

Gluten Sensitivity v. Celiac Disease- What do we know?

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A great deal changed in 2009 in the area of gluten sensitivity and celiac disease. My book, *The Gluten Effect* was published early in the year and I must confess that my co-author and I felt like quite the renegades during the year we were writing it and for several months following its publication. The reason was that there seemed to be two distinct camps in the field: those that felt that celiac disease was the only “real” diagnosis and those that “knew” that gluten sensitivity was a very real condition.

Dr Peter Green wrote the book “Celiac Disease” in 2006 and had been heard to say that it was cruel and unusual punishment to remove gluten from the diet of someone who didn’t have celiac disease. Yet in 2009 he has embraced gluten sensitivity and spoke of it in his research.

Dr Alessio Fasano medical director of the University of Maryland Center for Celiac Research also felt similarly. Yet in 2009 he was quoted as saying in *Scientific American*: “Celiac disease and gluten sensitivity are subsets of gluten intolerance. Anyone who has celiac disease or gluten sensitivity is, by definition, gluten intolerant.” I encourage you to read this very elegant article in the August edition.

Genetically we face a mixed bag with these conditions. While almost 100% of people with celiac possess either the DQ2 or DQ8 genes, up to 40% of the general population also possess one of these markers. Dr Fasano reported that half of the gluten sensitive people have the genes and half don’t, making it possible to be gluten sensitive without having either one of the genes. He also stated as regards genetic testing for DQ2 or DQ8 that: “A positive result doesn’t imply much. It has little predictive value on the lifetime risk of developing celiac disease.”

Add to that fact that in the April 2009 Celiac Disease Symposium held in Amsterdam evidence was presented that nine other genes associated with celiac disease have been discovered.

So where do we stand as regards genetic testing. If having the gene doesn’t mean that you’re going to definitely get celiac disease and not having the gene doesn’t rule out gluten sensitivity, what really is the purpose of performing these tests? Some people just want to know and that’s fine, but do know that nothing definitive comes from the results.

While celiac creates severe destruction of the villi of the small intestine and gluten sensitivity seems to “spare” the villi to some degree, a gluten sensitive person is no less likely to be chronically ill as a result of consuming gluten. There is some debate whether a celiac is more likely to contract autoimmune disease than a gluten sensitive patient, but the jury is still out. I can only state

that clinically I have seen many patients with autoimmune disease who were gluten sensitive.

We also know that gluten, in sensitive individuals, extends its negative effects far beyond the gastrointestinal tract. *Cellular & Molecular Life Sciences* 2005 reported: "celiac disease has also been termed gluten sensitive enteropathy because the small intestine is the main target of injury; however, the clinical manifestations are extremely diverse, suggesting the disorder is in fact a multi-systemic disorder."

Pediatrics 2001 stated: "The brain seems to be particularly vulnerable."

Pediatrics 2004 commented: "neurologic disorders or findings were found in 51.4% of patients with celiac disease."

Journal of Neurology Neurosurgery and Psychiatry 1997 found: "The immune response triggered by sensitivity to gluten may find expression in organs other than the gut; and the central and peripheral nervous systems are particularly susceptible."

Journal of Clinical Gastroenterology 2006 reported : "43.3% of Celiac Disease patients in our study presented with thyroid involvement."

Hepatology Journal 2007 found: "liver blood test abnormalities affect patients with classical celiac disease or may be the sole presentation of atypical celiac disease." "A gluten free diet leads to normalization of the blood in 75% to 95% of patients with celiac disease, usually within a year of adherence to the diet." "Even more, celiac disease was found to be associated with an 8-fold increased risk of death from liver cirrhosis."

World Journal of Gastroenterology 2003 stated: "both miscarriage frequency and babies' low birth weight would normalize in response to a gluten free diet."

"Untreated celiac disease in women resulted in an 8.9-fold increase in the relative risk of pregnancy miscarriage and in a 30% reduction of the baby's birth weight."

Lancet 2001 found: "death was most significantly affected by diagnostic delay, pattern of presentation, and adherence to the gluten free diet...Non-adherence to the gluten free diet, defined as eating gluten once-per-month increased the relative risk of death 600%."

We do know that the average celiac visits more than 5 doctors and suffers for over a decade before receiving a diagnosis. And while celiac affects 1% of the population, estimates for those suffering from gluten sensitivity vary from a conservative 10% to well over 40%. Even the conservative viewpoint points to millions of people suffering needlessly because they haven't been educated on the possible dangers.

Why are we so poor at diagnosis?

The *Archives of Internal Medicine* 2003 reported: “a failure by physicians to appreciate that many individuals with the disease initially present without gastrointestinal symptoms is another reason why celiac disease testing may not be performed.”

Gastroenterology 2001 found: “...for every symptomatic patient with celiac disease there are eight patients with celiac disease and no gastrointestinal symptoms.”

Gastroenterology 2007 stated: “Delayed diagnosis of coeliac disease increases cancer risk.”

What is the most accurate method of diagnosis? While many of you may have been told that the intestinal biopsy is the gold standard of celiac testing that data seems to be antiquated according to many researchers who consider the test to be too gross and not the sensitive early marker needed to prevent serious health problems.

The *American Journal of Gastroenterology* 2006 reported: “conventional histology is not anymore a gold standard in the diagnosis. The diagnostic criteria need thus to be revised.”

Currently the best testing available for gluten sensitivity is both a gliadin antibody test and the “gold standard” of food sensitivity testing – elimination and provocation. While the gliadin antibody test can be a good early indicator that the immune system is being taxed and inflamed by the presence of gluten in the diet, the test has sensitivity problems meaning that false negatives can occur. *The New England Journal of Medicine* in 2007 supported elimination and provocation when they reported: “the diagnostic criteria developed by the European Society for Pediatric Gastroenterology and Nutrition require only clinical improvement with the diet.”

We live in exciting times where a tremendous amount of good research is being performed in this very critical field. I will keep you apprised. Please feel free to contact me should you have any questions.

To your good health,

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