans.<sup>5</sup> That is a very significant change in information!

The average length of time it takes to be diagnosed (the delay between onset of symptoms and diagnosis) in the USA with Celiac Disease is estimated at *eleven long years*.

Celiac Disease is a chameleon-like disorder, making it easy to be missed and misdiagnosed, because it presents itself in such a *variety of ways*. Many Celiac symptoms can be attributed to other illnesses. Doctors are not knowledgeable and there is a widespread deficit in up-to-date information about the disease, and only a handful of U.S. laboratories are experienced and skilled in testing for Celiac Disease. Despite the recent bevy of research, most physicians continue to consider the disease rare, looking only for the "classic" presentation of symptoms: chronic diarrhea, abdominal distention, and failure to thrive in babies and young children.

However, recent studies also show this profile is *not always seen* in Celiacs. Nearly half of celiac patients suffer from gastrointestinal distress, including chronic or intermittent diarrhea, constipation bloating, and severe cramping. Yet the other half do not experience any gastrointestinal upset, and *instead* present with "symptoms" such as fatigue, weight loss, asthma, migraines, depression, and anemia. And as many as 10% to 15% of patients with "mystery" conditions such as fibromyalgia and chronic fatigue syndrome have Celiac Disease.<sup>6</sup>

Many, many people who may have Celiac Disease have been told that they have *one of a myriad* of gastro disorders with *Irritable Bowel Syndrome* being the most common diagnosis. Doctors had told me over the years that I most likely had Irritable Bowel Syndrome or gall bladder disease.

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<sup>5</sup> *Archives of Internal Medicine*, 2003, USA.

<sup>6</sup> *Delicious Living Magazine*, March 2003, USA.

I believed that my gall bladder was more than likely diseased and eventually, would need to be removed. I had had intermittent gastro issues that were at times debilitating, but nothing like what I experienced in April of 2003. The doctor in the emergency room had suggested that I most likely had an ulcer. Others had clearly indicated that this might all be psychosomatic. No one had suggested Celiac Disease. In fact, I had never heard of it! No physician had ever ordered the upper and lower GI scopes, and even when these tests were finally ordered, the gastroenterologist was suggesting several other possible diagnoses...never Celiac Disease.

In the past, doctors in the USA have had a tendency to overlook checking for this disease. (My gastroenterologist mentioned to me "this is very rare".) Countless people suffer needlessly for years without receiving a correct diagnosis. However, in recent years and with recent studies that have brought more up to date information to light, this is now changing. Celiac disease is no longer considered rare.

## WHAT IS CELIAC DISEASE/AKA CELIAC SPRUE?

Celiac Disease is a malabsorption disease in which the lining inside the small intestine becomes abnormal due to the ingestion of gluten. Gluten is a protein found in the grains of wheat, barley, rye, spelt, kamut, etc. Buckwheat is not a true grain, but a seed, like a sunflower seed. Oats do not contain gluten, however, oats are usually grown directly adjacent to and/or milled on the same equipment as other grains that *do* contain gluten, so they are usually contaminated. (Oats that are imported from Europe are less likely to be contaminated.)

What happens in malabsorption is that nutrients: proteins, carbohydrates and fats, along with trace minerals and vitamins, are not properly absorbed into the body. Celiac Disease is a genetic inheritable autoimmune disease, just like diabetes and rheumatoid arthritis. But Celiac Disease interferes with the *digestion* process. Celiac Disease is NOT an allergy!

The body perceives gluten as a foreign invader, or antigen. When antigens enter the intestinal tract, the immune system reacts by producing antibodies, which then bind with antigens to protect the body by preventing their absorption.<sup>7</sup> In plain English, the body attacks *itself*!

Recent research indicates that as many as 50% of all Americans are sensitive to gluten. However, there is a difference between being *sensitive* to gluten, and having Celiac Disease, in which the villi of the small intestine are literally destroyed when the digestive system comes in contact with gluten in any amount.<sup>8</sup> So, when a celiac person eats foods that contain gluten, the immune system responds by damaging the villi of the small intestine. It is a matter of life and death for a person with Celiac Disease to avoid *anything* containing gluten!

Eventually, decreased absorption of nutrients can cause vitamin deficiencies that deprive the brain, peripheral nervous system, bones, liver, and other organs of vital nourishment, which can lead to other diseases. Unchecked, this response can lead to the serious intestinal damage already mentioned, along with fatigue, depression, growth failure, abdominal and bowel symptoms, malnutrition, osteoporosis, and even cancer. This can be especially serious in children, who need proper nutrition to develop and grow.

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<sup>7</sup> EnteroLab, Dallas, Texas, USA.

<sup>8</sup> EnteroLab, Dallas, Texas, USA.

## What are villi?

Villi are the thousands of tiny, hair-like projections that line the small intestine. These villi provide an enormous surface area for absorption. Their job in the digestion process is to extract nutrients from foods. The nutrients are then absorbed into the bloodstream through the villi. These nutrients are responsible for developing muscle, bone, red and white blood cells, and many other cells and tissues important in maintaining good health. The villi in the case of a Celiac are unable to absorb the needed nutrients for the body, causing malabsorption. So gluten-induced inflammation leads to the destruction of the lining cells and gradual flattening of the villi until the surface area available for absorption is reduced many fold.

## HISTORY

Celiac Disease has been recognized for nearly 2000 years. As far back as 250AD, Artetaeus of Cappadocia included detailed descriptions of an unnamed disease in his writings. When describing his patients he referred to them as "koiliakos", which meant "suffering in the bowels". Francis Adams translated these observations from Greek to English for the Sydenham Society of England in 1856. He thus gave sufferers the moniker "celiac," which is from the Greek word for "belly."<sup>9</sup>

Domestic wheat originated in Southwest Asia. The oldest archaeological evidence for wheat cultivation comes from ancient Mesopotamia. Cultivation of wheat began to spread into Europe beginning during the last phase of the Stone Age. (10,000 to 8,000 B.C.)

But it has only been within the past 50 years, that the link between certain grains and autoimmune disease has been acknowledged in our culture.

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<sup>9</sup> Gluten Intolerance, 2000, USA.

# **DISEASES THAT MIMIC CELIAC DISEASE AND ASSOCIATED DISEASES**

The following information is extremely significant. Your doctor may be suspicious, based on your symptoms, that you have one of several gastro issues. You may have already been given a diagnosis. However, it is very important that you become aware of the long list of illnesses that mimic Celiac Disease. That list includes, but is not limited to: pancreatitis, gall bladder disease, irritable bowel syndrome, inflammatory bowel disease (which includes three serious disorders: ulcerative colitis, proctitis, and Crohn's Disease) diverticulosis, intestinal polyps, colon and gastric cancer, gastroenteritis (which can be brought on by bacteria, amoebas, parasites, toxins, certain drugs, enzymes, or allergens in foods) and chronic gastritis and ulcers.

## **Related/Associated Diseases**

Dermatitis Herpetiformis is considered a "counterpart" disease to Celiac Disease. DH is a skin disease that is noticeable by clusters of watery, itchy blisters. This differs from Celiac Disease, in that lesions are noticeable on the skin, not in the small intestine. Gluten consumption is still at the source of the issue, and abstaining from gluten in one's diet is the only cure.

Unexplained anemia, (lacking any other symptoms), osteoporosis, gum problems, skin problems, easy or free bleeding, Multiple Sclerosis, Chronic Fatigue Syndrome, fibromyalgia, and candida, peripheral neuropathy/ neurological symptoms, infertility, and anxiety and depression are just a few diseases or disorders that have been associated with Celiac Disease. One serious illness that often occurs in tandem with Celiac Disease is osteoporosis (loss of calcium from the bones). Studies indicate that approximately 4% of patients who have osteoporosis have the bone disease as a *consequence* of having Celiac Disease! And about 5% of adults with Celiac Disease have anemia.<sup>10</sup>

People with Celiac Disease tend to have other autoimmune diseases as well, including thyroid disease, systemic lupus, type 1 diabetes, liver disease, collagen vascular disease, rheumatoid arthritis, Sjogren's syndrome.<sup>11</sup>

The connection between Celiac Disease and these diseases may be genetic.

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<sup>10</sup> Washington University School of Medicine, St. Louis, Missouri, February 28, 2005, USA.

<sup>11</sup> National Institute of Health.

Lactose intolerance is common in patients of all ages with Celiac Disease. It usually disappears after a few weeks or months of following a gluten-free diet.

Celiac Disease predisposes the patient to the development of lymphoma. A link between untreated celiac disease and a rare enteropathy-type T-cell lymphoma has been well established by several studies. There is also an increase in the prevalence of other types of lymphomas in those with Celiac Disease, such as B cell and non-intestinal lymphomas.<sup>12</sup>

## WHO GETS CELIAC DISEASE?

What can cause Celiac Disease to be “triggered” at a certain point in life? Think of it as a lock and key. Your lock is your genetic tendency to develop Celiac Disease. Something needs to unlock the gene and trigger the disease, such as: stress, surgery, overuse of antibiotics, an infection, overindulgence in gluten, or childbirth, for example. What is NOT known is *how many* triggers it takes to jump-start Celiac Disease.<sup>13</sup>

Slightly more women than men have the disease. In fact, it’s estimated that more than 1 million American women have Celiac Disease. Also, Celiac Disease symptoms and the onset of the illness are more severe and rapid with women.

Again, this disease is most commonly seen in people of European descent, although recent studies have shown that Celiac Disease may be more common in Africa, South America, and Asia, than previously believed. It is logical that Asian cultures that focus on rice as their grain mainstay are going to be less likely to have a high instance of Celiac Disease, however, as our societies become more global in nature, and those of Asian descent migrate to European countries and the Americas, this may not be the case. It is of the utmost importance that no group is isolated as being free of the occurrence of Celiac Disease.

Celiac Disease runs in the family. You may have inherited the tendency to get this disease from your parents. If one member of your family has Celiac Disease, about 1 out of 10 other first order members of your family are likely to have it also. However, those family members could be asymptomatic.

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<sup>12</sup> Dr. Karen Ekstrom Smedby of the Karolinska Institute, January 20, 2005, Sweden.

<sup>13</sup> *Delicious Living Magazine*, March 2003, USA.

# SYMPTOMS

Symptoms commonly appear during the first three years of life, after cereals are introduced into the diet. A second peak incidence occurs during the third decade. Some people develop symptoms as children, others as adults. One factor thought to play a role in when and how Celiac Disease appears is whether and how long a person was breastfed. The longer one was breastfed, the later symptoms of Celiac Disease appear and the more atypical the symptoms.

The symptoms of Celiac Disease can vary with each individual. They can range from no symptoms at all to one or more of the following:

- irritability
- depression
- muscle cramps,
- joint pain
- recurrent abdominal bloating and pain
- chronic diarrhea
- malodorous, oily, floating stools
- weight loss
- fatigue
- anemia
- delayed growth
- painful skin rash
- pale sores inside the mouth
- tingling numbness in the legs
- seizures
- bone pain
- mental fog
- dental problems and discoloration of the teeth
- menstrual irregularities\*

\*1 in 16 infertility patients has Celiac Disease, and all people with unknown infertility problems should be tested for it. Women with a history of miscarriages, stillbirths, fetal growth retardation, and premature menopause need to be screened as well. In recent years, it has become more evident that Celiac Disease in the pregnant mother could have an adverse effect on the fetus.

Offspring to mothers with Celiac Disease are more often pre-term and low birth weight than offspring to mothers without Celiac Disease. This may be due to the mother's inability to absorb all the nutrients she eats.<sup>14</sup>

Another common occurrence is the patient's diminished ability to absorb foods with a high fat content.

Adults who begin to be ill with Celiac Disease might have a general feeling of poor health. Some people with the disease may not have symptoms at all. The *undamaged portion* of their small intestine is able to absorb enough nutrients to prevent symptoms. However, people without symptoms are still at risk for the complications of Celiac Disease.

In adults, the symptoms of Celiac Disease may be mistaken for Irritable Bowel Syndrome (IBS) or inflammatory bowel syndrome, such as Crohn's Disease.

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<sup>14</sup> *Delicious Living Magazine*, March 2003, USA.

# CELIAC DISEASE IN CHILDREN

In children, as in adults, the disease can cause different problems at different times:

- An infant with celiac disease may have abdominal pain and diarrhea (even bloody diarrhea), and may fail to grow and gain weight after the introduction of cereals to the diet. (Failure to thrive.)
- A young child may have abdominal pain with nausea and lack of appetite, anemia (not enough iron in the blood), mouth sores and allergic dermatitis (skin rash).
- A child could be irritable, fretful, emotionally withdrawn or excessively dependent.
- In later stages, a child may become malnourished, with or without vomiting and diarrhea. This would cause the child to have a large tummy, thin thigh muscles, and flat buttocks.
- Teenagers may hit puberty late and be short or unusually thin. Affected children may not reach their normal growth potential. Celiac Disease might even cause some hair loss.

Celiac Disease is split about 50/50 between being a disease of children and a disease of adults. In textbooks, it is likely to be described as a pediatric condition with the typical symptoms of diarrhea and big belly developing a few weeks after grains are introduced into a child's diet. If there is anything like a classic form of this condition, it is the one diagnosed in very young children.<sup>15</sup>

Teenagers, in particular, occasionally rebel against dietary restrictions and suffer relapses or complications as a result.

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<sup>15</sup> Dr. Alessio Fosano, MD.

# DIAGNOSIS

Diagnosing Celiac Disease can be difficult because some of its symptoms are similar to those of *other diseases* already mentioned here. But...

1) Eliminating gluten from the diet and observing the body's response is primary, particularly if you are symptomatic. But, be aware that gluten is a common ingredient in many foods including most grain, pasta, and cereal foods as well as many processed foods. Hidden sources of gluten include additives, preservatives, and stabilizers found in processed food, medicines, and mouthwash. The best confirmation is to observe if your symptoms go away when you follow a strict gluten-free diet.

Yet, the gluten-free diet can be complicated. It requires a completely new approach to eating that affects a person's entire life. People 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 midnight snack. Eating out can be a formidable challenge as the person with Celiac Disease learns to scrutinize the menu for foods with gluten and question the waiter or chef about possible hidden sources of gluten. (See *Reference Guide* at end of booklet.)

2) Have your doctor schedule an endoscopy. Be certain the physician performing the endoscopy is knowledgeable about Celiac Disease, and will be particularly aware of looking for damage to the small intestine while doing biopsies.

Also be aware that even though there may be no clear damage to the villi of the small intestine, that only 1 in 200 patients display intestinal damage severe enough to be seen on biopsy. So you may be gluten-sensitive and have issues with malabsorption, but not have severe damage to the small intestine....yet.<sup>16</sup>

In addition, to avoid false negative results, the first endoscopy must be done while the patient is on a normal, gluten-containing diet or very shortly after going on a gluten-free diet. Sometimes the endoscopy is repeated after the patient has been on a gluten-free diet, in order to ensure that the bowel has healed.

However, upper endoscopy carries a risk of false negative results. This is because Celiac Disease may or may not damage villi throughout the *entire* small intestine, and upper endoscopy only examines the *upper part* of the intestine. In a patient whose intestinal damage is located further down, the biopsy may come back negative. If the endoscopy is positive, the diagnosis is confirmed, but if it is negative, the diagnosis is not necessarily excluded.

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<sup>16</sup> EnteroLab, Dallas, Texas, USA.

3) Get gluten anti-body blood work completed. Testing is usually initiated with blood tests for antibodies against gliadin (the toxic sub fraction of wheat gluten) or for antibodies produced against an enzyme present in the intestine and elsewhere in the body. However, in the early stages of the reaction, OR when the immune response is directed at organs other than the small bowel, these *antibodies may be absent from the blood*, resulting in false negative or indeterminate results in many cases.<sup>17</sup> Like the endoscopy, these tests are not accurate in patients who have been on a gluten-free diet for some time; they must be performed while the person is on a normal diet or within a very short time after eliminating gluten.

The following are the blood tests that must be completed:

1. Endomysial antibody (EMA-IgA)
2. Tissue transglutaminase antibody (TTG-IgA/IgG)
3. Anti-gliadin antibody (AGA-IgG, AGA-IgA)
4. Total serum IgA

The exception is children under the age of 2 years in which tTG and EMA may not be present. 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) genes that are associated with celiac disease may be helpful. This genetic testing (HLA) does not diagnose celiac disease, but the *absence of certain genes* in this testing almost always rules it out.

(Most doctors will not consider positive blood tests as definitive proof of Celiac Disease, but will require biopsy confirmation. Because upper endoscopies are uncomfortable, expensive, and may produce false negative results, some doctors consider the blood work and a positive response to eliminating gluten from the diet to be sufficient for diagnosis.)

4) EnteroLab near Dallas, Texas, has developed a unique screening test for gluten sensitivity that can be analyzed from stool material rather than from blood tests. One of their particular areas of focus relates to intestinal conditions caused by immune reactivity to the protein gluten. The rationale of using stool matter rather than blood for testing for food sensitivity is that immunologic reactions to proteins in the diet that cause these reactions are centered within the intestinal tract and *not in the blood*.<sup>18</sup>

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<sup>17</sup> EnteroLab, Dallas, Texas, USA.

<sup>18</sup> EnteroLab, Dallas, Texas, USA

## TREATMENT

*"It is not bad news to be diagnosed with Celiac Disease. How many conditions are there where you can get a lot better with little or no medication?"*

Treatment is quite straight forward: eliminate all sources of gluten, eliminate dairy products initially, correct underlying nutritional deficiencies, treat any associated conditions, and determine and eliminate all food allergens.

Maintenance of a strict gluten-free diet is quite difficult in the United States, due to the random distribution of gluten and other activators of Celiac Disease in processed foods. (See *Reference Guide* at end of booklet.) The widespread use of wheat byproducts in prepared food, soups, and sauces can make dining out very problematic. The lifelong diet can be difficult and socially troublesome, especially in young adults, but it is crucial in order to avoid serious health consequences. Exposure to gluten eventually leads to subclinical disease, and *the importance of removing gluten entirely from one's diet is imperative.*

It is important for celiacs to understand that one does not "get over" Celiac Disease; it is present for life. Patients must be encouraged to read labels carefully in order to avoid hidden sources of gluten, such as is found in some brands of soy sauce, modified food starch, ice cream, soups, beer, some wines, vodka, whiskey, malt, etc. (see *Reference Guide*)

For a newly diagnosed Celiac, the following nutritional support regimen may be required:

1. A good quality digestive enzyme should be taken several times a day before meals. It may take some time for the digestive tract to return to normal and this is one supplement to make available to the digestive tract while this process takes place.
2. In addition to the digestive enzyme, a quality calcium citrate supplement may be required to restore bone density. (This product has been proven to be absorbed by the bone, especially when taken in conjunction with magnesium.)
3. Since anemia is one of the most common medical conditions that is found to develop as a result of malabsorption, taking a nutritional liver supplement is always prudent.

4. An acidophilus (probiotic) product is also useful. The acidophilus provides friendly bacteria for the small intestine plus supports digestion and regularity. Digestive enzymes, acidophilus, liver supplement, and a quality calcium citrate supplement can be found either at your local health foods market, or from an alternative health care practitioner. A Celiac must carefully read labels, as these supplements may contain hidden sources of gluten.

For most people, following the very strict diet will stop symptoms, heal existing intestinal damage, and prevent further injury. Improvements begin within days of starting the diet, and the small intestine is usually completely healed; meaning the villi are intact and working...within three to six months following the diet change. However, this process may take up to two years or longer for older adults who have gone for decades without diagnosis.

In addition, researchers also know that celiac patients are frequently prone to other gastrointestinal disorders long after maintaining a gluten-free lifestyle. Conditions such as lactose sensitivities and malabsorption, giardia, and intestinal bacterial overgrowth were seen in patients in an Italian study.<sup>19</sup>

A small percentage of people with Celiac Disease do not improve on the gluten-free diet. These people often have severely damaged intestines that cannot heal even after they eliminate gluten from their diet. Because their intestines are not absorbing enough nutrients, they may need to receive intravenous nutritional support. These patients also need to be evaluated for complications of the disease. In other patients, the intestinal damage of Celiac Disease may have been *aggravated* by other problems, such as intolerance to the dietary proteins found in eggs, milk, or even soy.

There *are* efforts under way to find a cure other than dietary restrictions. Celiac disorder is unique in that it is the only autoimmune disease for which all elements are known. The trigger, gluten, is well understood. And the genes involved, though there may be more, also are known, as is the part of the body that is attacked. This may be a real blessing to scientists, who hope to come up with a cure within the next ten years.<sup>20</sup>

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<sup>19</sup> Celiac.com research, July 12, 2003, USA.

<sup>20</sup> Dr. Alessio Fosano, MD.

## POINTS TO REMEMBER!

- People with Celiac Disease cannot tolerate gluten, a protein in wheat, rye, barley, and possibly oats.
- Celiac Disease damages the small intestine and interferes with nutrient absorption.
- Treatment is important because people with Celiac Disease could develop complications like cancer, osteoporosis, anemia, and seizures.
- A person with celiac disease may or may not have symptoms.
- Diagnosis may involve stool tests, blood tests, biopsy, and possibly abstaining from gluten to observe the results.
- Because Celiac Disease is hereditary, family members of a person with Celiac Disease may need to be tested.

Eliminating all gluten from the diet currently treats Celiac Disease. The gluten-free diet is a lifetime requirement.

## IN REVIEW:

# HOW YOU CAN DETERMINE WHETHER YOU HAVE CELIAC DISEASE

1. Ask your doctor if she/he is familiar with celiac disease. Ask them what process *they* use to determine whether or not a patient has celiac disease. Determine if they are current on the most recent studies and information about this illness. If your doctor doesn't respond in a knowledgeable manner, find another physician! If your insurance will cover a specialist (gastroenterologist), refer yourself or ask your primary care physician to make a referral to one for you.
2. If you are experiencing any gastro issues, ask your doctor to schedule both an endoscopy and a colonoscopy with biopsies, pending your insurance coverage. This testing can be very expensive, if you pay out of pocket. (These tests are standard protocol and routine for anyone over 45 years of age to rule out colon cancer, so you may decide to kill two birds with one stone!)
3. To rule out gluten sensitivity, ask your physician to review the most recent info from EnteroLabs, in Dallas, Texas. This lab's testing procedures are less expensive and much less invasive than bowel scopes, and possibly more accurate. This laboratory's approach is considered by many as the new "cutting edge" diagnostic standard in determining if one is gluten-sensitive.
4. You and your physician may opt to have the "celiac panel" blood work done. This, also, is not inexpensive, but is usually standard procedure to rule out celiac disease. Keep in mind that this lab work is not always reliable in definitely obtaining a diagnosis.
5. Banish gluten from your diet and observe the results. (*Note: Do not do this if you are in the process of scheduling antigen antibody blood work or the bowel scopes as this may interfere with the accuracy of your test results.*) Also, this may or may not be an effective measure to determine if you are a celiac. Results of removing gluten from your diet can vary with each individual, depending on how symptomatic you are and how far down into the small intestine that damage exists.
6. Do a little research within your family. Determine whether or not anyone on either your mother's or your father's side of the family has had a history of gastro issues. A few decades ago, a relative may have had an illness that was even referred to as "wasting disease."

## SUMMARY

Advances in the diagnosis and treatment of celiac disease have allowed many to re-establish their health and reclaim fulfilling, pain-free lives. Unfortunately, many more endure the symptoms of gluten sensitivity and Celiac Disease because current medical practice fails to identify many cases of this insidious disease.

I was retested in October 2004 with an endoscopy and the antigen blood work. The results were negative. If the scope was extended deep enough into the small intestine, then it is good news that the villi in my small intestine seemed healthy and had repaired themselves. This was in direct contrast to my endoscopy results from Spring of 2003.... improvement after nearly a year and a half of eating gluten-free...and after 53 years!

Researchers are now better understanding the link between Celiac Disease and the immune system. While dealing with the *overt* issues that are inherent with Celiac Disease is no longer a challenge for me, I believe that the *secondary autoimmune issues* that I have been plagued with over the years.... and that continue to this day... are more than likely attributable to the fact that I went for most of my life without being correctly diagnosed. I also believe that at least a portion of my illnesses that continue (i.e., neurological disease, generalized systemic illness and fibromyalgia, etc.) are directly or indirectly related to the disease. A much wider knowledge of the illnesses' manifestations is definitely called for.

So, again, it is my hope that *getting this information* to as many people as possible will help others to avoid what I was not able to avoid in my own personal experience. My hope, also, is that the new information in recent studies will change the perspective of the health care community and that physicians will begin to routinely test their patients for Celiac Disease.

*Update: 2009*

*This book was initially written in the Spring of 2005. Since that time, there have been tremendous strides taken in the United States toward information about celiac disease becoming more available to the general public. It is now much more common than it was at the first writing of this document for doctors to routinely test their patients for CD.*

# REFERENCE GUIDE

## Whole Foods To Avoid

If these products are marked "gluten-free" on the packaging, then they should be okay. Otherwise, you can skip these. The reasons to avoid these are stated in parenthesis after each, if the reason isn't obvious.

- bagels
- beer
- biscuits
- bread
- broth (check ingredients)
- cake
- cookies
- couscous (a cracked wheat)
- crackers
- croutons
- cupcakes
- doughnuts
- french toast
- graham crackers
- macaroni
- malted milk (malt is made from barley)
- matzo
- muesli
- muffins
- noodles
- oatmeal
- pancakes
- pasta
- pastry
- pie
- pretzels
- semolina
- soup (check ingredients)

## Taboo Ingredients To Avoid

The reasons to avoid these are stated in parenthesis after each, if the reason isn't obvious.

- barley
- bran (usually wheat; sometimes oats)
- bulgur (a form of wheat)
- cake meal
- couscous (a cracked wheat)
- durum flour
- flour (means "wheat flour" unless any other grain is specifically stated)
- gliadin (part of wheat)
- gluten (a part of wheat)
- graham flour
- kamut (a form of wheat)
- malt (made from barley)
- malt flavoring (made from barley)
- malted milk (malt)
- malt vinegar (made with malt)
- matzo meal
- oatmeal
- oat bran
- oats
- rolled oats
- rye
- semolina (made from wheat)
- seitan (made from wheat)
- spelt (an older form of wheat)
- triticale (a wheat-rye blend)
- wheat
- wheat berries
- wheat germ
- wheat starch and whole wheat

## Nebulous Ingredients to Question & Other Hidden Sources of Gluten

This is the most difficult and most important category of ingredients to study, because here you will find the ingredients that may - or may not -- contain gluten. When you understand where the risks lie with these items, you'll know what questions to ask of manufacturers when they show up on the ingredients list. And speaking directly -- and politely -- to the manufacturers is the best way to (1) get the most up-to-date information and (2) work toward change in the food industry. The more calls those 800-numbers get inquiring about the gluten-content of food, the more the manufacturers will become educated to a Celiac's needs and feel it is in their best interest to respond by cooperating with better, clearer labeling.

- binders (may be made from toxic grains)
- bleu cheese
- broth (original ingredients may have included toxic grains)
- brown rice syrup
- caramel color (source can be a toxic grain)
- catsup (what is it made from?)
- cereal (what grain?)
- cheese (annatto color; starting molds may be introduced on bread crumbs)
- coatings
- curry powder (may have flour as a hidden ingredient to improve flow)
- dextrans
- dispersing agents
- emulsifiers (may be wheat-derived)
- excipients (may be made from toxic grain; these can be added to prescription medications to achieve desired consistency)
- extracts
- farina (usually made from wheat)
- fillers (can be anything!)
- flavorings
- flours, breads, cereals, crackers, pasta, sauces, and condiments made with the above listed grains or their derivatives.
- food starch (what is the source of the starch?)
- gluten (corn gluten is not toxic)

- grain alcohol
- gum (may be oat gum)
- homeopathic remedies
- hydrolyzed plant protein (HPP) (which "plant" is used?)
- hydrolyzed vegetable protein (HVP) (if source not identified) (which "vegetable"? -- it can be wheat!)
- leavening (what sort of leavening, what is it made of?)
- malt or malt flavoring
- modified food starch (may be either corn or wheat in the US and elsewhere)
- mono & diglycerides (may use a wheat derived carrier)
- MSG (may be made from wheat outside U.S.)
- natural flavor (this can be anything; there is no disclosure requirement)
- oils
- preservatives
- rice syrup (may use barley enzymes)
- seasoning (may have flour as a pouring agent)
- shortening (vitamin E from wheat germ may be added)
- sour cream (may contain food starches)
- soy sauce (wheat and alcohol used in most brands)
- spices (may have flour to improve flow; watch out for chili powder)
- stabilizers (may be made from toxic grains)
- starch\*
- stock (original ingredients may have included toxic grains)
- textured vegetable protein (TVP) (same as HVP)
- tomato paste (hidden ingredients may include HVP)
- vegetable gum (may be made from forbidden grains)
- vegetable shortening (may be made from forbidden grains)
- vitamin E oil
- white pepper (flour to improve flow?)
- yeast (may be grown or dried on wheat flour)
- yeast extract (same problem as with yeast)

\* In the U.S. "starch" is safe as it should always be cornstarch; in other countries it may be wheat starch. "Food starch" and "modified food starch" may be either corn or wheat, in the U.S. and elsewhere.

## Ingredients

### **Alcohol**

Alcohol can be made from many substances; each has its own manufacturing method and list of ingredients. See "grain alcohol."

### **Annatto color**

A coloring agent derived from the seeds of the Achiote, also known as the Lipstick tree (*Bixa orellana*), it is often used in cheese but also in many other orange-colored foods. The seed itself is unlikely to contain any gluten, it is the processing of the seed into a colorant that causes concern as it appears to use alcohol in the process. There is also suspicion that caramel color may be included in the annatto colorant. Anecdotal evidence has some celiacs reacting to foods with annatto color in them but this may be a non-cec reaction to the annatto itself.

### **Distilled alcohol**

The distillation process puts a gas up into the air in an enclosed vat and lets the gas circulate through a series of tubes in which it cools and drips out into another vat. No solid -- and the gluten in the grain used to make some alcohol is definitely a solid -- can be carried into the distillate. If the alcohol is genuinely distilled, it should be gluten-free.

### **Distilled vinegar**

Is safe

### **Flavorings**

Almond extract, vanilla extract, or the many other types of flavorings are usually in a base of alcohol. See "distilled alcohol" for a discussion of the risks you need to consider before using alcohol.

### **Grain alcohol**

Because it is derived from grain -- which could be wheat (or rye, or barley, or even oats), we need to consider whether some of the toxic peptide chains from the originating grain can end up as part of the alcohol. Since not all alcohol is distilled, it is certain that some grain alcohols will have harmful gluten in them.

### **Mono- and di-glycerides**

These are fats, used as stabilizers in foods. Although current FDA regulations require that mono-glycerides and di-glycerides in the U.S. be made from corn starch or potato starch -- gluten-free -- these ingredients only remain pure in their original "wet" form.

For many applications, mono- and di-glycerides may be dried, and anti-caking ingredients added to the mix, which could contain wheat (although it is clear that most mixes do not). The situation is even less clear when you find mono- and di-glycerides in drugs.

Here it is important to understand that in drugs mono- and di-glycerides are allowed to be made from toxic grains, however, one researcher found that in the U.S. all manufacturers used cornstarch. This means that it is possible that in the future a drug containing these ingredients could contain wheat, but at this time they should not.

### **Vanilla extract**

The problem many celiacs have with vanilla extract is that it usually contains, in large part, alcohol. Usually this is distilled alcohol (see above) since it does not have much flavor, and the extract makers want the flavor you taste to be the vanilla, but it could conceivably be another form of alcohol.

### **Vinegar**

Vinegar, when listed on an ingredient list all by itself (as in: Ingredients: Water, Corn Syrup, Vinegar, Tomatoes...) is apple cider vinegar, and is gluten-free.

### **Wheat starch**

Some countries use wheat starch that has had its gluten content reduced in foods labeled as "gluten-free." Although in laboratories it is possible to remove gluten, most plants are not as thorough as lab scientists are, and some gluten gets through, so it is thought that even gluten-reduced wheat starch is not safe. Certainly wheat starch in the United States and Canada is not safe as it is not gluten-reduced.

## Gluten Free Flours

Gluten-free flours are generally used in combination with one another. There is not one stand alone gluten-free flour that you can use successfully in baked goods. Be sure to know the procedures your flour manufacturers use, cross contamination at the factory can cause diet compliance issues for the gluten intolerant.

### **Arrowroot Flour**

Can be used cup for cup in place of cornstarch if you are allergic to corn.

### **Bean Flour**

Is a light flour made from garbanzo and broad beans. To cut the bitter taste of beans, replace white sugar with brown or maple sugar in the recipe (or replace some of the bean flour with sorghum).

## **Brown Rice Flour**

Is milled from unpolished brown rice and has a higher nutrient value than white rice flour. Since this flour contains bran it has a shorter shelf life and should be refrigerated. As with white rice flour, it is best to combine brown rice flour with several other flours to avoid the grainy texture. Ener-G Foods and Bobs Red Mill produce a finer, lighter brown rice flour that works well with dense cakes such as pound cake.

## **Cornstarch**

Is similar in usage to sweet rice flour for thickening sauces. Best when used in combination with other flours.

## **Guar Gum**

A binding agent, can be used in place of xanthan gum for corn sensitive individuals. Use half as much guar gum to replace xanthan gum. Guar gum contains fiber and can irritate very sensitive intestines.

## **Nut Flours**

Are high in protein and, used in small portions, enhances the taste of homemade pasta, puddings, pizza crust, bread, and cookies. Finely ground nut meal added to a recipe also increases the protein content and allows for a better rise. Ground almond meal can replace dry milk powder in most recipes as a dairy-free alternative.

## **Oats (Caution!)**

Appear on the "taboo" list of most celiac society lists; I myself do not eat them. Oats do not have the offending peptide chain in them that wheat, rye and barley do, that triggers the autoimmune response in celiacs. However, in the U.S. oats seem always to be grown in rotation with wheat, and so it is believed that it is impossible to get an uncontaminated supply of oats (you would have what they call "volunteer" wheat sprouting in the same field as the oats). Very controlled research in other countries indicates that oats in and of themselves are probably safe. And there are now uncontaminated oats available in this country.

Some celiacs react to the protein in oats even when it is from a pure source. Most doctors now say that a celiac should be well healed and settled on the GF diet, displaying no symptoms and no antibodies in their blood work before they try uncontaminated oats. They then should be followed closely by their doctors for any sign

of antibody reaction and/or symptoms...which may take some time to appear.

### **Potato Flour**

Has a strong potato taste and is rarely used in gluten-free cooking.

### **Potato Starch Flour**

Is used in combination with other flours, rarely used by itself.

### **Sorghum Flour**

A relatively new flour that cuts the bitterness of bean flour and is excellent in bean flour mixes.

### **Soy Flour**

Is high in protein and fat with a nutty flavor. Best when used in small quantities in combination with other flours. Soy flour has a short shelf life.

### **Sweet Rice Flour**

Is made from glutinous rice (it does not contain the gluten fraction that is prohibited to the gluten intolerant). Often used as a thickening agent. Sweet rice flour is becoming more common in gluten-free baking for tender pies and cakes. It has the ability to smooth the gritty taste (that is common in gluten-free baked goods) when combined with other flours.

### **Tapioca Starch Flour**

Is a light, velvety flour from the cassava root. It lightens gluten-free baked goods and gives them a texture more like that of wheat flour baked goods. It is especially good in pizza crusts where it is used in equal parts with either white rice flour or brown rice flour.

### **White Rice Flour**

Is milled from polished white rice, best to combine with several other flours to avoid the grainy texture rice flour alone imparts. *Try to buy the finest texture of white rice flour possible.*

### **Xanthan Gum**

Is our substitute for gluten; it holds things together. See usage information on Multi Blend recipe page. Xanthan gum is derived

from bacteria in corn sugar, the corn sensitive person should use guar gum (using half as much guar gum to replace xanthan gum).

## Alternative Flours

The national patient support groups agree that the following flours are fine for the gluten intolerant providing you can find a pure source (grown in dedicated fields and processed on dedicated equipment). These flours greatly improve the taste of gluten-free baked goods. To incorporate into your favorite recipe, replace up to 50% of the flour in a recipe with an alternative flour. Pizza crust and bread proportions don't follow this rule.

### **Amaranth**

Is a whole grain that dates back to the time of the Aztecs- it is high in protein and contains more calcium, fiber, magnesium, Vitamin A and Vitamin C than most grains. Amaranth has a flavor similar to graham crackers without the sweetness

Amaranth is the tiny seed of an herb, and is not a member of the cereal family at all. It may well be that some celiacs have reacted to this grain -- but if so, it was unlikely to be a celiac reaction. The likelihood of this seed, unrelated to the grasses, having a peptide chain similar to those in wheat, rye and barley is astronomically against. Amaranth provides good nutritional value, and was prized by the Aztecs.

### **Buckwheat**

Probably has gotten a bum rap for a variety of reasons. Buckwheat pancake mix is widely available, but is mixed with wheat flour, which would certainly give celiacs a bad reaction. There is always the possibility of cross-contamination either in bulk-food bins or even in the field. But the grain itself is not related to wheat, rye, barley or oats. Buckwheat is the seed of a plant related to rhubarb; it is high in fiber, protein, magnesium and B vitamins. Dark buckwheat flour turns baked goods purple, so you may only want to use light buckwheat flour.

### **Millet**

A small, round grain that is a major food source in Asia, North Africa and India. Is another grain that is unrelated to wheat. Cross-contamination may have given it a bum rap, in that it is frequently milled to flour on the same equipment that mills wheat flour. However, whole millet should be quite safe, and you can always mill it into flour yourself.

## **Teff**

An ancient grain from Ethiopia, now grown in Idaho. Teff is always a whole grain flour since it is difficult to sift or separate. High in protein, B vitamins, calcium, and iron. Often used to make the Ethiopian bread, "injera" teff is a grain with African origins. It is unrelated to wheat, rye, barley or oats, and provided that it does not suffer from cross-contamination problems, should be safe for celiacs.

*\*Substitutions for gluten-containing flours in recipes are typically tapioca flour, arrowroot powder, garbanzo bean flour, sorghum flour, rice flour, and potato flour. Mixes can also be purchased online or at health food stores.*

## **Quinoa**

A staple food of the Incas. Quinoa is a complete protein with all 8 amino acids; quinoa contains a fair amount of calcium and iron. A member of the goosefoot family, quinoa (pronounced "KEEN-wah") is a closer cousin to beets, chard and spinach than to wheat, rye, barley or oats. Prized by the Incas, this "mother grain" packs terrific nutritional value.

## **Sorghum**

More closely related to corn and millet than to wheat, this grain even looks like corn as it grows in the field. Used primarily in making molasses, it is becoming a popular gluten-free grain to cook with, particularly under the name of "Jowar Flour" -- it is also known as "milo."

But I Heard That It's Not Safe To Eat...

### **Distilled vinegar**

In the United States, almost all distilled vinegar comes from corn, not wheat. In the rare instances where wheat is the original source of the distilled alcohol that gets fermented into vinegar, the distillation process will remove all appreciable amounts of gluten (gliaden, peptide chains). A "mother" is added to the distilled alcohol to begin the process of fermentation, but research and interviews with industry experts (including the provider of vinegar to Heinz) indicate that gluten-containing ingredients are not used in this "mother" -- so distilled vinegar is safe.

### **Rice**

The usual concern about rice is that it has been enriched. According to research done by Ann Whelan, after talking to a staff

dietitian at the U.S. Rice Council and published in her Gluten Free Living newsletter, some commercial rice is coated with an enrichment mixture that consists of a carrier and synthesized vitamins and minerals. These are applied to the surface of some white rice grains. Another interview with a manufacturer of the enrichment mixture revealed that the carrier is usually cornstarch, sometimes rice starch, and rarely, calcium carbonate, while the vitamins and minerals added are gluten-free. The reason enriched rice packages discourage you from rinsing your rice, and have you cook it in the minimal amount of water necessary is so that you won't rinse off this surface layer of added vitamins and minerals.

### **Vinegar**

If food manufactured in the United States has vinegar listed as an ingredient, where just the word "vinegar" appears between commas (for example, "Ingredients: water, vinegar, tomato paste)" the FDA's Compliance Policy Guide for Vinegar requires that the vinegar must be apple cider vinegar. So if you see just "vinegar" listed as an ingredient (not "malt vinegar" or any other modification), the vinegar is apple cider vinegar.

## *Starter Guide to Eating Gluten Free*

The simplest way to eat gluten-free is by centering meals around a simple protein, a simple vegetable, and a carbohydrate (if you desire) such as a gluten free pasta, a potato, rice, or corn. Keep the meals simple until you have determined that you are a Celiac or are wheat-sensitive. Then I would recommend certain staples that you should have on hand on a regular basis and expand your skill over time as you acquire knowledge about how to cook gluten-free.

### **Protein suggestions**

I have found that a great deal of the meats in the groceries these days have solution added to them before market. Walmart meats are almost entirely pumped up in this manner. Watch the small print on the label: "enhanced with up to 13% solution", etc. Many grocery store pork products (Moist 'n Tender brand) contains added solutions as well. What I am noticing is that when I consume these meats, I will frequently become ill afterward.

Until it is determined what makes up these solutions, I would steer clear. It is also a known fact that many turkey and turkey breast products have gluten in broth that is injected into them. Watch for the words "gluten free" on the label to be on the safe side. But read your labels carefully and check with the manufacturers when in doubt! In recent years, many products have become gluten free that were not previously listed as GF.

I usually have these **flours** on hand: soy, tapioca, potato (starch), cornstarch, sorghum, brown rice flour, sweet rice flour, white rice flour, garbanzo bean flour and some corn meal. I don't particularly care for the flavor of garbanzo bean flour and the bean flours that are often recommended for Celiacs. Remember that soy flour can only be used in much smaller ratio when attempting to make breads and baked goods with these flours. It also burns easily. Just one of the flours by itself is not recommended.

Sorghum flour is excellent in cookies as part of a flour blend. You can find or order these flours at your local health food market or online. I also have gluten free corn flakes on hand. (made without malt as malt has gluten) They can be used as a substitution for breadcrumbs in meat loafs, meats balls, or on top of casseroles. They are also wonderful as a breading for baked chicken.

Celiacs, or those who attempt to eat wheat or gluten free, may be disappointed with much of the bread that is available in the market place. I have found that the recipe for making the muffin-like bread that I am including here is probably one of the best-tasting breads available for a Celiac. If you don't bake, ask your mother or a partner or a friend to help you out with this recipe. It is really quite good as long as you don't over bake it. Over baked, it is like eating cardboard!

# A Week of Eating Gluten Free

(Recipes are shown below with asterisks.)

## **Day #1**

### Breakfast

Eggs (use whole eggs, no egg substitutes!)

GF muffin\*

Turkey sausage\*

Juice made from concentrate and fresh juice, or V-8; no juice with additives or fillers

Juice, coffee or tea

### Lunch

Beef tacos with ground cumin, jalapenos, and cilantro, with cheddar cheese and corn tortillas. (Use no bottled Mexican seasoning mixes, unless you have checked ALL the ingredients to be gluten free! And maltodextrin is a no-no, unless it specifies that it is made with corn malt!)

Lettuce/tomato salad

### Dinner

Balsamic chicken breast\*

Green Beans with Mustard Sauce and Toasted Almonds\*

Steamed rice

Lemon Squares\*

## **Day #2**

### Breakfast

High Protein Sunday Pancakes\*

Bacon or GF sausage

Juice, coffee or tea

### Lunch

Chicken breast and romaine salad with olive oil and balsamic vinegar (use leftover chicken breast from night before)

### *Dinner*

Chicken Parmesan\*

Green salad with diced garlic (garlic powder) olive oil and red wine vinegar

## **Day #3**

### Breakfast

Ham and egg casserole\*

Homemade hash brown potatoes

Juice, coffee or tea

### Lunch

Warm apple and goat cheese salad\*

Dinner

Lemon Pork Chops\*  
GF Vegetable/s of your choice  
Parmesan cheese potato slices\*

**Day #4**

Breakfast

Omelet with feta cheese and scallion, or your choice of GF fillings  
GF muffin\*  
Juice, coffee or tea

Lunch

Simple Taco Salad\*

Dinner

Marinated Pot Roast\*  
Steamed baby carrots  
\*Optional: baked potato with real butter or GF sour cream  
Chocolate chip cookie\*

**Day #5**

Breakfast

Eggs scrambled with cream cheese and smoked salmon  
GF Muffin\* toast  
Juice, coffee or tea

Lunch

Sliced roast beef sandwich with roast from last night's pot roast.  
GF muffin/bun\*  
Potato chips

Dinner

Spaghetti and meat sauce (prefer Newman's Own bottled sauce w/ either ground turkey or lean ground beef.)  
Green salad with olive oil and balsamic vinegar dressing  
GF muffin\* garlic toast  
Vanilla ice cream (Breyers or GF quality brand)

**Day #6**

Breakfast

Vegetable Frittata\*  
Juice, coffee or tea

Lunch

Simple Taco Salad\*

### Dinner

Baked Cornflake Chicken\*  
Steamed vegetables  
Chocolate ice cream (Breyers or good quality brand)

## **Day #7**

### Breakfast

Eggs  
Turkey sausage\*  
Juice, coffee, or tea

### Lunch

Chicken leftovers from dinner the night before  
Green salad

### Dinner

Picante Beef Casserole\*  
Green salad with olive oil and balsamic vinegar  
Peanut butter balls\*

**Notes:** *Some sour creams may contain gluten; always use real butter as margarines and imitation butters often contain gluten.*

## **Eating Out**

Personally, I would avoid restaurants for a time, until it is determined whether or not you are a Celiac. But if you do decide to venture into what can often be the treacherous waters of restaurant dining, the best practice is always to call ahead and inform the establishment that you are eating gluten free and then asking what they would recommend.

If this still leaves you feeling queasy, I would just order a simple meal when dining out: *plain* chicken breast or *plain* salmon or steak and a green salad or baked potato with *plain* butter. Emphasis on plain! Often meat is seasoned with spice mixtures that contain gluten, so be aware! I tend to avoid most restaurant *chains*, since the majority of their foods are processed and come with added seasonings, fillers, etc., especially prepared and packaged for that particular chain.

I recall going to an Applebee's a few years ago, when the restaurant manager came out to inform me that he knew for a fact (he was familiar with Celiac disease, which was VERY unusual at that time) that there was nothing they had in their kitchen that I could safely eat, except for a steak, a plain green salad, and baked potato with nothing on it. Their butter was not pure butter, and they had no olive oil or balsamic or cider vinegar on the premises, so that I could dress my own salad!

I have had some success going online and checking restaurant and fast-food

chains nutritional info for gluten-free foods. More and more restaurants are seeing the need to specifically list their gluten-free items. Outback Steakhouse. offers an optional gluten-free menu. In 'n Out Burger offers a burger "protein style" that is the burger wrapped in iceberg lettuce. In 'n Out Burgers states that their burgers are not grilled on the same surface that their buns are toasted on, so there may not be cross-contamination. I would double check with your local management.

If you take a little time to go online and explore all the nutritional information on the menus of your favorite eating establishments, you will find MANY choices in gluten free dining. This is totally in contrast to what a celiac would experience as little as three to five years ago, so things are improving!

I have also found it helpful to give my server at a restaurant a small brochure that I carry with me about Celiac disease. This helps establish the seriousness of the matter and gives the server information that he/she may or may not utilize to assist you in your dining experience. This is a time when assertiveness can really, really pay off and one cannot take chances with ingesting even the tiniest microbe of gluten! I have had some very good experiences with restaurant managers coming out to our table to inform me that what I have just ordered has flour in a certain sauce, and do I mind if they do not include that sauce in my particular meal?!?!

Over all, however, restaurant dining can be and frequently is, like walking through a land mine for a celiac. I have found that better quality dining establishments do tend to work with you more on catering to your needs and do offer foods with better quality ingredients that are more free of the additives, emulsifiers and extenders that American food is so infamous for.

# Recipes

## Breakfast Recipes

### High Protein Sunday Pancakes

1¼ c. ground nuts and seeds of choice (toasted before grinding; hazelnuts and sunflower seeds best)

1¾ c. flour (blend sorghum, soy, tapioca flour)

¾ c. white rice flour

1 t. xanthan gum

2 T. sugar

2 t. ground cinnamon

1 ½ t. baking powder

½ t. baking soda

½ t. salt

2 large eggs

3 c. buttermilk (or 1 ½ c. plain yogurt and 1 ½ c. plain soy milk)

3 T. melted butter

Salad oil for frying

Combine all ingredients except nuts. Do not over mix. Then stir in 1 c. of nuts, and reserve ¼ c. of nuts for sprinkling over top of finished pancakes.

### Breakfast Sausage

1½ # ground turkey or pork

1 finely chopped Macintosh apple

2 T. maple syrup

1 t. cinnamon

½ t. nutmeg

¼ c. chopped onion or scallion

1 T. chicken seasoning or Cajun seasoning, or 1 t. each sage and thyme

Salt and pepper

Shape into palm-sized patties and fry until caramelized. Great with gluten free biscuits and eggs.

### Vegetable Frittata

2 T. butter

1 small onion, sliced

½ c. fresh mushrooms, sliced

4 asparagus spears, cut into ½ inch pieces

½ small zucchini, sliced

8 eggs, beaten

½ c. milk

½ t. salt

Pinch of pepper

1 t. thyme  
Dash hot sauce  
**Optional:** turkey sausage

Sauté onion in butter, then add mushrooms, asparagus, and zucchini and sauté 5 more minutes. Combine eggs, milk, and seasonings and pour over vegetables in 9-inch quiche dish.

Bake at 350 degrees for 25-30 minutes. Four servings.

### **Ham and Egg Casserole**

3 c. bread cubes (GF bread recipe)\*  
2 c. sharp cheddar cheese, shredded  
¼ c. green onion, finely chopped  
½ c. canned sliced mushrooms  
1 c. ham, cut into ½ inch cubes  
4 eggs  
½ c. milk  
1 t. dry mustard  
1/8 t. pepper  
Dash hot sauce

In 2-quart oblong glass baking dish, place bread. Sprinkle with cheese, green onion and mushrooms. Top with ham cubes. Beat together eggs, milk, dry mustard, pepper and hot sauce. Pour over ham. Cover with wax paper. Microwave at Medium/High (7) 12 to 15 minutes until knife inserted in center comes out clean. Let stand 5 minutes. Four to six servings.

## **Main Dishes**

### **Balsamic Chicken Breasts**

3 boneless, skinless chicken breast halves  
½ t. dried rosemary leaves  
1 clove garlic, minced  
Salt /pepper  
2 T. virgin olive oil  
¼ c. balsamic vinegar

Combine the rosemary, garlic, salt and pepper in a small bowl and toss with the chicken pieces and olive oil. Cover and refrigerate over night. When ready to cook, place chicken in covered pan on stove top for about 10 minutes on medium, adding a small amount of oil if it sticks to pan and turning once, till juices run clear. Drizzle the vinegar over the chicken in pan, lower heat, and simmer another 10 minutes, until the vinegar becomes thick and caramelized. Drizzle thickened vinegar over chicken and serve. Three servings.

## **Chicken Parmesan**

½ c. crushed cornflake crumbs, seasoned with Italian herbs  
¼ c. grated Parmesan cheese (use the fresh stuff from the deli case)

¼ t. paprika

1 egg, beaten

¼ c. water

4 boneless, skinless, chicken breasts, pounded thin

1 c. or more spaghetti sauce

1 c. mozzarella cheese

Preheat oven to 400 degrees. In small mixing bowl, combine cornflake crumbs, Parmesan cheese and paprika. Set aside. In shallow dish, blend egg and water together. Dip chicken in egg mixture and then in crumb mixture. In 2-quart oblong baking dish, arrange chicken. Pour spaghetti sauce over top; cover. Bake 30-35 minutes until chicken is done. Sprinkle with cheese and continue baking 5 minutes until cheese is melted. Four servings.

## **Marinated Pot Roast (Microwave)**

2½ to 3 pound boneless chuck roast

1 c. Italian salad dressing (or homemade olive oil and GF vinegar + Italian herbs)

Salt /pepper

¼ t. garlic powder

Water

½ pkg. fresh baby cut carrots

1 c. sliced fresh mushrooms

Pierce roast on both sides with fork. Place in zip lock plastic bag. Combine dressing, salt and pepper and pour over roast. Seal bag and refrigerate 6-8 hours, or overnight, turning occasionally.

Drain meat, reserving 1/3 c. marinade; add enough water to reserved marinade to make a 1 cup. Place meat and marinade mixture in 2-quart oblong glass baking dish; cover. Microwave on high (10) ten minutes. Microwave at low (3) 60 minutes; turn roast over after 25 minutes. Add carrots and mushrooms. Cover and microwave at medium (5) 12 to 15 minutes until vegetables are tender.

## **Low-fat Crispy Baked Chicken**

½ c. gluten free flour mixture (soy, rice, sorghum, tapioca, potato starch; combination of any three)

½ t. salt

¼ t. black pepper

1 t. thyme

2 eggs

¼ c. milk

2-3 c. crushed GF cornflakes

1 T. melted butter, to drizzle over top of finished chicken

4 chicken pieces

Preheat oven to 375 degrees.

Mix the flour, salt, pepper, and thyme in a bowl. Mix the eggs and milk in another bowl. Place the cornflakes in a third bowl.

Skin the chicken. Dip the pieces into the flour, then the egg mixture, then and the cornflakes. Place them on a baking sheet.

Place the chicken in the oven, and bake for 35-40 minutes, or until the internal temperature reaches 140 degrees. Drizzle with melted butter. Four servings.

### Picante Beef Casserole

1# ground beef  
1 c. onion, chopped  
1 (11 oz.) can or frozen corn, drained  
1 (8 oz.) can tomato sauce  
2/3 c. picante sauce or salsa  
1 (4 oz.) can chopped green chilies, drained  
½ t. garlic salt  
½ t. chili powder  
¼ t. oregano  
8 (6 inch) corn tortillas  
1 c. shredded cheese, divided

In 2-quart casserole, combine ground beef and onion, cover. Microwave at High (10) 5-7 minutes until meat is browned, stirring after 3 minutes. Drain well. Add corn, tomato sauce, picante sauce, green chilies, garlic salt, chili powder, and oregano; stir to combine.

Place 4 tortillas on bottom of an 11x7x2 inch glass baking dish. Spread half of meat mixture over tortillas. Sprinkle half of cheese over meat mixture. Repeat layers. Microwave at High (10) 11-14 minutes until heated through, or cook in a conventional oven at 375 degrees about 25 minutes till heated through. Six servings.

### Lemon Pork Chops

4 rib pork chops, ¾ inch thick  
½ t. salt  
¼ t. pepper  
¼ t. thyme  
1/c chili sauce or salsa  
1 T. brown sugar  
4 onion slices  
4 lemon slices

Sprinkle chops with salt, pepper, and thyme. Arrange chops in 2-quart casserole. Combine chili sauce and brown sugar; pour over chops. Place onion and lemon slice on each chop. Cover. Preheat oven to 350 degrees. Cook 40-45 minutes till tender. Four servings.

## Salads, Vegetables, and Side Dishes

### Warm Apple & Goat Cheese Salad

2 T. red wine vinegar  
½ t. Dijon mustard  
1 small clove garlic; minced  
½ t. salt  
½ t. pepper  
1/3 c. olive oil  
1T. chopped parsley leaves  
3 Belgian endives, cored and separated into leaves  
1 bunch spinach, washed  
1 Granny Smith apples, thinly sliced  
4 oz. mild goat cheese  
¼ c. chopped toasted walnuts

Using a glass jar with a tight lid, combine the first seven ingredients and shake well to blend.

On four plates, arrange the endive leaves like spokes on a wheel. Arrange the spinach in the center.

Preheat the broiler, and arrange the sliced apples, slightly overlapping in four fan shapes and place in broiler pan. Cut the cheese into four slices and top each apple fan with the slices of cheese.

Broil cheese-topped apple fans until golden; about five minutes. Using a spatula, carefully place the apple slices and cheese on top of the endive/spinach. Drizzle the dressing over the salads and sprinkle with walnuts.

**Note:** Please check with cheese mfg. to determine if the blue cheese product that you are using is gluten free or not.

### Green Beans with Mustard Cream Sauce and Toasted Almonds

2 t. butter  
1/2 of (16 oz) pkg. frozen pearl onions or small whole onions  
1 pound snapped green beans, cut into 2 inch pieces  
Salt  
¾ c. milk (or plain soy milk)  
¼ c. chicken broth  
2 T. Dijon mustard  
1½ T. flour  
Freshly ground pepper  
¼ c. slivered, toasted almonds

Heat 1T. butter in a large, deep skillet over medium-high heat. Add onions; sauté, shaking pan occasionally, until golden brown, 5-7 minutes. Dump onions onto a large cookie sheet.

Add green beans, water, and salt to the unwashed skillet. Turn heat to high, cover and cook until wisps of steam escape around the lid. Set timer for 5 minutes; cook until bright green but tender.

Drain beans; transfer to cookie sheet with onions and spread out to cool. Microwave milk, broth, and mustard in a 1 qt. Pyrex measuring cup until steamy. Heat remaining 1T. of butter in the skillet. Whisk in flour, then hot milk mixture, until smooth and simmering. Add beans and onion. Simmer till sauce is thick enough to cling, about 5 minutes. Season with salt and pepper to taste. Transfer to serving bowl and sprinkle with toasted almonds. Serve immediately.

### **Simple Taco Salad**

1 ½ # ground chuck

½ c. onion

1 c. green pepper, chopped

1 (16 oz) can black beans, drained

1 can gluten free salsa; (no modified food starch) Herdez brand is GF, good, and authentic.

1 (10 oz.) package corn chips

1 c. cheddar cheese, shredded and divided

4 c. lettuce, shredded

2 c. tomatoes, chopped

Optional: sour cream and guacamole for topping

Sauté beef, onion, green pepper till cooked. Drain well. Add drained black beans. Set aside mixture.

In large salad bowl, layer corn chips, meat/vegetable mixture, half of cheese, lettuce and tomatoes. Top with salsa and sprinkle with remaining cheese and optional toppings, if desired. Serve immediately. Six-eight servings.

### **Parmesan Cheese Potato Slices**

2 large baking potatoes, sliced ¼ inch thick

2 T. butter, melted

1/3 c. grated Parmesan cheese (the real stuff, ok?)

Preheat oven to 400 degrees. Place sliced potatoes on 12 inch pizza pan, brush with butter. Sprinkle Parmesan cheese over potatoes. Bake 25.30 minutes. Six servings.

### **Notes:**

## Breads

Folks, this is an important recipe! If you don't make bread, get someone to do it for you!

### Basic French Bread (can be used for buns)

#### *Column #1*

2 c. rice flour  
1 c. potato starch  
1 c. tapioca flour  
¼ c. brown sugar  
3½ t. xanthan gum  
1½ T. clear jell (Knox)  
2/3 c. dry milk powder  
1 ½ t. salt  
1½ t. baking soda\*  
1½ t. lecithin\*  
\*Optional extra leavening

#### *Column #2*

1¼ c. warm water  
½ stick butter  
1 t. GF vinegar (cider vinegar is fine)  
3 large eggs at room temperature  
½ c. warm water (110 degrees)  
1 t. sugar  
4 ½ t. dry GF yeast

1. In a large mixing bowl, blend the dry ingredients in the first column. Use your electric mixer.
2. Combine warm water, butter, and vinegar. (Top three items in Column #2) Warm in microwave till butter melts. Place this bowl next to mixer.
3. Break open room temperature eggs in small bowl and blend by hand with fork. Place next to last bowl.
4. In 2 c. measuring cup, combine warm water, sugar, and yeast. (Last three items in Column #2) Let stand to proof while moving on to next step. Place next to eggs.
5. Into the dry ingredients add the butter mixture, blend on low mixer speed, add eggs, and blend again. Then beat on high for three minutes. You can go right down the row of bowls when adding.
6. Cover mixer bowl and let rise until near double.
7. Preheat oven to 350 degrees (or 375 degrees at higher elevations.) Use middle oven rack.
8. Prepare pans with GF spray or oil. Beat dough again for three minutes.
9. Fill pans about 1/3 full. Keep a cup of water with a metal spoon in it next to pans. After you have put the dough in the pans, take the wet spoon and smooth the top of the dough. Dip in water again after each pass, so it won't stick. Continue until dough is smooth. Don't worry about how wet it gets; it will help the bread brown. Try topping dough with poppy or sesame seeds.

10. Let rise about five minutes, covered, and out of drafts.  
11. Bake for 25 minutes for buns and rolls, 35 minutes for loaf pans. For bread loaves, make a slit the length of the dough with a sharp paring knife. For buns, or sandwich rolls take this same dough and drop by giant spoonfuls (bun size) onto oiled baking sheet. Smooth tops of dough with spoon and water as above. Bake as per instructions above. Let cool, then freeze on trays if desired. After frozen, put in zip lock bags or vacuum seal bags for freezer storage.

## Desserts

### Chocolate Chip Cookies

1  $\frac{3}{4}$  c. sorghum flour  
1/4 c. garbanzo flour (or soy flour. much easier to find)  
1/4 c. rice flour  
2 t. xanthan gum (Can be found at health food stores. Expensive, but you will use in most of your baked goods, unless you are using pre-mixed gluten free flour blends in your cooking.)  
2 t. baking soda  
1/2 t. salt  
1 c. chopped nuts (optional)  
1 c. shortening (or 1/4 c. shortening + 3/4 c. peanut butter for peanut butter cookies)  
3/4 c. granulated sugar  
3/4 c. gluten free brown sugar, firmly packed  
1 t. gluten vanilla (yes, regular vanilla contains gluten!)  
2 eggs at room temperature  
2 c. semi sweet chocolate chips (avoid the ones with chocolate liquor)

Preheat oven to 375 degrees. Cream shortening and sugars.

Add egg and vanilla. Combine thoroughly the sifted flours, baking soda, and salt. Stir into the sugar/egg mixture until combined. Stir in the chopped nuts and chocolate chips.

Line the cookie sheet with parchment paper. Drop in walnut-sized dough mounds. Bake 10-12 minutes. Makes about 72 cookies.

## Lemon Squares

1 c. GF flour mixture  
½ t. xanthan gum  
¼ c. brown sugar  
Dash salt  
1/3 c. butter  
2 eggs, beaten  
1 c. sugar  
3 T. GF flour  
½ t. baking powder  
2 T. lemon juice (not lemon flavoring!)  
1 T. grated lemon rind

Preheat oven to 350 degrees.

In small mixing bowl, combine 1 c. flour, ¼ c. sugar, and salt. Cut in butter until mixture is the size of peas. Grease bottom of 8 inch square baking dish. Press mixture evenly into baking dish. Bake 20 minutes or until set.

In medium mixing bowl, blend eggs, 1 c. sugar, 3 T. flour, baking powder and lemon rind. Pour mixture over crust. Return to oven. Bake about 30 minutes more until filling is set. Makes 24 bars.

1 c. peanut butter  
¾ c. honey  
2 c. powdered milk  
1 ½ c. crushed cornflakes (GF without malt, found at your local health food market or online)  
1 c. powdered sugar  
Optional: mini chocolate chips

Mix peanut butter, honey, and milk together in a large bowl to form very thick mixture. Roll mixture in small balls about the size of a walnut. Roll the balls in either the crushed cornflakes, finely chopped nuts, or powdered sugar. Place on waxed paper and refrigerate for twenty minutes.

**Notes:**



## What on Earth is a Celiac?

"Here's a disease for which there are good tools for diagnosis, an effective remedy and the potential of relieving a large population of people from a lot of misery and discomfort, and yet the disease is being grossly undiagnosed."

~ *The Wall Street Journal*, 6-19-03

"It is now clear that the textbook description of this once-obscure ailment is woefully incomplete and describes only a minority of cases. Below the tip of the so-called Celiac iceberg is a diverse world of illness that may include thousands of people suffering from various, seemingly unrelated conditions, such as anemia, osteoporosis, infertility, irritable bowel syndrome (IBS) and chronic fatigue."

~ *The Washington Post*, 2-11-03

My hope in offering this booklet is that this information will contribute to an overall heightened awareness in the general public about this disease. If you find that your symptoms are not Celiac Disease, then please pass this information on to your loved ones or someone else you know that may fit the Celiac Disease profile!

~ *Diane Jacobs, author*

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Prescott, Arizona

[Http://www.celiacdiseaseinfo.org](http://www.celiacdiseaseinfo.org)

