

Primer on Gluten Grain Sensitivities



Wheat Allergy₁

Gluten Grain Intolerances₁₀₋₁₃

Celiac Disease_{2,3}

This primer reports information from most major medical viewpoints of understanding

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What is “gluten”?³²

Gluten is a large protein molecule found in grains and is the stretchy part of bread dough. Certain versions of even smaller parts of gluten that are found in wheat, (gliadin) rye, (secalin) barley,(hordein) and perhaps oats*(avenin) can become toxic to some people.** In cases of “non celiac” gluten grain intolerances, some researchers think gluten itself (not just the smaller parts) or possibly something still unidentified in grains, does not process properly, or these parts cross react badly with other foods or substances in the body.²¹

What are the differences between the terms gluten grain sensitivity, wheat allergy, celiac disease/gluten intolerance, and “gluten grain” intolerance?

Gluten grain sensitivity is an umbrella term for unhealthy responses to wheat, rye, barley and *oats. Wheat allergy¹, gluten grain intolerances²⁴, and celiac disease² are gluten grain sensitivities but “gluten” *may* not be a culprit in wheat allergy or “gluten grain” intolerance.

Wheat allergy¹ is usually an immediate, histamine type of reaction to only the “wheat” grain, which can include swelling, rash, sneezing and respiratory symptoms, similar to an allergic reaction to a bee sting. It can be mild or severe and is well understood by allergists. Skin scratch tests for a type of (IgE) antibody identify this reaction. People with wheat allergy may need to reduce or completely avoid only wheat.

There are 2 categories of gluten grain intolerances, 1) celiac disease and 2) other gluten grain intolerances.²⁴ These conditions look similar, but test differently. Compared to wheat allergies, they are both different, often slower processes. The term “gluten intolerance” is loosely used for either type, but gluten or something else unidentified in grains may or may not cause “gluten grain” intolerance.

a. Celiac Disease appears to some researchers to be a subset of gluten grain intolerance and is the only category that has been studied. It is a genetic, autoimmune disease^{2,3} that was identified after World War 2 but for the next 50 years it was mistakenly thought rare in the USA. Studies now show that 1 in 133 Americans have this potentially serious disorder. Only half of these patients, 1 in 56, have recognizable symptoms. Few patients or doctors know about celiac disease, or if they know about it, they do not realize how common it is, or how many varied symptoms are associated with it.

b. Other unstudied gluten grain intolerances²⁵ look like celiac disease, and may respond just as well to the gluten free diet, but celiac blood and/or biopsy tests are negative. Most people who react to gluten grains, many more than 1 in 133, are in this “non-celiac gluten grain intolerant” category²⁵. Without research, these patients often study celiac disease *and other possibilities* for clues to their condition.

Note: Experts say celiac research is still in its infancy, and there are **no** validated studies on non-celiac gluten grain intolerances. This is because originally specialists thought celiac disease was the only type of gluten grain intolerance. Recently many doctors are changing their minds as growing numbers of negative testing but symptomatic patients with the same genes and suspicious medical history respond just as well to the gluten grain free diet.

It is crucial a. to know there are several medical viewpoints of understanding among celiac and gluten intolerance specialists and researchers, and b. to learn the differences in order to make informed decisions regarding testing and treatment. See page 23.

Is there a cure for celiac disease?

No, there is no cure that prevents the autoimmune celiac damage, but a strict gluten free diet stops gluten exposure and usually allows healing, often quickly if other side effects^{***} have not developed².

A “strict gluten free diet” means to **stop²** eating all products containing wheat, barley, rye, and oats^{*}. This includes breads, pasta, and foods that contain these grains even in very small amounts. At this time this restriction has no exceptions, regardless of how the gluten grains are farmed or prepared. Today’s agricultural and grain preparation methods *are* being questioned for clues regarding some types of gluten and grain intolerances, but more study is needed.)

***** Some but not all researchers say that oats do not contain a version of the smaller part of gluten that causes this reaction⁹. However, all oats in the United States may be mixed with unacceptable levels of wheat, barley and rye due to crop rotation, transportation, and processing. those following a strict gluten-free diet usually choose to avoid oats.

****** http://csaceliacs.org/celiac_treatment.php

******* Some celiac patients find they have already developed an irreversible condition called “refractory sprue”, usually cancer. In that case they use the diet to stop further gluten exposure, but their symptoms do not necessarily disappear.

When, Why and How Could Eating Regular Bread Hurt Me if I Have These Gene(s)?

In **Celiac Disease**^{2,3}, a life stressor (like an accident, illness, divorce, the flu, or even exposure to gluten⁴ etc.) can trigger certain genes along with other unknown environmental factors to mistakenly identify these particular gluten parts as invaders or enemies, as they would the flu or a cold. The body then tries to destroy them with antibodies and killer cells in an **autoimmune response**. These cells also attack your small intestine, and damage your villi, where the glutes are being digested. (Villi are tiny finger-like projections lining the intestinal wall that absorb nutrients). This mistaken attack causes lesions (damaged tissue) and inflammation in your small intestine, and may upset digestive balance so the body can no longer digest other foods properly such as milk. Sometimes the damage also manifests as an ongoing skin condition, (dermatitis herpetiformis), or as blisters in the mouth or mucous membranes. Current conventional research indicates that once this reaction is triggered, it is ^{2,3}lifelong. In cases of non celiac gluten intolerance some researchers suspect that other areas or functions of the body are damaged instead of the villi¹¹⁻¹⁴. They also suggest that some of the unstudied non celiac gluten grain reactions may be due to **missing enzymes or other reasons** rather than an autoimmune antibody reaction. But they seem to produce inflammation, damage, and many symptoms very similar to celiac disease.

When **digestion is damaged**, food is not broken down well, nutrients may be poorly absorbed, and intestinal inflammation can occur^{2,3}. **Nutrient deficiencies** may lead to anemia, growth failure, osteoporosis and **malnutrition**. **Inflammation** may damage body systems including the skin, thyroid, nervous, immune, reproductive, and skeletal systems, or muscles and organs (liver, pancreas, heart, gall bladder, spleen). See pg 31 and 32 for symptom lists from several viewpoints of medical understanding. Over 200 celiac associated and secondary conditions are known so lists vary and all lists are incomplete.

Gluten intolerance and celiac disease *may* cause chronic **“classic” digestive problems**^{2,3} including gall bladder trouble, weight loss or gain, irritable bowel symptoms, stomach pain, bloating, belching and gas, digestive pain, distended abdomen, chronic constipation and/or diarrhea, or intolerances to other foods the body is too damaged to handle. Only one third of celiac patients have classic digestive symptoms.

Interestingly, over half of celiacs do NOT have chronic digestive symptoms^{2,3}. Some are **“atypical” celiacs**. Their symptoms are “extra intestinal” or non digestive such as seizures. More puzzling is that nearly half of all celiacs have no warning signs for years. These **“silent celiacs”** are often discovered in family screenings. This is troubling as serious illness including Type 1 diabetes, thyroid problems, cancer and autoimmune diseases may develop from silent damage before they suspect a problem.

^{2,3}How does Celiac Disease Develop?

(How other subsets of Gluten Grain Intolerance develop, if those processes are different from Celiac Disease, are either not yet studied or not yet validated.)

99% of diagnosed celiacs inherit the associated genes DQ 2, and DQ 8. But most experts believe other factors are also involved because not everyone who carries these common genes can be diagnosed with celiac disease. Many non celiac gluten grain intolerants carry these genes. A few researchers now include DQ 1, 7 and 9 for gluten sensitivity .

1. **Celiac patients must eat these gluten grains, (wheat, barley, rye, oats*).**
2. **Autoimmune celiac disease is triggered by a stressor** that can occur at any time of life, but this is believed to often occur in early childhood or even before birth.
3. **After the trigger, symptoms may develop quickly.** However, in children early symptoms may recede and resurface later, particularly in the early 20's and beyond.²⁹
4. **Many patients are “silent celiacs” for decades** without noticeable symptoms, unknowingly damaging their bodies by consuming these gluten grains. Perhaps this is because damage may occur in areas that have few nerves for pain. Eventually they may become more aware as the damage accumulates or is worsened by stress, and aging, or a secondary illness develops.
5. **If undiagnosed, untreated celiacs continue to eat gluten, they may eventually develop other illnesses²¹,** many of them serious and/or life-threatening, like cancer/lymphomas, autoimmune diseases, osteoporosis, liver trouble, Type 1 diabetes, thyroid trouble, neurological damage, infertility or reproductive problems, not knowing celiac disease was the underlying cause. Or they may develop refractory sprue, usually a cancer, which means the previous damage will not reverse.

Is there a test for Gluten Grain Intolerances or their best known subset, autoimmune Celiac Disease?

Gluten Grain Intolerance – No, non “celiac” gluten grain intolerances can NOT be diagnosed with current standard celiac tests, although there are unvalidated tests¹¹ available. Therefore, for many people who receive negative tests that they question, **their only indicator is improvement on the gluten-free diet**⁵. They may use symptoms, history, iron levels, bone density tests, and the celiac gene test as clues.

Celiac Disease –Yes, there are tests for celiac disease although they are not always accurate^{6,7}.

Do many patients get a standard celiac disease test just in case they may have that particular subset of gluten grain intolerance?

“Yes”, many patients doctors recommend testing. Informed patients realize these tests are for the celiac subset only, not necessarily other gluten or gluten grain intolerances. Their chance of a positive “celiac subset” dx is 1 in 56⁵ if they have classic (digestive) symptoms. If they do test positively the diagnosis is very helpful.

People find these advantages to a celiac diagnosis, if they can obtain one.

- A celiac diagnosis helps **them** comply with their diet, and helps family and friends understand their situation. They say this is a most helpful aspect, particularly for children and teens.
- A celiac diagnosis may facilitate medical/dietary treatment in hospitals, although this is becoming easier with or without formal dx as awareness of celiac and gluten grain intolerances increases.
- A celiac diagnosis may encourage family members to be tested who may not understand other undiagnosable gluten intolerances. This cannot be helped if the diagnosis is not obtainable.
- A Celiac Disease diagnosis carries a small tax break for extra food costs only if medical bills are high.

Here are crucial considerations when pursuing “Celiac Disease” testing*.

- **Most tests require that you eat gluten regularly beforehand.** People who have already stopped eating gluten for a period of time may feel very sick and some may have been seriously harmed by reintroducing gluten for the length of time needed for testing.
 - **The standard testing process¹¹⁻¹³ may be expensive, disheartening, and misleadingly inconclusive.** False positives may occur. False negatives may mislead if celiac disease is not understood to be one small subset of gluten grain intolerances.
 - **The “correct” blood tests⁵ must be ordered, processed and read correctly,** using experienced doctors and labs.
 - **Endoscopy with villi biopsy, the “gold standard” diagnostic tool⁵, may not ¹⁰catch villi damage** if damage is patchy, submicroscopic, or if it is further down the intestinal tract than the examiner takes his endoscope tool. Some researchers believe that if something *else* is being damaged other than the intestinal villi¹¹⁻¹⁴, villi biopsy in those cases is useless and therefore misleading. However, endoscopies are useful for checking for other abnormalities like tumors, etc. Endoscopies are commonly performed, and rarely have lingering side effects, but any invasive procedure carries some risk.
 - **Even one accurate negative test process is insufficient, because the disease could trigger afterwards.**
 - **Perhaps the most troubling aspect of attempting a celiac diagnosis is that negative⁶ testing patients and their doctors may dismiss the possibility of other types of gluten grain intolerance¹⁰⁻¹³.** At this time, many doctors are looking only for the celiac subtype, thinking that villi damaged celiac disease is the only type of gluten intolerance. They and their often symptomatic patients assume that a negative blood test and/or endoscopy indicates that the patient can safely eat gluten grains. For some people who are not gluten grain intolerant at all, this may be correct, but for others who have another type of gluten intolerance, it is misleading or even harmful. Even if negative testing patients still realize that gluten grains bother them, they may lose the full benefit of a gluten grain free diet by being less strict than their condition actually warrants. They are confused by their negative tests.
- * 1 in 56 people with classic digestive symptoms test positively for the “villi damaged celiac disease subset” of gluten intolerance^{2,3}. They are fortunate to receive a clear, straightforward diagnosis. A much wider and nearly completely unstudied group of people who also have symptoms, history, genes, and a positive response to the gluten grain free diet, test negatively in standard celiac tests. They may be “non celiac gluten intolerant” and/or they may have other problems unrelated to gluten grains that benefit from the gluten free diet for unknown reasons.

Warning!

If you have already eaten strictly gluten grain free for a period of time, and this has helped you, it may be wise in some cases to consider yourself on a one way street and stay carefully gluten free. Backtracking to a gluten grain containing diet for more than a very short time has been miserable for many people and even harmful for at least a few people. Always consult appropriate *well informed* medical professionals.

How Patients Attempt to Identify Celiac Disease or possibly other Gluten Grain Intolerances

First, they continue to eat gluten grains until testing is finished?

- If they wish to undergo standard celiac tests,⁵ they continue to eat gluten grains normally until they are finished with the dx process. They need to eat gluten regularly for a prolonged time for the standard tests to work.
- If they have stopped eating gluten for a while, intentionally reintroducing it for several weeks or months for diagnosis purposes is called a “**gluten challenge**”. It’s purpose is to intentionally injure the body enough to be able to find and biopsy actual villi damage. Doctors recommend testing *first* in order to avoid this dilemma. If a patient chooses to undergo a gluten challenge, they need close medical supervision by an informed, experienced specialist. Many people have undertaken gluten grain challenges, but they have been miserable experiences for many of them and appear to have been accompanied by lingering negative consequences, even psychiatric symptoms, for at least a certain few of them. Some people who reacted severely had previously been gluten grain free for longer periods of time.* Some think became acutely sensitized to gluten grains at the time of the challenge.
- Many people who have avoided gluten grains for more than a short time, *and feel better*, who still strongly find a need to try to confirm suspicion that they are gluten grain sensitive have used the gene₅ test, family history, and their symptoms and response to the diet as guides. They look for possible malabsorption clues such as history of anemia and low bone density screens. Some try other unvalidated tests such as stool, or less standard blood** and saliva tests. They rely on their improvement on the gluten grain free diet as their best definite clue. Even for diagnosed celiacs this is the final diagnosis confirmation. Sometimes it takes time to pinpoint clear gluten grain free diet related benefit if other conditions mask the diet response. (Rarely, the patient does not improve on the diet because a condition known as “refractory sprue” has begun. This means the diet is needed to halt further damage, but present damage is too great and will no longer reverse.)

* This statement is anecdotal, meaning it is based on personal patient experiences, not researched studies. There is little comment on this phenomenon in validated literature other than comments by several specialists that they are usually uncomfortable with gluten challenges and try to avoid them

**New research suggests support for this type of IgG antibody testing. "Clin Lab. 2004;50(9-10):551-7. "Comparison of different salivary and fecal antibodies for the diagnosis of celiac disease." Halblaub JM, Renno J, Kempf A, Bartel J, Schmidt-Gayk H. http://celiac.com/st_prod.html?p_prodid=1116

If a patient still eats gluten grains and wishes to test for celiac gluten grain intolerance:

- 1. Blood tests -They can get a Celiac Panel of 5 blood antibody tests.** They **may** or may not^{6,7} (even in the presence of villi damage) show antibodies for celiac disease. Positive tests usually indicate a need to biopsy but negative testing patients may need individual evaluation for biopsy against symptoms, history and known diet response. Mass screenings miss some of these questionable negative results, and patients may be told to seek medical advice if they question the results. These tests are hard for operators to process and read.
- 2. Biopsy -If their Celiac Blood Panel⁵ is positive, conservative doctors recommend a duodenal biopsy (of the villi of the small intestine done via endoscopy)^{5,10}** – Under sedation, a tube is inserted in the mouth, throat and stomach into the duodenum to observe and collect samples of damaged villi. This is the conservative gold standard of celiac testing. **Disclaimer:** A previously respected, credible gastroenterologist and researcher, **Dr. Ken Fine MD, does not usually recommend a biopsy¹¹⁻¹³** unless there are other reasons. He believes gluten grain damage may not always be to villi, meaning sampling villi for diagnosis is misleading in those cases. According to him, negative biopsies mean little, but a positive biopsy usually indicates celiac. His work is unfinished, and his stool test in a patent process.
- 3. Bone density scans and iron levels** are clues doctors check for poor nutrient absorption if other tests are inconclusive.
- 4. A gene test** (blood or cheek swab)^{2,3,5,11} indicates whether the person carries genes **HLA DQ 2**, or **HLA DQ 8**. These associated genes are carried by persons with confirmed celiac disease 95-99% of the time. This test need only be performed once unless research identifies more associated genes. It is not necessary to eat gluten grains for this test. Not everyone with these genes develops the celiac disease subset so conservative doctors think other unknown factors are also involved. The gene test rules “in” the possibility of developing celiac disease. Since there are 1% of celiac patients without either gene, a negative gene test does not completely rule it “out” but is a strong indicator. ²⁷It is possible to inherit one half of the DQ 2 gene from each parent, meaning a child could possess a whole DQ 2 gene carried by neither parent *. **Note: Dr. Ken Fine includes the DQ 1 gene** for “gluten sensitivity”. The following identical statement was lifted from lab reports received from 2 of Dr. Fine’s Laboratories at Bonfils gene tests. One test reported both DQ 2 and DQ 8 genes, and the other reported 2 copies of DQ 2. *“This genotype also can predispose to microscopic colitis and other autoimmune syndromes. Two copies of these genes are an even stronger predisposition than having one gene and the resultant immunologic gluten sensitivity and disease may be more severe. Furthermore, having two copies of the gene means that each of your parents, and all of your children (if you have them) will possess at least one copy of the gene as well”*
- 5. Stool test - Some patients get an Enterolab mail order stool test*¹¹ for “gluten grain sensitivity”. This does not give them a “celiac” diagnosis.** They do this particularly if the standard celiac tests are negative and the patient suspects they are incorrect. Dr. Fine claims this test can indicate the presence of several antibodies in the stool and also measures intestinal malabsorption. He also claims it will work for a while after they have stopped eating gluten grains. Many conservative doctors don’t use this test since the research has not been validated.
- 6. One-day gluten challenge¹³** -Some patients undergo another unpleasant, unvalidated **one-day gluten challenge¹³ test** for celiac disease and gluten grain intolerances.
- 7. Blood and saliva tests** -There are mail order **saliva**, and finger stick **blood tests for IgG antibodies¹⁶**. Less understood alternative tests and treatments are available for food and environmental allergies and sensitivities, such as bioenergetics and kinesiology.
- 8. When testing is finished, switch to 5gluten-free foods.⁵ Improvement in your health⁵ is the final proof** that you are in some way intolerant to gluten grains, regardless of test results ⁶ (except in the case of irreversible refractory sprue³⁰).
- 9. Have regular checkups³⁰** to check for gluten in the diet, for further complications from previous gluten grain damage, and other reasons.

List of and Instructions for Obtaining Standard Tests and Current Costs for Celiac Disease and Less Validated and Less Widely Accepted Tests for Gluten Grain Sensitivity

Blood testing 5

“Celiac only” (not gluten sensitivity) blood panels or just tTG blood screening is sometimes available during October, Celiac Awareness month, at Celiac Disease conferences, locally sponsored screening drives, or research labs.

The “*celiac only*” blood test panel according to U of Maryland Celiac Program

EMA - IgA Anti endomysial antibodies
tTG - IGA Tissue transglutaminase IgA
AGA - IgG Antigliadin antibodies IgG
AGA - IgA Antigliadin antibodies IgA
Total IgA - Checks for IgA deficiency

. Note: the Chicago Celiac Disease Program no longer uses AGA-IgA or AGA-IgG to test for celiac disease

Immunosciences Lab., Inc.
8693 Wilshire Blvd., Suite 200
Beverly Hills, CA 90211
www.immuno-sci-lab.com Email – immunsci@ix.netcom.com
Phone : (310)-657-1077 Toll Free (800) 950-4686

NOTE: This lab includes **IgM** antibody testing in their celiac panel. Some doctors order this test *in conjunction* with more detailed panels looking not only for antigliadin antibodies but cross reactions with other tissues, foods or non food substances. “Celiac only” panel (above) price \$99 They require a dr script and will send a specimen transport kit. Prices for more detailed gluten sensitivity other sensitivity cross reaction panels vary.

Celiac Panel –requires 2 ml serum
Gliadin (**IgG, IgM, IgA**) 2 ml serum
Transglutaminase (IgG) 2 ml serum
Intrinsic Factor (IgG) 2 ml serum
Parietal cell IgG 2 ml serum

Patients call the doctor or gastroenterologist ahead of time to be sure the correct tests will be ordered and SENT TO A RECOMMENDED LAB. Immco Diagnostics, Prometheus labs, and Mayo clinic, are commonly used celiac labs. Most doctors do not have accounts with them and must make advance arrangements to use them. If the patient waits until the blood is drawn to request them, it may be too late. PATIENTS MUST BE FIRM AND MAKE THE ARRANGEMENTS THEMSELVES IF NECESSARY. Operator handling and interpretation of these tests is crucial. A lab may be licensed to perform them, but in actuality, their technicians may be inexperienced due to the relatively small number of tests they have handled, they may do outdated, less specific tests, or use inferior materials to cut costs, and your test results may or may not be accurate.

Some doctors refuse to use these specialty labs because they are not set up to bill the patient separately for their mark up on the test fees. In that case, patients find a doctor who has an account with a recommended lab, or will work with them regarding direct payment to the lab.

Prometheus Laboratories 9410 Carroll Park Drive. San Diego, California 92121 USA 888-423-5227 San Diego Area: (858) 824-0895 (www.prometheus-labs.com). They will send specimen transport kits to patient or doctor, no doctor account needed. Send specimen with doctor script, and payment (insurance info, or a form of cash). 25% discount for “advance pay” (cash with order). Results sent to doctor. Prices: \$440 - gene test for HLA DQ 2 and HLA DQ 8, \$76.50 - tTG-IgA, and \$290 - celiac panel includes AGA-IGA, AGA-IgG, tTG-IgA, EMA-IgA and Total serum IGA tests.

Immco Diagnostics 60 Pineview Drive, Buffalo, NY, 14228, USA, Phone 800-537-8378, Int 716-691-0091 www.immco.net. This specialty lab requires doctor script with payment (no payment discounts, no dr account needed). The celiac panel, including EMA-IgA, ARA (anti reticulin, an older test – both IgA, IgG), and tTG (IgA and IgG), is \$275. The HLA-DQ blood based gene test is \$350. (10/05) Special transport kits are not needed.

Endoscopy 5

Patients always check to be sure the gastroenterologist is ¹⁰well trained in celiac disease, and takes multiple samples (at *least* 6-8) in case damage is patchy. They discuss the possibility that ¹⁰damage could be further down the intestinal tract than normal. Villi sampling will only be positive *if* gluten induced damage is happening to the villi, not another ¹¹structure or function in the intestine or another part of the body, *and if*

the samples happen to be taken on damaged villi. It is also crucial that the gastroenterologist specify on the order that the pathologist look for celiac disease, and that the pathologist is aware of current protocol for identifying celiac disease. They ask the doctor to specify that the laboratory look for traces of intraepithelial cells that indicate early damage. Endoscopies are performed in a few minutes. The patient is under anesthetic for a very short time, and normally can walk out afterwards. Cost can run from \$900 to several thousand dollars. Some doctors have been willing to negotiate for 1.5 % above Medicare.

Stool tests for gluten, dairy, yeast and egg sensitivity, intestinal malabsorption and colitis.¹¹

Enterolab (www.enterolab.com), 10875 Plano Rd. Suite 123, Dallas, TX, 75238 972-686-6869 owned by Dr. Kenneth Fine, offers stool testing for gluten, milk, egg, yeast, dairy, intestinal malabsorption, and active chronic colitis. Cheek swab gene testing for DQ 2, DQ 8 and DQ 1 is also offered. (Dr Fine believes DQ 1 is connected to gluten sensitivity) Dr. Fine is a well known gastroenterologist who is continuing the research work of a retired European researcher, Dr Marsh, and a late researcher, Anne Ferguson. These Dr/researchers developed testing methods they claim are very sensitive and can detect gluten sensitivity even after a person has stopped eating gluten for a short time. Other researchers have not been able to duplicate their work; so many doctors do not accept their test results. A US patent process is now completed. Time will tell whether these doctors are correct. Enterolab processes a high number of positive tests for gluten sensitivity. They also receive a high number of samples from people who are so suspicious that their negative blood tests are inaccurate that they are willing to pay out of pocket for Enterolab testing. (Many insurance companies do not pay for this test.) A prescription is not required, collection kits are mailed to the home, and results are emailed to the patient. The gluten sensitivity/gene package, (02/28/06, 2005) (AGA-IgA, tTG-IgA, intestinal malabsorption, gene test, and free diary test) is \$369. A separate gene test, \$149. Gluten sensitivity without gene test, \$249. The egg/yeast/soy package, \$199.

Dangerous Grains by Ron Hoggan & James Braly, MD, p.72-74 discusses an unvalidated **1 day challenge** similar to a colonoscopy/intestinal biopsy that some patients try. Ron is a patient/high school teacher who has researched gluten intolerance and co-authored with Dr. Braly.

Genetic testing

Kimball Genetics (<http://www.kimballgenetics.com/tests-celiacdisease.html> 1-800-320-1807) tests for DQ 2 and DQ 8 genes, blood sample or cheek swab. Cost \$325 for insurance claims. Advance cash payment -10% discount, (\$292.50) and additional family members, \$260/ea.. Results sent to any doctor or nurse. The genetic counselors are very helpful. Conservative doctors recommend blood over cheek swab to avoid contamination from gene carrying food particles. Kimball Labs does not find a difference in properly collected specimens.

Enterolab, (www.enterolab.com) tests for DQ 2, DQ 8 and DQ 1 due to Dr Fine's unvalidated research theories. The Enterolab gene test is a mail order cheek swab test processed by Laboratories at Bonfils. Its work is accepted as valid by competitors, although tests are done differently in more detail. Gene tests, processed by both Enterolab (cheek) and Prometheus (blood) produced identical results. Cost is \$149.

Prometheus Labs uses a blood sample to test for the genes HLA DQ 2 and HLA DQ 8. Price, \$440, see previous page for discounts (10/05)

Other food sensitivity tests

York Nutritional Labs, www.yorkallergyusa.com, 888-751-3388, offers home mail order finger prick blood testing for over 100 food sensitivities and inhalant type allergies, etc. Some conventional allergists do not accept this testing. York cites research published in Gut, October, 2004, to back up their claims. Their celiac rapid test (\$99) includes tTG -IgA, IgG, and IgM. Other panels range from \$59.95 to \$449.95

Follow up testing advice for celiacs and Dr. Fine's followup testing advice specifically for gluten sensitivity are here:

Celiac <http://homepage.mac.com/sholland/ceciac/index.html> (middle) **Gluten sensitivity** http://www.enterolab.com/What_Happens/ (bottom)

What Foods Do People Avoid on a Gluten Free diet?

All wheat, rye, barley, and *oat grains, flours and products made from them.
Triticale, spelt, durum, seminola, kamut, rous, cous cous, bulgur, graham, fu, emmer, einkorn,
Breads, pastas and breaded products, malt vinegars and malt extracts, beer

What Foods Do People on the Gluten Free Diet Question?

Caramel colors, artificial color and artificial and natural flavors, additives,
Food starches from unspecified sources, soy, tamari and teriyaki sauces,
Seasonings (spice mixes), condiments, dry cereals (barley malt), MSG
Sauces/gravies, lunch meats, pre-basted, seasoned or marinated meats and turkey,
hard Candies, thickeners, HVP, dextrin, miso, maltodextrin and citric acid from outside US,
Hair and mouth care products including toothpaste, mouthwash, makeup, medications

See CSA Product Guide www.csaceliacs.org, SmartLists - www.clanthompson.com ,
CDHNF/NASPGHAN Gluten Free Diet Guide for Families <http://celiachhealth.org/pdf/GlutenFreeDietGuideWeb.pdf>
Celiac.com - "Safe and Forbidden lists" - http://www.celiac.com/st_main.html?p_catid=12&sid=91hH9H1FjJuXBC7-45105427072.b0

* The safety of oats is still in debate although for most celiacs it appears to be safe. Most oats in the USA are contaminated with gluten grains.

New labeling laws require that the 8 top allergens be listed in plain language on food labels, to take effect Jan, 2006. This includes Dairy, Eggs, Wheat, Fish, Shellfish, Tree Nuts, Peanuts, and Soy. Barley, Rye, and Oats are not on the list. Some companies are including Corn, Sesame, Sulfites, MSG and even Potatoes on their labeling statements.

Caution!₂₁

People with celiac disease cannot just “eat less bread”!

All gluten must be eliminated.

~

**Even crumbs and
hidden ingredients matter.**

~

No cheating allowed!₂₁

The medical community considers celiac disease to be life threatening!₂₋₄

There are few researchers to comment regarding the risks of non celiac gluten grain intolerances. Dr. Fine’s preliminary articles indicate that he believes the risks are similar to celiac disease.₁₁₋₁₃

Conversely, verbal comments by celiac disease program staff indicate that although celiac programs do not address non celiac gluten grain intolerances, they do not think they are autoimmune or life threatening (Winter, 2005). There is no validated research with which to scientifically assess risk.

A strict gluten grain free diet requires careful separation of food from possible cross-contamination with gluten grains, (like a separate toaster), and careful cleaning procedures to insure that wheat or other gluten grain crumbs or particles not come in contact with food eaten by a person on a strict gluten grain free diet.₂₀

Basic Gluten Grain Sensitivity/Celiac Disease Terms₃₁

Gluten Grain Intolerance/Sensitivity – One or more unhealthy reactions to the gluten grains wheat, barley, rye (oats) in the diet.

Celiac Disease – The best understood and most researched subset of gluten grain intolerance/sensitivity. It is a genetic autoimmune reaction to gluten in grains that causes disease, inflammation, and damages villi in the small intestine, triggering degrees of various medical and psychiatric conditions and malnutrition and inflammation related problems.

Enteropathy – Disease of the intestine

Lesion – Abnormality involving any tissue or organ due to a disease or injury. In simple terms it means damaged tissue.

Autoimmune disease – A disease in which the body's immune system reacts against its own tissues in a damaging way.

Antigens – Substances that are identified by the body as offensive or invaders.

GF - "Gluten Free" **GFCF** – "Gluten free casein free" Casein is milk protein **Casein free** means no milk at all **Lactose free** means no milk sugar.

DX – An abbreviation for the word "diagnosis"

ANTIBODIES – Chemicals that identify foreign invaders, and if improperly activated can contribute to the damaging autoimmune process.

AGA are antibodies to gliadin, **Gluteomorphins** are antibodies to gluten **EMA** are antibodies to the endomysium (A sheath of connective tissue that surrounds muscle fibres **Anti-tTG** is an antibody to tissue transglutaminase - a chemical that the blood of celiac patients misrecognizes as an enemy

IMMUNOGLOBULINS **IgA, IgG, IgM, IgE, IgD** take part in immune/antibody responses to bacteria or foreign substances like allergens

GENES - Inherited materials that carry design information in the cells, like a "blueprint".

HLA-DQ 2, HLA DQ 8, The 2 genes associated to actual Celiac Disease. Half of the DQ 2 gene can be inherited from each parent **27**

HLA DQ 1 Some researchers identify this gene as also associated with for gluten intolerance/sensitivity.

Other gene numbers (HLA DQ _) that are seen in celiac literature are actually components of these main 3 genes.

THE GLUTEN GRAINS - Wheat, barley, and rye possibly oats. Their glutens and possibly other substances may become toxic to some people.

Wheat – This word is not only used to identify the actual wheat grain but it is also often used loosely to mean all the offending gluten grains wheat, barley, rye and possibly oats. This can be confusing. Check the context or ask the communicator if in doubt.

Gluten grains – Most grains contain their own type of gluten. but usually this term refers to grains containing the offender glutens in wheat, barley, rye and possibly oats. (The term "gluten grains" may also be used to indicate this particular list of grains, but in some cases of non celiac gluten intolerance possibly other unknown substances in the grain, not the gluten, are the culprits.

Gluten - The protein that makes dough stretchy. It can offend separately of the prolamin within its structure, or both may be toxic.

Prolamin – An alcohol soluble protein found in plants. It is an important component of gluten

Gliadin, Hordein, Secalin, Avenin - The prolamins found in the gluten in wheat, barley, rye and oats, respectively.

Peptides – strings of two or more amino acids bound to each other in particular ways to form protein molecules. In the case of gliadin, the string is 33 links long, and resists being broken down

PARTS OF THE BODY

Duodenum, jejunum, ileocecum – Three parts of the small intestine affected by Celiac disease

Villi – Tiny, fingerlike, porous projections that line the small intestine like a soft brush. They absorb nutrients during digestion. The villi are damaged by the celiac disease process and may no longer properly absorb nutrients.

FAQ's - Help, I'm so confused!

Question: I have digestive problems, and/or non digestive symptoms. Might people like me have gluten grain intolerance, or its' well known subtype, "celiac disease" ?

Not necessarily. There are other causes of these symptoms that are unrelated to gluten intolerance. But people in your situation may seriously consider gluten grains and/or or some other type of food intolerance as a possibility.

Question: I have no symptoms of gluten grain sensitivity or celiac disease. Do people like me have no problem with gluten grains and don't need to consider the possibility?

Not necessarily. People with relatives who have or had symptoms of celiac or gluten grain sensitivity may consider the possibility in case they have a silent, non-symptomatic type. Most celiacs do not have severe digestive symptoms-instead symptoms may include fatigue, seizures, headaches, migraines, joint pain, depression, mood disorders, infertility, and other non intestinal symptoms.

Question: I already know wheat bothers me. Are people like me gluten sensitive?

Perhaps. It depends on the type of reaction(s). Wheat alone causes some people allergies with immediate symptoms like breathing difficulty, hives or swelling. Their reaction is different from "gluten" intolerances and may not include barley, rye or oats. The wheat allergy diet is similar but not always as strict. But some people say they have allergy *and* intolerance. If they are sure "gluten grains" bother them in some way , then they employ *well informed* common sense and *well informed* advice from health care professionals regarding testing and the GF diet.

Question: If my celiac blood test and biopsy are negative, can people like me eat gluten grains?

Perhaps, but not always.

1. If they carry the gene(s), disease can trigger later.⁵ They need to check every so often.
2. Some celiac test panels do not test for IGA deficiency. IGA deficiency makes blood tests inaccurate and tests are interpreted differently. They check Total IGA to be sure.⁵
3. They may still have a non celiac gluten grain intolerance that benefits from a gluten free diet.

Question: I am diagnosed celiac, but the gluten free diet has not helped (completely) after a long time on the diet. My doctor can't find other reasons, and he has ruled out a false positive and refractory sprue. What do other patients do in my situation?

1. A very helpful resource is the Gluten Free Diet Guide for Families at <http://celiachhealth.org/pdf/GlutenFreeDietGuideWeb.pdf>
2. Patients check to be sure they are truly gluten free. They may find unnoticed gluten in personal care items or from cross contamination, even kissing. They consult a knowledgeable dietitian if necessary.
3. Patients check for other infections such as yeast and fungal infections and other food or non food sensitivities (milk, soy, sugar, yeasts, nightshades such as tomatoes, potatoes, green peppers and eggplant, or toxic heavy metals like lead, tin or mercury) that some researchers say may cross react³⁴ with gluten/gliadin or each other and prevent healing. They investigate diets such as the Specific Carbohydrate Diet²³ and Candida Diets. These diets focus on removing other substances, (including starches and sugars in ALL grains, starchy vegetables and table sugars), until digestive balance is restored. They use various blood, urine, or saliva tests, detection diets and energy based tests to find other sensitivities.
4. Probiotics and fermented foods provide digestive enzymes and friendly bacterias needed for healthy digestion. The Maker's Diet and Restoring Your Digestive Health by Jordan Rubin, N.M.D and Joseph Brasco, M.D., and Dr. Mercola's Total Health Program teach these and other common sense principles.
5. Food additives like MSG, (particularly in spices, natural flavorings, and meat flavorings) HVP, or aspartame bother some people.
6. ²⁸Some researchers insist we are not eating enough of the fats found in grass fed animals, fish, and unprocessed coconut and palm oils. These fats contribute to proper digestion and nutrient absorption. www.westonaprice.org > Know your fats
7. Ancient cultures prepared their seeds, nuts and grains by presoaking them. The slow sourdough process also soaked the flours. Years ago, grains weathered (sweated) in fields in shocks for days or weeks before storage. All seeds contain phytic acid in the hulls or bran, and various enzyme inhibitors not meant to be eaten. These antinutrients preserve seeds and prevent them from sprouting until they are in a setting suitable for growth (i.e., warm spring rains). Enzyme inhibitors suppress germination in dry seeds, but if eaten unsoaked, they interfere with enzymes in our digestive system, increasing the load on the pancreas and other enzyme producing organs. Unsoaked phytic acid prevents absorption of important minerals in our bodies. Long soaking neutralizes these chemicals, allows enzyme and nutrient levels to rise, and germination to occur, increasing nutrition and general digestibility. *Soaking does **not** neutralize gluten!*, but certain sourdoughs are being studied for their effects on gluten grains. www.westonaprice.org
8. Acupuncture and alternative energy therapies claim to relieve other food sensitivities, but some patient's and their practitioner's anecdotal experience indicate that gluten intolerance consistently is **resistant** to permanent treatment. They do **NOT** work for gluten.
9. Patients incorporate many other doable lifestyle strategies to support health and digestion, such as proper exercise, rest and sleep during normal night hours, eating slowly, chewing well, good posture, forgiveness. They may simplify finances, possessions, relationships, occupational stresses and committments to reduce emotional stress.

Question: My standard celiac tests are negative, I am not IGA deficient, and my doctor has checked for infections, and many other possibilities. I really think gluten grains make me sick. Why? What do other people in my situation do? My doctor says I am not Celiac.

Why ~ Many people test negatively for celiac disease, nevertheless they feel much better ¹⁰⁻¹³off gluten grains. Some researchers term them “gluten grain intolerant” or “gluten grain sensitive” and recommend a gluten grain free or similar diet. They ¹¹⁻¹³suspect:

1. There may be unknown disease processes or intolerances involving gluten, or for some people there may be another unidentified toxic component, not the gluten, in these same “gluten grains”.
 2. Some researchers believe other structures and functions of the intestine or other parts of the body may be damaged instead of villi, so damage does not show in biopsies.¹¹
 3. Some researchers believe villi damage is a more severe degree of damage. ¹¹
 4. Patients and researchers consider non autoimmune factors, like missing enzymes, consumption of inappropriately processed oils (hydrogenated vegetable oils), inadequate (healthy) forms of saturated fat needed for digestion, unsoaked whole grains that still contain phytates (phytic acid which blocks absorption of minerals) and enzyme inhibitors that are not meant to be eaten²¹. They evaluate unhealthy fast food and high sugar intake, bacterias, infections and stresses that may contribute to these issues.
 5. Patients report success with diets that conventional doctors question or that are not well researched.
- The **Candida Diet**²² removes carbs to curb yeast overgrowth. “The Yeast Connection”, by William Crook.
 - The **Specific Carbohydrate Diet** removes certain sugars and starches including ALL grains and starchy vegetables temporarily until digestive balance is restored and the bonds between the sugar and starch molecules can be broken down²³. Undigested sugars and starches ferment in the gut and produce toxic, inflammatory byproducts or feed yeast overgrowth. Breaking the Vicious Cycle” by Elaine Gottschall.
 - The **Primitive (Traditional) Diet** focuses on nutrient dense foods eaten by ancient cultures around the world, and their food and grain preparation methods before modern food processing. Nutrition and Physical Degeneration, by Dr. Weston A Price, D.D.S. www.westonaprice.org, www.price-pottenger.org
 - The **Blood Type Diet**²⁴ categories foods for each blood type. “Eat Right 4 Your Type” by Peter D’Adamo.
 - The Maker’s Diet, and Restoring Your Digestive Health by Jordan Rubin N.M.D. and Dr. Joseph Brasco, M.D., and the **Metabolic Typing Diet**, discussed in Dr. Mercola’s Total Health Program are both programs that include probiotic therapy and common sense principles that many people have found very helpful.

What have other patients in my situation done? - If they test negatively for celiac disease but have reason to think they should not eat gluten grains they have tried some of the following strategies...

- A gene test⁵, anemia test or bone density scan has given them clues in some cases.
- Some people investigate emotional issues, environmental toxins, or other food related intolerances.
- Some first try traditional grain preparation methods such as soaking, and sourdoughs and changing dietary fats²¹, in case they are only reacting to the improper preparation methods. But if they find they are truly *gluten* intolerant they should carefully consider that these presumably healthier methods are **not proven safe enough to prevent gluten induced damage**. There is early research interest in certain sourdoughs and their effects on gluten grains but much more research is needed.
- Some people try non standard testing like the IgM and gluteomorphine antibody tests, stool tests¹¹, finger prick blood or saliva food sensitivity tests, the 1 day gluten challenge, or alternative tests like bioenergetics or kinesiology. Often bioenergetics practitioners advertise at health food stores.
- Many people find the gluten grain free diet or a similar diet helps them, even though doctors cannot tell them why at this time. Some tests do not work after a person is gluten grain free⁵ so they consider all testing options first. They consider the gluten grain free diet probably a lifetime choice.

Question: I have NO symptoms, my celiac tests were negative, but I have suspicious family history, and I carry the gene. I might be “silent,” gluten (grain?) intolerant. What have people in my situation done?

- Some maintain a normal diet and healthy lifestyle, and retest, aware that silent damage is a possibility.
- Some people are returning to dietary practices used by cultures around the world for centuries before modernization. These methods involve soaking grains and seeds to deactivate certain chemicals not meant to be eaten, eating mercury free wild caught sea food, and grass-fed animal products that have healthier fats, and healthy gelatin and mineral rich broths from naturally raised animals and fish. This approach incorporates unprocessed saturated coconut and palm oils, and live culture, enzyme rich fermented foods like yogurt, kefir, sourdoughs, etc. It also avoids most processed and junk foods.²¹
- Some symptom free people with suspicious history and genes choose to eat “gluten grain free”, but understand that it might not be safe to go back to a gluten containing diet later. The gluten grain free diet is medically considered healthy, but is a lifetime choice, and not easy particularly at first.

Question: If I just eat a lot fewer bread products wouldn't that be easier and helpful enough?

No, not for certain. Long term research on diagnosed celiacs suggests that if a person is is celiac, and consumes a mainly gluten free diet but cheats regularly, even once or more a month, this can create a damaging “on/off” effect called ischemia-reperfusion injury, and raise the incidence of autoimmune disease and overall mortality rate significantly.³⁰

Because research has not found clear answers, many Celiac Disease Programs only diagnose “villi damaged celiac disease”. They may not address the needs of people who may be “gluten grain intolerant”, but who do not test positively for celiac disease. Research is needed on these very common, similar conditions and accurate tests developed for them.

Note: Sometimes people who adopt restrictive diets later find that other foods begin to bother them as well, at least for a while. Some ¹¹researchers think that as the body/immune system heals it better identifies foods that it should not have and reacts more strongly to them, or that bacteria becomes trapped during stages of the healing process.¹¹ You may wish to discuss this with a *well informed* medical/or alternative professional.

Question: Corn is another common grain that has a gluten (zein). Is Corn a problem?

Answer: Yes, some people say they react to corn, sometimes very seriously. Corn is not recognized by the FDA as a problem. Patients manage their own research and care.

Here are some corn allergy related websites

**<http://allergies.about.com/cs/corn/a/aa053199.htm>
www.immune.com/allergy/allabc.html**

Comment: In this paper, many vague words are used like “may, sometimes, researchers suspect, possibly” Why is this information so unspecific. Isn’t anything proven?

Answer: The use of these vague words are necessary, since there is so much that is not yet researched or proven in this field today. Research studies require that the participants be biopsy proven celiacs, thus limiting the results to only that specific kind of villi damaged autoimmune reaction. Also doctors are not in agreement regarding whether so many patients who fit the profile of celiac disease but do not test for it are actually gluten (grain?) intolerant. Research appears to be behind anecdotal evidence among patients today. *Unresearched* anecdotal evidence is not considered credible by the medical community. This primer reports varying schools of understanding to inform the patient of available options.

Question: What foods can be used instead of gluten grains?

Answer : Common non gluten grain substitutes include rice flour, tapioca flour, potato starch and flour, corn meal and corn starch. These foods contain more carbohydrates and lower protein and fiber than whole gluten grains. Therefore, flours made from less known plants from ancient times are also being introduced to mix with these flours. This increases the product’s fiber and protein content. They include quinoa, amaranth, teff, sorghum, montina, buckwheat and meals ground from beans, mesquite, nuts, and flax. Many gluten free foods are very tasty and nutritious. Here are helpful gluten free diet guides.

<http://gluten.net/downloads/Quick-Start-Mar04.pdf>

http://csaceliacs.org/gluten_grains.php

http://csaceliacs.org/ceeliac_treatment.php

<http://celiachhealth.org/pdf/GlutenFreeDietGuideWeb.pdf>

Diabetics must account for the higher carbohydrate content of some gluten free products. Many gluten grain intolerant people respond better when they reduce their intake of even non gluten grain bakery products that are still not very healthy due to their high sugar, processed vegetable oil, and carb content.

Years ago, food preparation methods included long soaking of all seeds including grains, beans, seeds, and nuts. This deactivates certain antinutrients and enzyme inhibitors that preserve seeds from sprouting prematurely. (These methods can be used in *addition to*, not a *replacement for* the GF diet.) Also, mineral and gelatin rich bone broths, and certain unprocessed saturated fats all aid digestion. Fermented foods such as kefir, yogurt, kombucha tea, sauerkrauts, cheeses, fermented vegetables and sourdoughs containing healthy live probiotic enzymes have been used for centuries to preserve food. A cookbook for these methods is “Nourishing Traditions”, by Sally Fallon. This cookbook is NOT gluten free. (See the work of Dr. Weston Price, a dentist who studied the diets and health of primitive cultures compared to modernized societies in the 1930’s,) www.westonaprice.org, www.price-pottenger.org .

Is this diet just a fad? I think this might be worth investigating to help my problems, but I don't want to upset my lifestyle or lose my friends.

That is a good question and has no easy answers. It is possible to become so obsessed with healthful eating that it consumes and damages overall quality of life, and irritates friends and family members. A book that addresses this problem is Health Food Junkies, Orthorexia Nervosa: Overcoming the Obsession with Healthful Eating by Steven Bratman, MD with David Knight.

The Primitive, (Traditional) Diet strategies are simply healthy practices, not a “medical diet” per se, but the Gluten Free, Specific Carbohydrate Diet, Candida Diet, and Diabetic Diets and other diets specific to certain health conditions are strict medical diets. Some have been utilized for over 50 years. They are not fads to be tried on a whim, in contrast to many popular weight loss diets. As more people adopt these diets for valid medical reasons, they may become better understood and accepted as has the diabetic diet. But unless or until new knowledge is uncovered the Gluten (Grain?) Free Diet at least is a lifelong lifestyle and should be thoughtfully considered.

It is natural that any strict medical diet requires education and an adjustment period, including a grieving stage. But patients find it wise to be sure that after a healthy adjustment period, life goes on normally without undue fixation on the matter. The Gluten Grain Free diet is considered a nutritionally healthy diet, naturally encourages better food choices, excludes a lot of junk food, and is a delicious , often colorful and appealing way to eat.

Books that teach living and loving the gluten grain free lifestyle and address the grieving process are Wheat Free Worry Free, the Art of Happy, Healthy Gluten Free Living, and Kids with Celiac Disease by Danna Korn. Her encouraging principles apply equally to similar diets. Another book is Eating Gluten Free, by Shreve Stockton.

For over 50 years, many people have been helped by their celiac diagnosis and the gluten free diet, and other similar diets. Naturally, they tell their friends and family their good news, and in the case of Celiac Disease they are encouraged by their doctors to do so, since these conditions are genetic. That is fine, but celiac/gluten/grain intolerant patients prepare that everyone processes new information and change differently. Many people do not appreciate this information particularly at first, and do not accept it even if it might benefit them. That is their decision and they make that choice just as we all make life choices that are not always healthy. Once clear information has been presented, it is wise to leave the subject alone as possible. Food issues raise puzzlingly strong reactions that hurt the messenger and damage relationships. Forgiveness, patience and understanding smooth ruffled feelings when these dynamics appear. People who react negatively at first may later begin to understand the condition and implications more clearly and change their minds.

Observations of 7 Medical Viewpoints of Understanding of Gluten Sensitivities and Celiac Disease

Doctors Who are Unaware of New Gluten Intolerance/Celiac Research – These doctors have not heard of or accepted the latest research. They think celiac disease is a rare pediatric illness that justifies testing ONLY if severe gastrointestinal symptoms are present, and likely are unaware of non celiac gluten intolerance. These doctors rarely, if ever, consider celiac disease as a possible diagnosis. Many good doctors are unaware, but this is changing as the medical community and the public learn of this disorder together. Find a doctor who will listen and learn.

The Conservatives – Most celiac disease programs and specialists. They use blood testing, biopsy, and only then diet response and lowered antibodies as primary diagnostic tools. They also check bone density, iron levels, and gene tests. They most commonly consider diarrhea and other gastrointestinal symptoms as the only symptoms to justify testing. They now recognize but do not treat other non villi damaged gluten intolerances, and only prescribe the gluten-free diet when these diagnostic criteria are met. If blood tests are negative, they often do not perform a biopsy, but recommend a gluten-containing diet, and may advise to retest later. Some now acknowledge but do not treat non autoimmune gluten intolerance and comment that “nobody NEEDS wheat”.

The Moderates - These doctors use the same diagnostic methods as the conservatives, but recognize that some negative testing (blood and/or biopsy) patients with suspicious history, genes, symptoms, and positive diet response, should also not eat gluten grains.

The Maverick – Dr. Ken Fine, (Enterolab), a well known conventional researcher and gastroenterologist has continued the work of English researchers Michael M. Marsh and the late Anne Ferguson. He has developed tests he claims address the needs of the gluten sensitive/non celiac community. His work including a stool test patent is in process. It has not been duplicated/validated so many doctors do not use his tests. Dr. Fine teaches that the DQ 1 gene is also involved in gluten sensitivity, and that gluten induced damage may not always be to villi, but to other structures and functions of the small intestine, or even in other parts of the body. He processes many positive tests, many from people who question their negative blood tests and biopsies. Other researchers including M. Hadjivassiliou, R A Grunewald and G A B Davies-Jones, Sheffield, England have published similar findings. Also published, Clin Lab. 2004;50(9-10):551-7. Comparison of different salivary and fecal antibodies for the diagnosis of celiac disease. Halblaub JM, Renno J, Kempf A, Bartel J, Schmidt-Gayk H.

The Allergists - Conventional scratch testing for histamine type, IgE *allergies* may not be helpful for delayed reaction intolerances, but it is thought that allergists may help unravel the less easily diagnosed delayed reaction types of gluten intolerance. York Nutritional Labs is one of the labs that offer services to the gluten intolerant community. They perform finger stick blood testing for many food and airborne allergies, utilizing only IgE or IgG antibody levels for analysis.

The Alternatives, Functional Medicine – Alternative doctors offer bioenergetics testing, blood testing, kinesiology, homeopathy, energy therapies and other diets. ~ Some believe humans never completely digest most grains, unlike some animals with more than one stomach or who chew the cud. Others believe cattle should eat their natural diet, grass, not grains, creating better animal health and much better omegas 3 and 6 fatty acid balance (1:1 on grass, 1:20 on grains) ~ Knowledge of new gluten research varies widely. ~ Some only emphasize grain reduction depending on metabolic body type.. ~ Some claim they can correct some food sensitivities with energy and acupuncture manipulations that restore energy balance in ways they themselves do not understand. Most warn however that these therapies do not work reliably or permanently for gluten. They as with all medical professionals, *also* recommend healthy lifestyles including sleep, proper diet, water, light, exercise, and stress management to maintain their treatments. Some advocate returning to unprocessed saturated fats from coconut and palm oils, and pasture fed animals, use of rich bone broths, presoaking grains nuts and seeds, and fermenting many foods for better digestion.

Spiritual and Emotional/Psychological Components - This discipline addresses stressors and traumas such as abuse, accidents, illnesses etc., that may trigger physical damage in the body, and emotional dynamics that strengthen the immune system such as joy and love. These professionals also address eating disorders, fears, and phobias that can accompany over focus on a severe diet.

Historical landmarks relating to digestive illnesses (references in process to be posted at www.glutensensitivity.net history page)

- BC The book of Exodus refers to related general and digestive symptoms in reference to bread and grains.
- 100 AD Comment describing celiac symptoms in ancient medical literature
- 300 AD Comment and description by Aretaeus, refers to “Coeliac disease”, meaning “abdominal”.
- 1855 Dr. Gull Guy’s Hospital Reports, symptoms described symptoms of gluten intolerance.
- 1887 Dr. Samuel Gee, “We must never forget that what the patient takes beyond his power to digest does harm.”
- 1850’s+ Bechamp-Pasteur debate re: microbiology/vaccines. Continues for many years. Bechamp’s predictions fulfilled.
- 1850’s+ Processed flour, sugar and commercially canned vegetables and milks become more widely available with industrialization.
- 1900 Coronary Heart disease is no more than 10% of annual cause of death from all causes. Butter consumption 18 lbs/person
- 1908 Drs. Emmett Holt and Christian Herter publish “On Infantilism from Chronic Intestinal Infection”
- 1910 Myocardial infarction,(blood clot in heart is rare.Butter substitutes, little used, are made from coconut oil, animal tallow, lard
- 1911 Crisco, a soft hydrogenated vegetable oil, is introduced as a butter substitute. It is inexpensive and has a long shelf life.
- 1914 Dr. Paul Dudley White a young internist, introduces a new electrocardiograph machine to colleagues at Harvard U.
They advise him to concentrate on a more profitable branch of medicine. Few patients needed it.
- 1921-51 Holt reads “Prolonged Intolerance to Carbohydrates”. Haas, his assistant, seeks suitable carbohydrates for better nutrition.
- 1922 Dr. Robert McCarrison warned colleagues that intestinal disorders were increasing.
- 1930 Myocardial infarction is responsible for no more than 3000 deaths in 1930.
- 1932 Dr. B.B. Crohn speaks of “new intestinal disorder” he calls “regional ileitis”, now called Crohn’s Disease.
- 1939 Dr. Weston A. Price publishes his 10 year travel research “Nutrition and Physical Degeneration”, detailing his comparisons of health and diets of isolated cultures with “modern” societies, and related butter and soil fertility studies.
- 1940-50 Dr. Willem Dicke notices certain patients’ digestion improves during grain shortages in Holland during World War 2. Their illnesses relapse when grain is again available. This turns attention to gluten grains.
- 1949 Drs. Sidney and Merrill Haas successfully treat 600 cases of “celiac disease” with the Specific Carbohydrate Diet.
- 1950 Butter consumption has dropped in the US from 18 lbs/person in 1900 to 10 lbs/person per year, 1950’s. Hydrogenated vegetable oils replace butter. Coronary heart disease is now the leading cause of death, 30%.
- 1951 Drs. Haas publish “The management of Celiac Disease” in 1951, focusing on certain complex dietary sugars and starches.
- 1952 University of Birmingham tests ten children and concludes that gluten, not starch is the culprit. The new focus on gluten widens the number of foods allowed, but few patients meet the diagnostic criteria and recognized symptoms are narrow, mainly wasting diarrhea and failure to thrive in children. They are diagnosed with “gluten induced celiac disease” via early blood and later newly developed capsule biopsy testing. USA doctors are taught that “celiac disease” is rare and they will likely never see a case. Most practitioners don’t think of it, so most gluten induced celiac patients *and* those who might have responded to a carbohydrate based approach alike fall by the wayside.
- 1950-60s Numerous researchers perform studies finding benefit in saturated animal fats and tropical oils vs. disturbing results from inexpensive hydrogenated vegetable oils.
- 1960 The American Heart Association launches the Prudent Diet (replace red meat, eggs on TV networks based on the “lipid hypothesis” amid an era of protests from lipid researchers and heart specialist Dr. Paul Dudley White. "I began my practice as a cardiologist in 1921 and I never saw an MI patient until 1928. Back in the MI free days before 1920, the fats were butter and lard and I think that we would all benefit from the kind of diet that we had at a time when no one had ever heard the word corn oil."
- 1960 Myocardial infarction claims 500,000 lives in 1960.
- 1960 Margot Shiner and Cyrus Rubin separately invent a small bowel biopsy capsule facilitating dx of small bowel diseases.

- 1960's News reports/ads promoting inexpensive hydrogenated oils move the public away from butter, animal fats, and unprocessed tropical oils toward processed vegetable oils with emphasis on reduction of fat consumption.
- 1965 The Price-Pottenger Nutrition Foundation is established to preserve the research archives of Dr. Weston A. Price, DDS, and Dr. Francis M. Pottenger, MD. and other similarly focused pre 1950 researchers.
- 1970's Much research is done in Europe on gluten induced celiac disease. It is found to be common in the European population. Diagnosis time is eventually reduced to a few weeks in Europe. US awareness remains almost nonexistent.
- 1970's 80's Over 600 publications appear testifying that the Elemental Diet, with sugars common to the Specific Carbohydrate Diet, "effectively corrects mal-absorption and reverses many intestinal disorders". Breaking the Vicious Cycle-Gottschall
- 1990's Dr. Alesio Fasano from Naples, Italy joins the University of Maryland research team and asks "Where are the American celiacs?" This prompts a 5 year study, involving 32 states and 13,000+ participants. The study is published in Archives of Internal Medicine, February, 2003
- 1994 Zonulin is discovered, this provides basis for the "brain/gut connection, spurring medical advances, particularly in diabetes. Dr. Kenneth Fine pursues the research work of Dr. Michael Marsh, (England). He examines stool testing for earlier and more sensitive detection of gluten sensitivity. He enters a patent process and offers his unvalidated stool 2000 test to the public around 2000. His research paper is currently "in process.
- 2003 February, The landmark Fasano prevalence study is published in the Archives of Internal Medicine. This prompts a wave of publicity regarding celiac disease awareness. New US prevalence figures are revised from an older diagnosis rate of 1 in 4700 (and often misunderstood to be much higher) to 1 in 133 in the healthy population, 1 in 56 in the symptomatic population, and 1 in 22 or less among first degree relatives of a diagnosed patient. Half of these new diagnoses are "silent celiacs", or without symptoms. They are discovered in family screenings. Many patients finally find relief.
- 2003- 05 As publicity regarding celiac disease increases, a large body of patients with matching symptoms, history, genes and sometimes positive response to the gluten free diet "comes out of the woodwork". 1 in 56 of these symptomatic patients receives the "celiac diagnosis". Many of these diagnosed patients are fairly quickly helped by the gluten free diet. Others do not find complete improvement despite the strict gluten free diet. Generally they look to mistakes in the diet for hidden causes, or other unrelated problems, or other food intolerances possibly caused by celiac disease and secondary issues.
- Many negative testing patients with similar or identical symptoms find themselves in "No Man's Land". They suspect that gluten or something related to grains is still a problem and may try the diet anyway, some with success, but most assume they can safely eat gluten grains. Some of them may be misdirected. Still others who already know they do not digest gluten grains may try a gluten challenge, sure they will finally get their diagnosis, confirming to themselves and others that the diet is necessary. They do not consider that only 1 in 56 symptomatic patients are diagnosable celiacs. If they have been gluten free for a long time, they often suffer an uncomfortable or even unsafe gluten challenge and still test negatively.
- Research focuses on developing a drug or medical cure for celiac disease.
- Calls for further study of the large unstudied group of negative testing gluten intolerant patients are made in patient sourced articles, websites and newsletters. The Gluten Intolerance Group publishes a medically approved brochure recognizing non celiac gluten sensitivity, June 2005 and a seminar sponsored by the Gluten Intolerance Group, "Gluten Intolerance that is not Celiac Disease." acknowledges this previously unlabeled group
- 2006 Trans fats (in partially hydrogenated vegetable oils) are finally generally recognized by the public as unsafe, zero tolerance). Labelling laws for 8 top food allergens wheat, eggs, milk, soy, peanuts, tree nuts, fish, shellfish go into effect Jan 1, 2006.

Here are some well known “Celiac Disease” Programs and Specialists

<p>University of Chicago Celiac Disease Program http://www.uchospitals.edu/specialties/ceciac/index.php Dr. Stefano Guandalini www.celiacdisease.net Director: Michelle Melin-Rogovin 773-702-7593</p> <p>Celiac Disease Center at Columbia Dr. Peter Green 161 Fort Washington Ave. Room #645 New York, NY 10032 (212) 305-5590 www.celiacdiseasecenter.columbia.edu/CF-HOME.htm</p> <p>U of Maryland Center for Celiac Research Dr. Alesio Fasano, M.D. Director: Pam King 20 Penn Street, Room S303B Baltimore, MD 21201 www.celiachealth.org 410-328-6749 or 1-800-492-5538 www.celiaccenter.org</p>	<p>Children’s Digestive Health Center Dr. Joseph Levy, M.D. 3959 Broadway BHN-726 New York, NY 10032 212-305-5693</p> <p>Dr. John J. Zone, M.D. Department of Dermatology 4B454 School of Medicine 30 North 1900 East Salt Lake City, UT 84132-2409 appointments: 801-581-2955 office: 801-581-6465</p>	<p>Dr. Cynthia Rudert, M.D. 5555 Peachtree Dunwoody Rd. Suite 312 Atlanta, Ga 30342 404-943-9820</p> <p>Dr. Colin Rudolph, M.D. Children’s Hospital of Wisconsin Dept of Pediatric Gastroenterology 78701 Watertown Plank Road Milwaukee, WI 53226 414-266-3690 www.mcw.edu</p>	<p>Dr. Michelle Pietzak Pediatric Gastroenterology 4650 Sunset Blvd. Los Angeles, California 90027</p> <p>National Institute for Diabetes and Digestive and Kidney Diseases (National Institute of Health, NIH) http://digestive.niddk.nih.gov/ddiseases/pubs/ceciac/</p> <p>CDNHF/NASPGHAN www.celiachealth.org</p>
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Here are some Celiac Disease Support Organizations and Publications

<p>Celiac Sprue Association(CSA) www.csaceliacs.org</p> <p>PO Box 31700 Omaha, NE 68131-0700</p> <p>Toll Free: 877-CSA-4CSA Fax: 402-558-1347 Email: celiacs@csaceliacs.org</p>	<p>Gluten Intolerance Group (GIG) www.gluten.net</p> <p>15110 10th Ave SW • Suite A Seattle, WA 98166</p> <p>Phone: 206-246-6652 Fax 206-246-6531 info@gluten.net</p>	<p>The Celiac Disease Foundation www.celiac.org</p> <p>13251 Ventura Blvd #1 Studio City, Ca. 91604</p> <p>Phone: 818-990-2354 Fax: 818-990-2379 Email: cdf@celiac.org</p>	<p>R.O.C.K. Raising Our Celiac Kids</p> <p>www.celiackids.com ROCK@celiackids.com</p> <p>danna@celiackids.com</p> <p>Local chapters listed on www.celiackids.com.</p>	<p>Support magazines</p> <p>Living Without (www.livingwithout.com) Gluten Free Living, (www.glutenfreeliving.com) GIG Quarterly Newsmagazine (www.gluten.net) Lifeline-CSA(www.csaceliacs.org) Scott Free Newsletter (celiac.com)</p>
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Other Informative Web sites

(Most of these websites are not strictly conservative medical sites)

www.enterolab.com www.breakingtheviciouscycle.info

www.clanthompson.com www.glutenfreedom.net

www.celiac.com www.glutenfreemail.com www.mercola.com

www.livingwithout.com www.glutenfreerestaurants.org

www.GFlinks.com www.GFCFdiet.com www.foodintol.com

www.glutensensitivity.net www.price-pottenger.org

www.westonaprice.org www.greenpeople.com www.mercola.com

Online Forums

The St. John’s Celiac Listserv,

International gluten intolerance/ceciac disease related forums for patients, doctors, diabetics, and parents of autistic children
www.enabling.org/ia/ceciac/index.html (forum website)

To subscribe to the forum send an email with:

SUBSCRIBE CELIAC YourFirstName YourLastName
 in the body of a message to: CELIAC@LISTSERV.ICORS.ORG

The Delphi Forums On Line Celiac Support Group

<http://forums.delphiforums.com/ceciac/start>

Brain Talk – forum for neurological gluten intolerance symptoms

<http://brain.hastypastry.net/forums/forumdisplay.php?f=141>

Gluten Sensitivities Forum – www.glutensensitivity.net > Communications

Books, Cookbooks and other Resources on Gluten Sensitivities, Celiac Disease, other Food Intolerances, and related Conditions

Allergy Info and Allergy Related Cookbooks Not all Gluten Free
Food Allergies and Food Intolerances by Jonathan Brostoff, MD
The Ultimate Uncheese Cookbook by Joanne Stepaniak
The Allergy Self-Help Cookbook by Marjorie Hurt Jones, R.N.
The Complete Food Allergy Cookbook by Marilyn Gioannini

Gluten free Cookbooks

Bette Hagman Cookbooks - **The Gluten Free Gourmet, The Gluten Free Gourmet Cooks Comfort Foods, The Gluten Free Gourmet Cooks Fast and Healthy, The Gluten Free Gourmet Bakes Bread, The Gluten Free Gourmet Makes Dessert, More From the Gluten Free Gourmet Eating Gluten Free** by Shreve Stockton
Gluten-Free 101 - Easy Basic Dishes without Wheat by Carol Fenster
Gluten - Free Baking by Rebecca Reilly, and Romulo Yanas
Gluten Free Celebrations by Carol Fenster
The Gluten-Free Kitchen by Roben Ryberg
The Gluten, Wheat and Dairy Free Cookbook by Antoinette Savill
Special Eats - by Sueson Louis Vess www.specialeats.com
Wheat Free Recipes and Menus by Carol Fenster

Children's Books

Eating Gluten-Free with Emily by Bonnie J. Kruszka
GF Friends: An Activity Book for Kids by Nancy PFalini, MA, RD, LDN
Incredible Edible Gluten-Free Food for Kids by Sheri L. Sanderson
The Trouble that Jack Had by Jane and Diane Pintavalle
Wheat-Free, GF Cookbook for Kids & Busy Adults by Connie Sarros

Dining and Restaurant Support

Allergy Free Passport by Kim Koeller
GF, Wheat Free Guide to Eating Out- 2005 w/Dining Card by Jeff Beavin
Waiter...Is there Wheat in My Soup? by LynnRae Ries
Triumph Dining Cards. www.triumphdining.com
Bob and Ruth's Gluten Free Dining & Travel Club www.bobandruths.com
Food, medication lists, shopping resources
ClanThompson Celiac GF Pocket Guides, online listings, and "palm" software- www.clanthompson.com or www.glutenfreemail.com
CSA Product Listing 2005 1-877-CSA-4-CSA
CSA Guide through the Medicine Cabinet - www.csaceliacs.org
Ingredient list - <http://www.glutenfreeliving.com/> and www.celiac.com
Online shopping – www.glutenfreemail.com

Lifestyle

Against the Grain by Jax Peters Lowell
Food Allergy Field Guide by Theresa Willingham
The Gluten-Free Bible – The Thoroughly Indispensable Guide to Gluten-Free Diet – A Comprehensive Resource Guide by Shelley Case
Going Against the Grain by Jax Peters Lowell
Kids with Celiac Disease by Danna Korn
Living Well with Celiac Disease by Claudine Crangle
Negotiating Life without Wheat by Jax Peters Lowell
What, No Wheat? – by LynnRae Ries
Wheat Free, Worry Free, The Art of Happy, Healthy GF Living - D. Korn

Medical Information Books

- **Conservative Focus of Understanding**
New! **Celiac Disease – A Hidden Epidemic** –Dr. Peter H.R. Green
This excellent book acknowledges non celiac gluten sensitivity)
- **Moderate Focus of Understanding**
Dangerous Grains by Ron Hoggan and James Braly, MD.
- **"Maverick" Focus of Understanding (unvalidated)**
Celiac Disease Methods and Protocols (Methods in Molecular Medicine) by Michael N. Marsh
Breaking the Vicious Cycle by Elaine Gottschall
- **The Allergists**
Food Allergies and Food Intolerances by Jonathan Brostoff, MD
- **Alternative Focus of Understanding**
Eat Right 4 Your Type by Peter J. D'Adamo
Healthfood Junkies- Orthorexia Nervosa – Steven Bratman, MD
The Great Physicians Rx for Health and Wellness Jordan Rubin
The Maker's Diet by Jordan S. Rubin, N.M.D. and Joseph Brasco, M.D.
Nourishing Traditions by Sally Fallon and Mary G. Enig, PhD
Nutrition and Physical Degeneration by Weston A. Price, DDS
Pottenger's Cats A Study in Nutrition by Francis M. Pottenger, MD
Restoring Your Digestive Health by Jordan Rubin NMD & J BrascoMD
The Yeast Connection by William Crook
Healthfood Junkies- Orthorexia Nervosa – Steven Bratman, MD
- **Psychiatric and Religious Viewpoint of Understanding**
The Life Model James R. Friesen
Healing Life's Deepest Hurts –Edward M. Smith

Patient Perspective

A Personal Touch On...™Celiac Disease - by People Touched By Celiac
Sharing Their Stories To Help You edited by Peter R. Berlin and Jerry Stone

References for Conservatives

1. Allergy vs. Intolerance Lydia S. Boeken, MD http://celiac.com/st_prod.html?p_prodid=181&p_catid=11&sid=84X6ej10QJjo82T-21104580279.3e
2. Celiac Disease: Myths and Facts http://www.uchospitals.edu/pdf/uch_002799.pdf Dr Stefano Guandalini Director, University of Chicago Celiac Disease Program Professor of Pediatrics Section Chief, Pediatric Gastroenterology, Hepatology, and Nutrition University of Chicago
3. Prevalence of Celiac Disease in At-Risk and Not-at-Risk Groups in the United States Archives of Internal Medicine, Feb, 2003 http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12578508&dopt=Citation Alessio Fasano, MD; Irene Berti, MD; Tania Gerarduzzi, MD; Tarcisio Not, MD; Richard B. Colletti, MD; Sandro Drago, MS; Yoram Elitsur, MD; Peter H. R. Green, MD; Stefano Guandalini, MD; Ivor D. Hill, MD; Michelle Pietzak, MD; Alessandro Ventura, MD; Mary Thorpe, MS; Debbie Kryszak, BS; Fabiola Fornaroli, MD; Steven S. Wasserman, PhD, Joseph A. Murray, MD, Karoly Horvath, MD, PhD
4. University of Maryland Medical News Press Release, Feb 10, 2003 http://www.umm.edu/news/releases/celiac_study.html
5. How Can I Find Out if I have Celiac Disease? University of Chicago Celiac Disease Program http://www.uchospitals.edu/pdf/uch_002800.pdf
University of Maryland Center for Celiac Research <http://www.celiaccenter.org/faq.asp>
6. Seronegative celiac disease: increased prevalence with lesser degrees of villous atrophy. Dig Dis Sci. 2004 Apr;49(4):546-50 Abrams JA, Diamond B, Rotterdam H, Green PH. Department of Medicine, Columbia University College of Physicians and Surgeons, New York, New York, USA http://www.cdrc.org.uk/common/cdrc/assets/pdf/The_CF_Issue_15_Final171104115157.pdf (scroll down)
7. Antibody to Tissue Transglutaminase May Fall Short for Accurate Triage of Celiac Disease Peggy Peck Medscape Medical News 2004. © 2004 Medscape ACG 69th Annual Scientific Meeting: Abstract 4. Presented Nov. 1, 2004. Reviewed by Gary D. Vogin, MD
8. Nutritional Care: The Clinical Diet
Leon H. Rottmann, Ph.D., Professor Emeritus, U of Nebraska-Lincoln Excerpted from CSA Handbook, 1st Edition Lifeline Winter 1995, Vol XIII, No 1 pp 1-2
9. Gluten Contamination of Commercial Oats in the United States Thompson T. NEJM. 2004;351:2021-2022 (Nov. 4, 2004, Number 19)
Oats Intolerance in Celiac Disease Ludvig Sollid and colleagues, 2004 issue of Public Library of Science Medicine
21. Mortality in Patients with Celiac Disease and Their Relatives, a Cohort Study, Lancet. Vol.358, August 4, 2001
26. Sourdough Bread Made from Wheat and Nontoxic Flours and Started with Selected Lactobacilli Is Tolerated in Celiac Sprue Patients Applied and Environmental Microbiology, Feb, 2004, p. 1088-1096 0099-2240/04/\$08.00+0 DOI: 10.1128/AEM.70.2.1088-1086.2004 Vol 70, No. 2
27. Coeliac Disease: Dissecting a complex Inflammatory Disorder Ludvig M. Sollid Nature Reviews, Immunology Volume 2, September 2002 P.847
29. Celiac Disease, edited by Michael N. Marsh, first chapter, page 2, http://www.amazon.com/gp/reader/0896036502/ref=sib_dp_pt/103-8333068-1000606#reader-page
30. Refractory Sprue Culliford AN, Green PH Curr Gastroenterol Rep. 2003 Oct;5(5):373-8
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=12959717&query_hl=2
Association of celiac disease and intestinal lymphomas and other cancers. Gastroenterology. 2005 Apr;128(4 Suppl 1):S79-86 Catassi C, Bearzi I, Holmes GK http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15825131&itool=iconabstr&query_hl=1
Refractory Sprue by Michelle Melin-Rogovin, http://www.celiac.com/st_prod.html?p_prodid=877&p_catid=&sid=91hH9H1FtFCNB4X-15105316807.54

References for the Moderates

10. Dr Cynthia Rudert, on biopsy and negative testing patients who respond positively to the GF diet-Ask the Experts on www.clanthompson.com
25. Gluten Sensitivity Brochure by the Gluten Intolerance Group <http://gluten.net/downloads/infopackets/Gluten%20Intol%20not%20CD.pdf>26.

References for the Maverick, Dr. Ken Fine, and other Researchers

11. www.enterolab.com including Early Diagnosis, Before the Villi are Gone, Transcript of a talk given by Kenneth Fine, M.D. to the Greater Louisville Celiac Sprue Support Group, June 2003. FAQ's, Result Interpretation, Curriculum Vitae
12. Gluten Sensitivity as a Neurological Illness: From Gut to Brain Journal of Neurology Neurosurgery and Psychiatry 2002;72:560-563 **M Hadjivassiliou, R A Grünewald and G A B Davies-Jones** Department of Neurology, The Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF, UK Correspondence to: Dr M Hadjivassiliou, Department of Neurology, The Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF, UK;
13. Dangerous Grains James Braly, MD, and Ron Hoggan, MA Introduction page 5. Also one day challenge pages 72-74.
14. Gluten Sensitivity a Many Headed Hydra **M Hadjivassiliou, R A Grünewald and G A B Davies-Jones** BMJ 1999; 318; 17 10-1711
Marsh's "modern" definition of gluten sensitivity is to be recommended: "a state of heightened immunological responsiveness to ingested gluten in genetically susceptible individuals."¹⁰ Such responsiveness may find expression in organs other than the gut. Gastroenterologists, dermatologists, neurologists, and other physicians need to be aware of these developments if the diagnosis and treatment of the diverse manifestations of gluten sensitivity are advanced. The aetiology of such diverse manifestations presents the next challenge.
(10) Marsh MN. The natural history of gluten sensitivity: defining, refining and re-defining. *Q J Med* 1995; 85: 9-13.)

References from the Allergists

15. Allergy vs. Intolerance by Lydia S. Boeken, MD **Copyright © 1996 the Amsterdam Klikiek**
 16. Irritable Bowel Syndrome: Food elimination based on IgG antibodies in irritable bowel syndrome: a randomized controlled trial W. Atkinson, T A Sheldon, N Shaath, PJ Whorwell, *GUT* 2004;53: 1259-1464. doi: 10.1136/gut.2003.037697

References from the Alternatives

17. www.mercola.com
18. www.osteomed.com
28. The Oiling of America Mary Enig © 1999 Mary G. Enig, PhD and Sally Fallon. *Nexus Magazine*, Dec '98-Jan '99 and Feb '99-Mar '99.

References from the Psychiatric/Psychological and Spiritual Camps

19. Health Food Junkies, Orthorexia Nervosa: Overcoming the Obsession with Healthful Eating by Steven Bratman, MD with David Knight.
33. The Life Model by James Friesen, PH. D, E. James Wilder, Ph.D, Anne M. Gierling, MA, Rick Koepcke, MA, Maribeth Poole, MA Shepherd's House, Inc.

References for Information and research on similar or related diets and treatments

20. Quick Start Diet Guide <http://gluten.net/downloads/Quick-Start-Mar04.pdf> <http://celiachhealth.org/pdf/GlutenFreeDietGuideWeb.pdf>
21. Nutrition and Physical Degeneration Weston A Price, DDS www.westonaprice.org www.price-pottenger.org
22. The Yeast Connection – William G. Crook, M.D. 1986
23. Breaking the Vicious Cycle – Elaine Gottschall
24. Eat for Your Blood Type – Dr. Peter J. D'Adamo, Naturopath
25. Gluten Sensitivity Brochure by the Gluten Intolerance Group <http://gluten.net/downloads/infopackets/Gluten%20Intol%20not%20CD.pdf>**26.**
26. Sourdough Bread Made from Wheat and Nontoxic Flours and Started with Selected Lactobacilli Is Tolerated in Celiac Sprue Patients *Applied and Environmental Microbiology*, Feb, 2004, p. 1088-1096 0099-2240/04/\$08.00+0 DOI: 10.1128/AEM.70.2.1088-1086.2004 Vol 70, No. 2
27. Coeliac Disease: Dissecting a complex Inflammatory Disorder Ludvig M. Sollid *Nature Reviews, Immunology* Volume 2, Spetember 2002 P.847
28. The Oiling of America Mary Enig © 1999 Mary G. Enig, PhD and Sally Fallon. First published in *Nexus Magazine*, Dec '98-Jan '99 and Feb '99-Mar '99.
29. Celiac Disease, edited by Michael N. Marsh, first chapter, page 2, http://www.amazon.com/gp/reader/0896036502/ref=sib_dp_pt/103-8333068-1000606#reader-page
30. Mortality in Patients with Celiac Disease and Their Relatives, a Cohort Study, *Lancet*.Vol.358, August 4, 2001
Reaction to a gluten challenge. Karoly Horvath http://www.celiac.com/st_prod.html?p_prodid=54
31. www.medical-dictionary.com
32. http://csaceliacs.org/celiac_defined.php
33. The Life Model by James Friesen, PH.D, E. James Wilder, Ph.D, Anne M. Gierling, MA, Rick Koepcke, MA, Maribeth Poole, MA Shepherd's House, Inc
34. Immune Response to Dietary Proteins, Gliadin and Cerebellar Peptides in Children with Autism A. Vojdani, T.O'Bryan, J.a. Green, J. McCandless, K.N. Woeller, E. Vojdani, A.A. Nourian and E. L. Cooper *Nutritional Neuroscience*, volume 7 Number 3 (June 2004), pp. 151-161 Corresponding author. Address: Immunosciences Lab, Inc, 8693 Wilshire Blvd, Ste. 200, Beverly Hills, California, 90211, USA

Here are several lists of symptoms that are sometimes related to gluten intolerance. These cover several schools of understanding, and research that is rapidly changing so no list is complete.

- **Conservative Specialists** identify over 200 conditions related to Celiac Disease. Sources: Celiac Disease: Myths and Facts by Stefano Guandalini, MD, U of Chicago Fact Sheet, http://www.uchicagokidshospital.org/pdf/uch_007934.pdf, NIH <http://digestive.niddk.nih.gov/ddiseases/pubs/celiac/index.htm#5>, the University of Maryland Center for Celiac Research website, <http://www.celiaccenter.org/facts.asp>, Columbia University http://www.celiacdiseasecenter.columbia.edu/A_Patients/A01-HOME.htm
- Abdominal Distention (children)
- Abdominal Pain, bloating
- Anemia-Folate-Deficiency/Iron Deficiency Pernicious
- Anxiety
- Arthralgia or Arthropathy
- Arthritis – and Rheumatoid Arthritis
- Ataxia, primary
- Behavioral problems
- Carcinoma of Oropharynx, Esophagus, Small Bowel
- Collagenous Sprue
- Constipation, chronic
- Depression
- Dermatitis Herpetiformis
- Diabetes (Type 1)
- Diarrhea, chronic
- Down Syndrome
- Enteropathy-Associated T-cell Lymphoma
- Epilepsy with occipital calcifications
- Failure to Thrive (children)
- Fatigue
- Hepatitis (Chronic) with Hypertransaminasemia
- IBS - Irritable Bowel Syndrome
- IgA Deficiency
- IgA Nephropathy
- Infertility
- Kidney Disease
- Learning Difficulties
- Liver Disease
- Low Bone Mass
- Microscopic Colitis/Collagenous Colitis
- Miscarriage, repeated
- Nerve Disease
- Pregnancy, adverse effects on
- Osteomalacia, Osteoporosis Recurrent Aphthous
- Primary Biliary Cirrhosis
- Refractory Sprue / Celiac Disease
- Short Stature (only sometimes)
- Sjogren's Syndrome
- Skeletal problems
- Steatorrhea, occasionally, (Pale, foul smelling stool)
- Stomatitis, Recurrent
- Tooth Enamel Defects, Tooth Discoloration
- Turner Syndrome
- Thyroid Disease (Autoimmune), Thyroiditis
- Ulcerative Jejunoileitis
- William's Syndrome

List of disorders for which Dr. Ken Fine MD, www.enterolab.com, recommends gluten sensitivity stool tests.

Dr. Fine's research is in progress for scientific publication (01/06)

- Microscopic colitis
- Relatives of gluten-sensitive individuals
- Gluten-sensitive individuals 1 year after treatment
- Chronic diarrhea of unknown origin
- Irritable bowel syndrome
- Inflammatory bowel disease
- Gastroesophageal reflux disease
- Hepatitis C
- Autoimmune liver disease
- Other causes of chronic liver disease
- Dermatitis herpetiformis
- Diabetes mellitus, type 1
- Rheumatoid arthritis
- Sjogren's syndrome
- Lupus
- Scleroderma
- Autoimmune thyroid disease
- Dermatomyositis
- Psoriasis
- Any autoimmune syndrome
- Chronic Fatigue
- Fibromyalgia
- Asthma
- AIDS
- Osteoporosis
- Iron deficiency
- Short stature in children
- Down's syndrome
- Mothers of kids with neural tube defects
- Female infertility
- Peripheral neuropathy
- Cerebellar ataxia
- Seizure disorders
- Psychiatric disorders
- Depression
- Alcoholism
- Autism
- ADHD/ADD

Symptom list at www.glutenfreedom.net, (Danna Korn)

"Danna gets an A+ for accuracy in her knowledge of the gluten-free diet and the medical conditions that benefit from it." Cynthia Rudert, M.D. - Atlanta, GA. Danna has authored 2 books, "[Wheat Free Worry Free, the Art of Happy, Healthy, Gluten Free Living](#)", and "[Kids with Celiac Disease](#)". Danna is the mother of a child with Celiac disease, is a popular international speaker and consultant in the Gluten Free Community, and her work is reviewed by celiac specialists.

Fatigue, Chronic Fatigue
Addison's disease
Gastrointestinal distress (gas, bloating, diarrhea, constipation),
Headaches (including migraines)
Infertility
Mouth sores
Weight loss/gain
Inability to concentrate
Moodiness/depression
Amenorrhea/delayed menstrual cycles
Bone/joint/muscle pain
Dental enamel hypoplasia
Short stature
Seizures
Tingling numbness in the legs

Symptoms also include:

Abnormal liver test
Addison's disease
Alopecia
Anemia
Ataxia
Autoimmune hepatitis
Chronic abdominal pain
Crohn's disease
Dermatitis herpetiformis
Down syndrome
Epilepsy
Family history of celiac disease
Gall bladder disease
Hyperthyroidism/hypothyroidism
Total IgA deficiency
Insulin-dependent diabetes (type 1)
Infertility/spontaneous abortions/low birth-weight babies
IBS (Irritable Bowel Syndrome)
Malnutrition
Multiple sclerosis
Non Hodgkin's lymphoma
Osteoporosis, osteopenia, osteomalacia
Pancreatic disorders
Pathologic fractures
Peripheral neuropathy
Primary biliary cirrhosis
Psoriasis
Recurrent stomatitis
Rheumatoid arthritis
Sclerosing cholangitis
Sjogren syndrome
Systemic lupus
Turner syndrome
Ulcerative colitis
Vitiligo

Symptom list from the Celiac Sprue Association website

The medical information on this CSA list was last reviewed/updated on January 1, 2004.

A. Physical symptoms

- Abdominal cramping/bloating
- Abdominal distention
- Acidosis
- Appetite (Increased to the point of craving)
- Back pain (Such as a result of collapsed lumbar vertebrae)
- Constipation
- Decreased ability to clot blood
- Dehydration
- Diarrhea (See Stools below)
- Edema
- Electrolyte depletion
- Energy loss
- Fatigue
- Feet (Reduced fat padding)
- Flatus (Passing gas)
- Gluten ataxia
- Mouth sores or cracks in the corners
- Muscle cramping (Especially in the hands and legs)
- Night blindness
- Skin (Very dry)
- Stools (Loose? Hard? Small? Large? Foul smelling? Floating? Clay, Light tan or Gray-colored? Highly rancid? Frothy?)*
- Tongue (Smooth or geographic - looks like different continents)
- Tooth enamel defects
- Weakness
- Weight loss

B. The Patient's Emotional State

- Depression
- Disinterested in normal activities
- Irritable
- Mood changes
- Unable to concentrate

C. Additional Conditions

- Amenorrhea
- Iron-deficiency anemia
- Bone disease
- Hyperparathyroidism

Symptoms in children

How is the child developing?

- Slowly
- Not gaining weight
- Losing weight

Under age three:

- Growth failure
- Diarrhea
- Projectile vomiting
- Abdominal bloating/distention

Older children:

- Crankiness
- Difficulty concentrating
- Irritability
- Personality changes

Poor memory

* Note: Specific stool descriptions do not apply to all cases

Other symptoms lists and resources

- Other patient compiled lists of symptoms "definitely" connected with celiac disease, "probably" connected with celiac disease, and diseases that "resemble" celiac disease may be found at:

www.celiac.com > site index > Celiac Disease research: Associated Diseases and Disorders > Lists of Diseases and Disorders Associated with Celiac Disease

- It is helpful when researching a particular condition and its possible relationship to celiac disease or gluten sensitivities to examine the original research where available, remembering that research is far from finished and some areas are not researched at all.

<http://www.pubmed.gov/>, and search "celiac disease and (name of condition)"

Example: celiac disease and depression Note: Europeans spell celiac "coeliac".

Disclaimer --- I am a volunteer and not a medical expert, but I can share with you information that I have found helpful. Please contact a *well informed* healthcare professional for medical advice regarding your situation.

Please verify the gluten free status of products often for your own protection as ingredients change.

Please consider that research is rapidly changing and some information contained in this primer may become obsolete.

Please continue to stay in touch with *well informed* healthcare professionals and abreast of current research in order to make well informed decisions regarding your health care.