

Gluten-free diet may not reduce intestinal damage in all children with celiac disease

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In surprising findings, researchers from MassGeneral Hospital for Children (MGHfC) and Boston Children's Hospital (BCH) have discovered that nearly one in five children with celiac disease sustained persistent intestinal damage, despite strict adherence to a gluten-free diet. The findings are consistent with recent research in adults, which showed that more than 33 percent of adult patients on a gluten-free diet have persistent intestinal damage, despite a reduction of symptoms or the results of blood tests.

"This study confirms that we need to look more aggressively for mucosal healing in all patients, not just adults," says Maureen Leonard, MD, MMSc, clinical director of the Center for Celiac Research and Treatment at MGHfC and co-lead author of the report published online in the *Journal of Pediatric Gastroenterology and Nutrition*. Findings from the study have already been translated into revised clinical care practices at MGHfC, where most pediatric patients over the age of 10 will be monitored for mucosal healing with a repeat endoscopy, along with follow-up blood testing, after one year of treatment with the gluten-free [diet](#).

Current guidelines for pediatric [celiac disease](#) patients recommend a single biopsy at diagnosis and follow-up blood testing to monitor recovery of the intestinal mucosa. In a related commentary that has also been published online in JPGN, Ivor Hill, MD, of Nationwide Children's Hospital and the Ohio State University School of Medicine echoed the call to revisit current treatment guidelines and also raised questions about

the prevalence of intestinal damage in [children](#) with celiac disease and the best way to move forward, considering the results of the current study. "Until we have a reliable non-invasive means of determining mucosal healing in children with CD, it seems the biopsy will remain important both for initial diagnosis and subsequent monitoring," Hill wrote.

Although the long-term risks for children with persistent intestinal damage are not clear, such damage in adults has been linked to an increased risk of lymphoma, low bone density and fracture. The study authors also note, "malabsorption and inflammation in children may have negative repercussions on physical and cognitive development."

Alessio Fasano, MD, director of the MGHfC center and co-senior author of the study, was also surprised by the results, which were based on a retrospective examination of the biopsy and medical records of 103 children with celiac disease treated at MGHfC or BCH. The children had been on the gluten-free diet for at least one year and were determined by dietitians and other hospital health care practitioners to have complied well with the diet. But repeat biopsies found persistent intestinal damage in 19 percent of them. "The number of children who don't heal on the gluten-free diet was much higher than what I expected," Fasano says.

Another finding that surprised Fasano was that blood levels of the autoantibody IgA tTG - the primary lab test used to monitor celiac disease - did not accurately measure mucosal recovery. In fact, the authors note, neither blood test results nor patients' symptoms accurately predicted repeat biopsy results, and the tTG antibodies that are most effective for diagnosis were not as useful for monitoring the rate of mucosal healing.

Fasano explains, "In the 1970s, pediatricians would perform three endoscopies - one at diagnosis, one after a year on the gluten-free diet,

and a third during the following six months, to check for healing after the patient had been re-exposed to gluten and monitored for symptoms. When we developed robust blood screening tools in the 1990s, the number of endoscopies required for standard care was reduced to one and, most recently, to none in a subgroup of patients. We assumed that healing would occur once a patient was put on the gluten-free diet. Now that we have learned that this is not the case for all celiac patients, we are changing our clinical practice by repeating the endoscopy after one year of the implementation of the [gluten-free diet](#)."

More information: Maureen M. Leonard et al, Value of IgA tTG in Predicting Mucosal Recovery in Children with Celiac Disease on a Gluten Free Diet, *Journal of Pediatric Gastroenterology and Nutrition* (2016). [DOI: 10.1097/MPG.0000000000001460](https://doi.org/10.1097/MPG.0000000000001460)

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