Genetic Testing for Celiac Disease

Almost all of people who have celiac disease carry a gene for the disease that can be passed on to their children. If you, your partner or your child’s sibling has celiac disease, genetic testing can help figure out if your child can possibly develop celiac disease in the future. This handout can help you learn more about genetic testing for celiac disease and whether your child should have testing for the disease.

CAN CELIAC DISEASE BE PASSED ON TO MY CHILDREN?

Yes, celiac disease can be passed on to your children if you or your partner carry a gene for the disease. But, carrying a gene doesn’t mean your child will definitely have celiac disease. It means your child is at risk of developing celiac disease.

WHAT ARE THE GENES FOR CELIAC DISEASE?

There are 2 genes for celiac disease. These genes are called human leukocyte antigen (HLA) DQ2 and DQ8. Many people who have celiac disease have at least 1 of these genes. In very rare cases, a person won’t have these genes, but might develop celiac disease anyway.

HOW DO DOCTORS DO GENETIC TESTING?

Doctors will test your child for the genes through a blood test.

HOW CAN GENETIC TESTING FOR CELIAC DISEASE HELP MY CHILD?

Genetic testing can help your child by figuring out if he/she:

- Is at risk of developing celiac disease at any point in his/her lifetime
- If he/she carries the genes for celiac disease, which could be passed to his/her children in the future

WHAT DO THE TEST RESULTS MEAN?

- If the test results are positive for HLA DQ2 or DQ8, your child is at risk of developing celiac disease. It doesn’t mean he/she will definitely have celiac disease and the chance of developing celiac disease is still low. But, your child should have regular blood tests to see if/she has blood markers (signs in the blood) for celiac disease.

- If the test results are negative for HLA DQ2 or DQ8, your child does not carry the genes for celiac disease. He/she cannot develop celiac disease or pass it on to his/her children.

Sometimes, test results can be hard for doctors to read. Talk with a doctor who understands the genetics of celiac disease and who knows a lot about celiac disease. The doctor can go over the results if you choose to have your child genetically tested for celiac disease.

IS GENETIC TESTING COVERED BY MY INSURANCE?

In many cases, genetic testing for celiac disease is not covered by insurance. Testing can be expensive. If you want your child to have genetic testing for celiac disease, call your insurance company to ask about the cost and coverage of the test.

The insurance company might ask for the Current Procedural Terminology (CPT) codes or International Code for Disease (ICD). The current CPT codes are 81376 and 81382. The ICD is K90.0.