



**GLUTEN
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GROUP**



Celiac Disease Testing in Children

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For parents, there are a multitude of everyday children's matters and milestone marks that take up plenty of time and concern, so when there is a medical issue (especially one as complex as an autoimmune disease like celiac disease), it can be especially taxing. Doctor visits can feel rushed, confusing, and overwhelming, so we put together this guide to testing and diagnosis to make sure you don't miss a beat.

Is there a genetic risk?

Since celiac disease has a genetic component, a child of someone who has been diagnosed has a higher chance of developing it. The general incidence of celiac disease is about 1%, but for kids of those who have been diagnosed (as well as for other first degree relatives), the likelihood of developing celiac disease ranges from 4 - 16%.

- It is generally advisable for first degree relatives of those with celiac disease to be tested regularly. Consult with your personal/family physician regarding your unique situation, and to determine how often testing should be done.
- Do not remove gluten from your child's diet before testing.
- Children at risk for celiac disease are generally screened at age 3 unless symptoms are seen before this age. Consult with your personal physician regarding your family's situation.

What tests are necessary?

- Initial screening consists of a blood test to screen for celiac disease antibodies. Standard tests include the following (your physician will determine which tests are appropriate for you and your child's situation):
 - Anti-tissue transglutaminase (tTG)
 - Anti-endomysium (EMA)
 - Anti-deamidated gliadin peptides (DGP)
 - Total serum IgA (since an IgA deficiency can affect the accuracy of antibody tests and indicate that different versions of antibody testing are needed.)
- In young children the results of Anti tTG and Anti EMA testing may not be accurate. DGP testing may be more accurate. Discuss this with your physician.
- Positive antibody test results indicate that a person may have celiac disease, but they are not conclusive.

- *Discuss potential screening/testing with your healthcare provider.*
- *Initial screening is done by a simple blood test.*
- *A normal test does not rule out later development of celiac disease – this is why follow-up screening is necessary.*
- *Periodic follow-up screening is advised for individuals at risk.*

- A small intestine endoscopy is generally needed to confirm celiac disease, however it may not be recommended for very young children. Positive screening tests in combination with positive genetic tests and symptoms, may be considered sufficient to make a diagnosis. Discuss with your physician.

Genetic testing

- Genetic testing shows whether or not a person has the genes necessary for the development of celiac disease.
- A positive test does not mean that celiac disease is present, or that it will develop, since approximately one third of the general population has the genes.
- A positive test does indicate that celiac disease could develop, and in first degree relatives who possess the genes, regular screening is recommended. Consult with your doctor about frequency of screening.
- A negative genetic test rules out the possibility that celiac disease will develop. No continued screening is needed.
- Whether or not a person is eating gluten does not affect the results of genetic testing.

If all tests are negative

- If the genetic test for celiac disease is negative, it is virtually impossible to develop the disease, so continued screening is not necessary. If symptoms arise or persist, of course always follow-up with your physician.
- Remember that the genetic test looks at genes necessary for development of celiac disease. Gluten sensitivity (GS) is not thought to be genetically influenced, so GS could still develop or exist with a negative genetic test for CD.
- If screening blood tests are negative and your child hasn't had genetic testing for CD, **or**, if the genetic testing was positive, continued screening is advisable. Discuss frequency of future screening with your physician.
- Remember that gluten needs to be consumed regularly in order for the celiac disease screening tests to be accurate, so if your child will be undergoing future screening, don't remove gluten from the diet before testing is done.

References:

- Szajewska H, et al. Gluten Introduction and the Risk of Coeliac Disease: A Position Paper by the European Society for Pediatric Gastroenterology, Hepatology, and Nutrition. JPGN 2016; 62: 507-513.
- University of Chicago Celiac Disease Center <http://www.cureceliacdisease.org/faq/what-is-the-prevalence-for-others-in-my-family-to-have-celiac-disease-since-ive-been-diagnosed-with-it-2/> Accessed August 6, 2018.
- University of Chicago Celiac Disease Center <http://www.cureceliacdisease.org/faq/at-what-age-should-children-get-tested-for-celiac-disease/>. Accessed August 9, 2018.

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Other helpful information is available at www.GLUTEN.org.

Advances in celiac disease are fast-paced. If this document is more than 2 years old, please visit our website for updated documents.

This information should not be used to diagnose or treat gluten-related disorders or other medical conditions. For questions about these conditions consult your healthcare team when considering this information.

Please consider your local GIG support group as another resource.

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The Mission of the Gluten Intolerance Group is to empower the gluten-free community through consumer support, advocacy, and education.

To make a donation or become a volunteer to GIG, visit our website or call the office at 253-833-6655.