

# Genetic Testing in Youth with High Cholesterol

A CLINICAL PERSPECTIVE FROM THE NATIONAL LIPID ASSOCIATION



**What is genetic testing?** Genetic testing helps identify defects in genes that may cause high levels of blood cholesterol. Testing can be done at any age with a blood sample, saliva or cheek swab. It takes a few weeks to receive the test results.

## What results can I expect?

Genetic testing provides one of three answers:

- **POSITIVE result:** A genetic change **WAS FOUND** that is known to cause high cholesterol. This answers why your child's cholesterol is elevated.
- **NEGATIVE result:** A genetic change **WAS NOT FOUND**. However, there may still be a genetic cause for your child's high cholesterol that current testing cannot find. As new tests are developed, additional genetic testing may be helpful in the future.
- **UNCERTAIN result:** A genetic change **WAS FOUND**, but we are uncertain whether it causes your child's cholesterol to be too high. As more information becomes available, we may better understand this result in the future.

**How will genetic testing impact my child?** While genetic testing is helpful, the decision to use medication is based on your child's cholesterol levels, family history and other risk factors. Your healthcare team will review results and help you determine if medication is right for your child.

If your child's genetic test result is:

- » **POSITIVE** - Other family members could have the same genetic change. Cholesterol and genetic testing is recommended for all first-degree relatives to test for the same genetic change.
- » **NEGATIVE** or **UNCERTAIN** - Other family members should talk to their healthcare providers to determine if testing may be helpful.

## What else should I consider about genetic testing?

- » While the expense of genetic testing is often covered by insurance, know what your out-of-pocket cost will be BEFORE YOU AGREE to have your child tested.
- » Genetic testing sometimes identifies conditions that you or your child may not wish to know. Consider involving your child in determining whether genetic testing should be done now or perhaps delayed until your child is older.
- » Some parents have concerns about their child's privacy or the chance of discrimination based upon their genetic testing results. In the US, federal law prohibits denying health insurance based upon a child's genetic test results. However, insurance premiums may be higher for both health and life insurance - a genetic counselor can help you navigate whether to obtain such insurance coverages prior to undergoing genetic testing. For more information about genetic testing, ask a genetic counselor or qualified healthcare provider.