

Pediatric Familial Hypercholesterolemia

WHAT PARENTS AND CAREGIVERS SHOULD KNOW

Familial Hypercholesterolemia, or FH, is a genetic condition where people have very high levels of a type of cholesterol in their blood called low-density lipoprotein cholesterol (LDL-C), which is sometimes called the “bad” cholesterol. People who have this condition are at higher risk of early heart disease (heart attack or stroke) if their high cholesterol is not treated.

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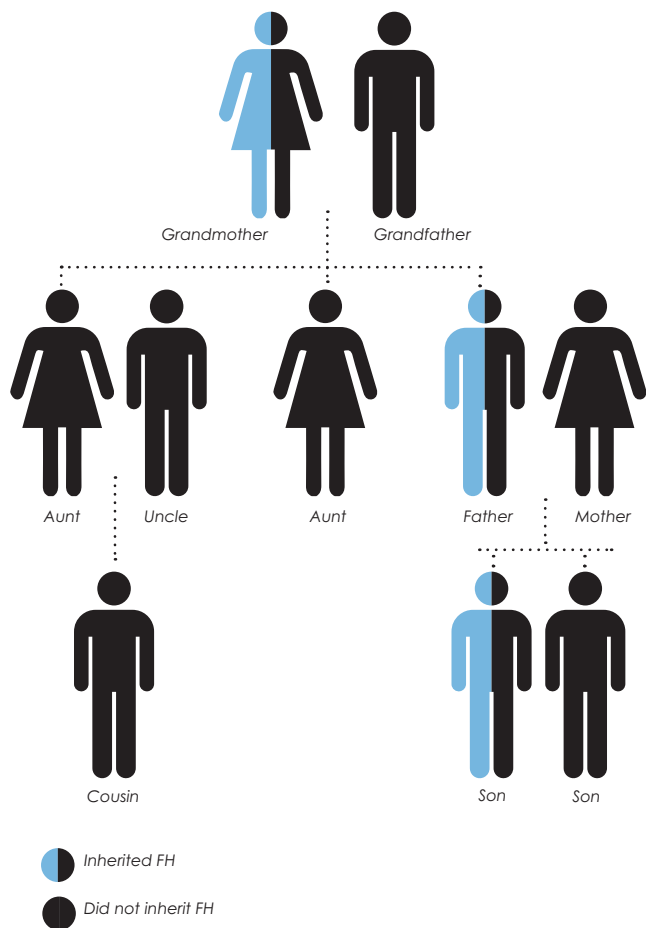
Occurrence Rate Worldwide

FH is usually passed from parent to child, and in most cases, a parent with FH has a **50%** chance of passing the gene that causes FH to their child.

Criteria for diagnosing FH in children, adolescents, and young adults (less than 20 years old):

The person has:

- » LDL-C \geq 160 mg/dL on at least two cholesterol panels after diet and after other causes of high LDL-C have been looked for and family history of early heart disease (heart attack, stroke, coronary stent, coronary artery bypass graft, or peripheral vascular disease) in a parent, grandparent, aunt, or uncle (\leq 55 years old for male relatives and \leq 65 years old for female relatives), or one close relative with FH.
- » Genetic testing shows the person has a pathogenic or likely pathogenic mutation associated with FH.



What Options Are There for Treatment of FH in Children and Adolescents?

The FDA has approved several treatments for children and adolescents with FH, and guidelines recommend children and adolescents diagnosed with FH start taking medication to lower their LDL-C between ages 8 and 10 years of age.



- » Statins are a first line oral medication and all statins have been approved by the FDA for use in children, some as young as 8 years old, others at age 10 and older.
- » Ezetimibe is an oral pill that may be used in addition to a statin and is approved by the FDA for children 10 and older.
- » PCSK-9 inhibitors are medications typically used in addition to statin therapy but may be used on their own based on the child's needs. One of the PCSK-9 inhibitors, evolocumab, is approved by the FDA for use in children 10 years or older. These medications are an injection that can be administered into an area of fat tissue, such as the abdomen, at home by a family member and given to a child every 2 weeks or every 4 weeks depending on the dose prescribed by the Healthcare Team.
- » Bile acid sequestrants are used less commonly; however, they may serve as a beneficial addition to a child's regimen to further lower cholesterol. Examples of these medications include cholestyramine and colesevelam.



Lifestyle recommendations for children with FH are very similar to lifestyle recommendations for all people. Eating a wide variety of foods with plenty of fruits and vegetables, lean proteins (chicken, turkey, tofu, and shrimp are a few examples), and whole grains are key to keeping LDL-C levels as low as possible and may be able to help minimize the amount of medication someone needs.

Regular physical activity is also very important! Encourage your child to try different activities to find something they like. Ideally, they will want to continue an active lifestyle on their own.

If your child or adolescent has been diagnosed with FH, it is important to see a lipid specialist. It can be challenging to find a pediatric FH specialist. Your child's primary care provider may know the pediatric FH specialists in your area. You can also use the "find a clinician" tool on [learnyourlipids.com](https://www.learnyourlipids.com).

