

Testing for gluten intolerance and celiac disease

This issue is one which is evolving. The one common denominator in all testing is that the ***patient should continue to consume gluten*** before and while being tested. If all testing comes back negative and there are still no “answers” that are definitive, the patient may want to consider a gluten free diet to see if there is any improvement in symptoms. Many individuals have found through trial and error that they felt so much better on a GF diet that it didn’t matter to them if they had a specific diagnosis.

Celiac Disease, by definition, is a condition which is characterized by damage to the villi in the small intestine. It can be occurring with or without the presence of symptoms. This disease was once thought to be rare. Currently, estimates place it as the most common genetic auto-immune condition in the world today possibly as high as 1:100 individuals. Unfortunately, diagnostic techniques and the medical community at large are not catching up quickly to the awareness of this fact. Length of time for diagnosis AFTER onset of symptoms is 11 years. Many patients who are currently experiencing conditions which result from malnutrition (osteoporosis, B12 deficiency, Vitamin D deficiency, anemia, bone/join pain, fatigue, etc.) – may, in fact, be undiagnosed celiacs. Estimates are that over 60% of celiacs do not have “obvious” and/or gastrointestinal symptoms.

Dermatitis Herpetiformis is a skin manifestation of CD characterized by extremely itchy blisters.

GSE (Gluten Sensitive Enteropathy – which means “any reaction to gluten” and includes a spectrum of disorders including gluten ataxia and possibly ADHD and autism) or Gluten Intolerance, on the other hand, has no official medical recognition as a condition or disease. However, there is mounting evidence to suggest that the symptoms that are resolved when gluten is withdrawn from the diet suggest that in fact, this is a real condition with a “cure” – the gluten free diet.

Individuals suffering from “related” autoimmune conditions (list is extensive) find that removing gluten from their diet, improves their symptoms and general health. In some cases, complete remission has been experienced.

BLOOD TEST: Medical procedure, requires a blood draw. This test was developed specifically to identify Celiac Disease. It is looking to find antibodies against gluten in the blood. The problem with this test is that in fact it is measuring the level of damage in the small intestine. The higher your numbers the more damage. A positive test result is accurate. However a negative result does not mean that you are not responding to gluten. It only means that you do not have high enough antibodies in the blood to have “measurable” damage in the small intestine. This panel, when ordered by your physician, will usually be covered by insurance, you may need to “push” to get them to order it for you. Full Celiac Panel – usually about \$125.

BIOCARD Celiac Home Test – available on-line and in Canada. This test is NOT approved by the US FDA. www.celiachometest.com – This is a tTG blood test. All items required are packaged in the box and there is nothing to return to any lab. You will know in less than 10 minutes if you have positive anti-tissue transglutaminase. The results will allow you to more strongly approach your physician to be tested with a conventional Celiac Panel (above) and possibly an endoscopy (biopsy is still the gold standard for celiac diagnosis). A negative test does *not* mean that you do not have GSE – cost \$50.

ENDOSCOPY: Medical procedure, expensive and considered invasive. Procedure requires preparation and sedation. The gastroenterologist will insert a thin tube down the esophagus with a built-in scope to inspect the walls of the small intestine and identify damage to the villi. A series of tissue samples will be taken to be reviewed by a pathologist. A positive result from this “viewing” and the biopsy slide will be a definitive diagnosis for Celiac Disease. However, a negative result does not mean that you are not responding to gluten. It only means that you do not have enough damage to be visible to the physician and or that the tissue samples taken did not include damaged villi. New viewing procedures in the future could include swallowing a tiny camera that would transmit images of the small intestine to a storage drive worn during the test and/or a microscope tiny enough to be used at the end of the endoscopy tools, which would improve visibility. Make sure to arrange for your insurance to cover this expense, can cost as much as \$7,000, for procedure, physician and extraneous.

Ultimately, this test is the “gold standard” for diagnosing Celiac Disease and conventional medical thinking

is that if you don't have a positive biopsy – you don't have Celiac.

SKIN BIOPSY: in the case of Dermatitis Herpetiformis a small skin sample is taken at the site of damage (blisters) and tested for deposits of IgA antibody. A positive result determines the CD diagnosis and no further testing is usually required. Prescription is gluten free diet.

INTESTINAL PERMEABILITY TEST: Non-invasive. Rapidly becoming more popular, this test literally measures the intestinal wall for structural integrity. Molecules of food should not be able to pass through “unprocessed”. This test determines whether or not that is occurring. Intestinal walls are damaged when subjected to food which the body has determined to be “antigenic”, i.e. it produces antigens against the food, believing it to be a toxic invader in the body. Genova Diagnostics (see links below) performs this test, your physician must order it for you. Usually tests ordered by your physician will be covered by insurance, cost \$350

NEW SALIVA TEST – A medical study just published 10/10/08 supports a *new* saliva test that may prove to be the best diagnostic tool yet. Laboratories have not yet begun to have this test kit available, check for more information and availability at www.glutenfreeway.info. NOTE: saliva tests that have been on the market prior to this time, have proven to have much greater levels of inaccuracy.

<http://www.ncbi.nlm.nih.gov/sites/entrez?Db=pubmed&Cmd=DetailsSearch&Term=18429945>

IgA/IgG STOOL TEST: Non-invasive. Developed by Entero Labs this test is looking to see if the body is producing antigens against certain foods (gluten, dairy, soy, etc.) It is a non-invasive test using a sample of stool material to look for evidence of antigens. The only test (as far as I know) for antibody production in the small intestine (which is your first line of defense in the body against bacteria, disease, etc. – your small intestine represents approx. 60% of your autoimmune system). You can order this test yourself on-line, or have your physician order it for you. The cost not usually covered by insurance - \$99-200 (plus shipping)

GENETIC TESTING: Non-invasive. Highly recommended, especially if all other testing is resulting in negatives but symptoms are continuing. It is possible to have the genes for gluten sensitivity and/or celiac disease and not be suffering any outward symptoms (caveat: see above regarding malnutrition). Frequently a “trigger” is experienced for a patient to evolve to an active form of the condition, where they are producing anti-bodies against gluten/dairy.

If you order this yourself (Entero Lab has a genetic test – see below) it will probably not be covered by your insurance company. You can discuss with your physician other tests or laboratories that may cover this expense.

Genova Diagnostics

<https://www.gdx.net/home/gsd/>

specifically describing the test for intestinal permeability: <https://www.gdx.net/home/assessments/jp/>

why you want this test: <https://www.gdx.net/home/assessments/finddisease/add/>

<https://www.gdx.net/home/assessments/finddisease/autism/>

On the issue of food intolerances, allergies, their affects, etc.

<https://www.gdx.net/home/assessments/allergy/index.html>

Entero Lab

FAQ - https://www.enterolab.com/StaticPages/Frame_Faq.htm

Quote from Stanford Medical School -

Those who carry this genetic type, HLA DQB1 0602, are also predisposed to a non-celiac gluten sensitivity which can cause widely varying neurological problems, and many symptoms related to nutritional deficiencies.

NEW Blood tests to diagnose GSE from website—www.drrodneford.com

If you have symptoms that suggest you could be have celiac disease or are gluten sensitive, the next step is to arrange to get your blood tests. It is important you have these blood tests *before* you go gluten free.

Please keep EATING gluten until you have had your blood tests.

Tissue damage tests: to look for celiac disease

Step one is to look for evidence of gut damage: this is to make a diagnosis of celiac (coeliac) disease. These "tissue damage" tests are called:

- DGP-IgG (Deamidated Gliadin Peptide – IgG) - NEW
- tTG (tissue TransGlutaminase) - IgA
- DPG-IgA (Deamidated Gliadin Peptide – IgA) - NEW
- EMA (Endomesial Antibodies) - IgA

Celiac disease is defined as the gut damage caused by gluten. When this happens, there is an over-reaction of the immune system in the gut. A harmful immune reaction is generated in the gut mucosa. This tissue injury involves inflammatory cells and the production of antibodies. These "tissue damage" tests can pick this up.

Studies demonstrate that where levels of these antibodies are elevated, more than 95% of patients will be found to have celiac disease. Not surprisingly, there are now claims that a high DGP or tTG level is all that is required to make a diagnosis of celiac disease.

DGP (Deamidated Gliadin Peptide)

This is a new type of gliadin test is being manufactured by Inova Diagnostics. It has been developed to more accurately identify people with *celiac disease*. Eventually, it is likely to overtake the tTG test because it is excellent at finding those people who have gluten-related gut damage. This test detects an immune response to a very specific fragment of the gluten molecule (this fragment is a short peptide of gliadin). In fact, it seems more reliable than the tTG test, however it will not detect gluten sensitivity in people who do not have celiac disease.

It will **not** pick up the people who have the other symptoms of The Gluten Syndrome. It does **not** replace the IgG-gliadin test.

Value of DGP: If both high, then celiac disease almost certain.

tTG antibody (also called IgA tissue transglutaminase antibody)

The tTG antibody test is a tissue damage test. tTG is a specific antibody made against muscle tissue damage in your small bowel. It is a very sensitive indicator of the small bowel damage that can be caused by the gluten in your diet. High levels of tTG mean that you might have gut damage (celiac disease). It is currently recommended that you confirm the likelihood of gut damage by having a small bowel biopsy (by endoscopy).

Value of tTG: If very high, then celiac disease almost certain. If slightly high, then maybe celiac.

EMA (Endomesial Antibodies)

This is an older test and becoming less popular. Nevertheless, it is quite sensitive at detecting the gut tissue damage of celiac disease.

Value of EMA: If positive, then high chance of celiac disease.

To look for gluten-sensitivity

Step two is to look for evidence of gluten harm: this is to make the diagnosis of **gluten-sensitivity** (reactions to gluten without the gut damage)- aka villous atrophy)

- Anti gliadin antibody – IgG
- Anti gliadin antibody – IgA

A positive test shows that you have an immune reaction to gluten. This might not be causing symptoms yet. Most gluten-sensitive people have a high IgG-gliadin test.

The conflict of the IgG-gliadin test

There is disagreement surrounding the interpretation of the gliadin antibody test. It is found in elevated levels in about 10% of the population.

Beginning in the 1990s, the anti-gliadin IgG antibody test (often referred to as the IgG-gliadin test) was used to verify suspicion of celiac disease. However, it is a poor predictor of celiac disease. By contrast, the "tissue damage" antibodies (see above) are set off by bowel tissue damage and are excellent predictors of celiac disease.

There are two opposing schools of thought. First, the medical establishment, represented by the gastroenterologists, has concluded that the gluten blood tests are inaccurate and misleading (in relation to celiac disease). Their total focus is on the gut damage: and justify their position with the fact that gluten (gliadin) blood tests are poor predictors of who has the tissue damage caused by celiac disease.

This is true, but they then go on to make a serious error of logic. They say that because the gluten tests are not useful in detecting celiac disease, consequently, these gluten tests are not good for anything, and should be abandoned.

Dr Rodney Ford's data shows another interpretation: **The IgG-gliadin test is a gluten test**

Research shows that the IgG-gliadin antibody test is valuable for detecting people who are reacting adversely to gluten (but who do not have villous atrophy associated with celiac disease).

The relationship between patient complaints and high levels of gluten antibodies has been widely investigated. Dr Ford's research has shown that high levels of gluten antibodies accurately predict a beneficial response to a gluten-free diet. High IgG-gliadin antibody levels are indicative of an immunological reaction to gluten, which can manifest as significant poor health – *The Gluten Syndrome*.

The books that tell you much more about this are: Are You Gluten Sensitive? And The Gluten Syndrome—both by Dr. Rodney Ford, M.D.

The following medical laboratories in the USA currently measure **IgG-gliadin** (using Inova Diagnostic gliadin IgG kits). *Please ask your doctor to send you to one of these labs for the gliadin test.*

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| • Duke University | • Clinical Pathology Laboratories |
| • Thomas Jefferson Univ. Hospital | • Allergy A.R.T,S, |
| • Alverno Clinical Laboratories | • Quest Diagnostics, MA |
| • University of Washington | • Meridian Valley Clinical Lab |
| • The Miriam Hospital | |

LabCorp also offers this test but as part of an overall **IBS** test panel.

See your Medical Practitioner

To get this test, you need your own GP to fill out your blood form. Ask for these tests for comprehensive testing for celiac and gluten problems:

- tTG antibody (called IgA tissue transglutaminase antibody)
- DGP antibody (called Deamidated Gliadin Peptide, IgA and IgG)
- IgG-gliadin (also called IgG anti-gliadin antibody)
- IgA-gliadin (also called IgA anti-gliadin antibody)

Also, these tests help with the interpretation :

- Total IgA antibody levels (looking for deficiency in IgA antibody production)
- Ferritin (a measure of your iron stores)
- Hb (Haemoglobin to check for anaemia)
- CRP (called C-Reactive-Protein to look for evidence of inflammation)