

## Just Say “NO!” to Poop Tests for Gluten Sensitivity

Gluten sensitivity is always a hot topic, and it’s gotten even more attention each time the newest celebrity goes gluten-free. In the past few years, rigorous research has demonstrated that gluten sensitivity is real and can be tremendously debilitating. Just like Celiac disease, symptoms vary widely from diarrhea, constipation, migraines, joint pain, fatigue, brain fog, depression and much more. For the newest information on gluten sensitivity, this article can be accessed freely online:

<http://www.biomedcentral.com/1741-7015/10/13>

In some ways, Celiac is easier to wrap our heads around—tests show autoimmune processes, biopsies show damage, and ready or not, you’re off to gluten-free land. Although there is no definitive test for gluten sensitivity, one of the most common questions I get is about stool testing. As stated by Alessio Fasano, one of the leading researchers worldwide on Celiac and gluten-sensitivity: ‘If anyone claims they have a test that is specifically for gluten sensitivity, there is no such thing, though I’m not ruling it out in the future.’<sup>i</sup>

Stool tests for Celiac and gluten-sensitivity have been around for over a decade, and can be ordered without a doctor. The problem is that there is currently no published research to support the test, and, in fact, most experts recommend against it for this reason. The company offers both a stool test to “diagnose” gluten-sensitivity and or Celiac disease and a gene test to determine if people have the genes that are linked to gluten sensitivity. One lab discusses doing years of research, but they provide no peer reviewed, published studies on their tests.

Why does it matter? Tests are researched to determine accuracy and utility. For accuracy, there are studies to show sensitivity and specificity. *Sensitivity* looks at the percentage of people with the problem that are correctly identified. *Specificity* looks at false positives—are we ONLY getting people with the problem, and not something else? So for example, the tissue transglutaminase (tTG) tests used for Celiac have a sensitivity of 97% and a specificity of over 91%<sup>ii</sup>, which is pretty high. One website claims to be 100% sensitive in detecting Celiac disease and gluten-sensitivity, but offers no information as to the sources of this figure, or specificity. As a physician on a Celiac listserv put it: “Just because something is measurable does not mean it is a predictor of a disease. Everyone I know with Celiac disease has a nose, but nose positivity is not specific for Celiac disease.”

A PubMed study on a different kind of stool testing in children with Celiac showed a maximum sensitivity of 82%, and specificity of 58%<sup>iii</sup> Those are very poor numbers, and since other labs haven’t published methodology, there’s no way to know if their numbers are better or worse.

Utility boils down to (as put by a doctor I work with) the “so what” test. So you have a certain gene, or antibodies in your stool. So what? What are the chances that changing to a gluten-free diet will enhance your health or lead to functional improvements? With Celiac disease, the case is pretty clear that intestinal damage heals nearly 100% of the time and there are huge benefits in decreased mortality, etc. But what about people defined as gluten sensitive by this test? How many feel better? Unfortunately, they don’t provide that information.

Their gene panels for gluten sensitivity are even more problematic. According to one website, “at least 81% of America is genetically predisposed to gluten sensitivity”, and “based on these data, almost all Americans, especially those descending from Europe (including Mexico and other Latin states because of the Spanish influence), the Middle East, the Near East (including India), and Russia, are genetically predisposed to gluten sensitivity.”<sup>iv</sup> If this is true, and almost all of us have the genes for gluten sensitivity, I’m unclear how the test provides additional useful information for the general U.S. public. Also, in the many years of working with people about gluten sensitivity, I’ve only had two clients who tested negative for the genes.

As a health care practitioner, there are so many red flags. It’s an expensive test (nearly \$400) which is not covered by insurance, and they recommend people repeat some of the panels yearly. There’s no research showing it does what it intends to, and the website specifically discourages the testing recommended by the NIH and Gastrointestinal groups “there is no reason to expose yourself to the risks, invasive nature, and expense of an intestinal biopsy.”<sup>v</sup> I do agree that biopsies may not be fun, but in my humble opinion, neither are stool tests.

It’s also troubling because this is a direct to consumer test, and most people, even people with a health care background, will just assume the test is what it claims to be. Many support groups talk about taking the test and going gluten-free and feeling so much better. However, most of the people who take the test are the folks already having gastrointestinal upset and Celiac-like symptoms, so these are the people who are most likely to feel better gluten-free regardless.

So rather than paying a lot of money for an unproven test, please, get yourself tested for Celiac via the blood test and/or biopsy. If the test is negative, and you are motivated to try a gluten-free diet, work with a dietitian to do a gluten elimination diet and see how you feel. If you are gluten-free, your options are the gene test, which provides limited information, a gluten challenge, or a lifelong assumption of Celiac disease. Save your money for a bread maker, or go to see a Registered Dietitian to learn about your new lifestyle.

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<sup>i</sup> New Guide to Who Really Shouldn’t Eat Gluten. WSJ. Feb 6, 2012.

<http://online.wsj.com/article/SB10001424052970204136404577206891526292590.html>

<sup>ii</sup> Volta, U. and Villanacci, V., Celiac disease: diagnostic criteria in progress. *Cell Mol Immunol* 2011. **8**: 96-102

<sup>iii</sup> Detection of secretory IgA antibodies against gliadin and human tissue transglutaminase in stool to screen for coeliac disease in children: validation study. *BMJ*. 2006 Jan 28;332(7535):213-4. Epub 2005 Dec 23.

<sup>iv</sup> <https://www.enterolab.com/StaticPages/FaqResult.aspx>

<sup>v</sup> American Gastroenterological Association. AGA Institute medical position statement on the diagnosis and management of celiac disease. *Gastroenterology*. 2006;131:1977–1980