

What You Need to Know Familial Hypercholesterolemia (FH)

What is Familial Hypercholesterolemia?

- FH is a hereditary high blood cholesterol problem. If a parent has the FH gene, there is a 1 in 2 chance that their child will have FH.
- When a person has FH, the liver cannot clear cholesterol out of the body in the usual way. People with FH have extremely high blood cholesterol levels even when they are infants or children.
- High blood cholesterol levels can lead to clogged arteries. Clogged arteries can cause a heart attack, a stroke, or other circulation problems. This can happen at a young age in people who have FH.
- There are many people with high blood cholesterol levels. Only about 1 in 500 people has FH. People with FH have extremely high blood cholesterol levels.



Reasons why your nurse or doctor may want to test you for FH

- If your bad cholesterol, or LDL level, is higher than 190. In children or teenagers, an LDL level over 160 is a reason for further testing.
- If you or other people in your family have had a heart attack or a stroke at a young age, like in their 20's, 30's, 40's or 50's.
- If your nurse or doctor can see signs of cholesterol deposits around your eyes, heels, or elbows when they examine you.

If You Have FH: What You Can Do

- Remember that FH, even though it is not curable, is treatable. You can lead a full life.
- Ask questions if there is something you don't understand.
- Take your medicine as prescribed. Cholesterol-lowering medicines can prevent heart attacks, strokes, and other circulation problems.
- If you smoke cigarettes, ask for help to quit.
- Ask your nurse or doctor to help you make a plan for exercise.
- Ask to schedule a visit with a dietitian to help you make healthy diet changes.
- Talk to your nurse or doctor about whether you need an appointment with a cholesterol or lipid specialist. You can find a lipid specialist located near you at: www.learnyourlipids.com/find-help
- Tell your immediate family members that you have FH. Tell them to have their cholesterol levels tested too. Have your children's cholesterol levels checked.



PCNA
Preventive Cardiovascular
Nurses Association
www.pcna.net

Details About FH

How is FH treated?

- **Cholesterol-lowering medicine** is the most important part of treating FH. Patients with FH have levels of cholesterol that are too high to bring to normal with only a healthy diet and physical activity.
- If you have FH, controlling your other risk factors for heart disease is important. Do not smoke cigarettes. Have your blood pressure checked. Take your blood pressure medicine regularly if prescribed. Strive for a healthy weight, and get regular exercise.
- Even if you are taking cholesterol-lowering medicine, it is still important to eat healthy foods. Talk to your nurse or doctor about a heart healthy diet. A dietitian can also give you tips about ways to make healthy changes in the foods you eat.

If I have FH, what does this mean for the people in my family?

- If you have FH, your children, parents, brothers and sisters each have a 1 in 2 chance of having FH. These family members are called your “first degree relatives.”
- If you have FH, have your children checked for FH. Tell your other first degree relatives to be checked for FH too. The sooner FH is found, the sooner heart disease prevention can be started.
- New guidelines recommend that all children have their cholesterol levels measured between ages 9 and 11. Certain children, including those who have a first degree relative with FH, should have their cholesterol levels measured earlier—as young as age 2.

Important Things to Remember about FH

- If you have FH, you will need regular medical follow up and prescription medicines to lower your blood cholesterol for your lifetime.
- If you have FH, a healthy diet and physical activity, while important, are not enough to lower your cholesterol level.
- **Treating your blood cholesterol level and other heart disease risk factors will lower your risk of heart attack, stroke, and other circulation problems.**
- The FH Foundation is a non-profit organization dedicated to serving those with FH. If you or someone you love has FH, the FH Foundation can help you find a specialist, get support, and improve your understanding this condition. Find out more at the FH Foundation website: thefhfoundation.org.

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Learn More About FH Online

- **PCNA:** www.pcna.net/clinical/FH
- **The Foundation of the National Lipid Association:** www.learnyourlipids.com
- **National Genome Research Institute, National Institutes of Health:** www.genome.gov/25520184
- **Daniels SR, et al.** Integrated guidelines for cardiovascular health and risk reduction in children and adolescents. Summary report available at: www.nhlbi.nih.gov/guidelines/cvd_ped/

