

WHAT YOU NEED TO KNOW

Familial Hypercholesterolemia (FH)

What is FH?

Familial hypercholesterolemia (FH) is a cholesterol problem found in families. Many people have high cholesterol but people with FH have **very high cholesterol**, starting in childhood or even at birth. People with FH also often have a pattern in their **family history of early heart disease**. Cholesterol levels can vary, but FH is suspected in adults who have “bad cholesterol” levels (also called LDL Cholesterol) that are above 190¹, or in children or teenagers with levels over 160. Cholesterol can build up in the walls of blood vessels and over time lead to heart attacks, stroke and blood vessel disease. It is important that FH is found early to prevent cholesterol build-up and the blood vessel disease it may cause.

Is FH common?

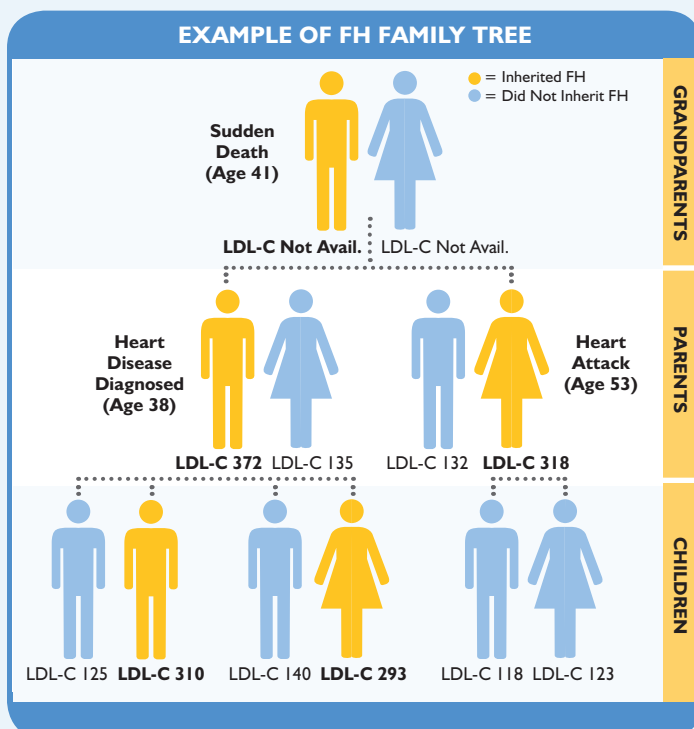
FH is one of the most common of all genetic problems. It affects one out of every 500 people and is found in all populations and ethnic groups.^{2,3} However, in some groups, FH can be 2 to 5 times as common as in the general population. Some of these groups include people of Lebanese, French Canadian, South African Afrikaner, and Ashkenazi Jewish descent.²



How is FH inherited?

The closest relatives of people with FH (parents, brothers and sisters, children) all have a 50% chance of also having FH. Because of this, FH families often have a pattern of people with very high cholesterol who may have had a heart attack or heart disease early, in their 20's, 30's, 40's or 50's.

On the left is a picture of an FH family. Below each family member are the numbers from their cholesterol test. The people in yellow have higher cholesterol levels, and some also have heart disease at an early age: these family members have inherited FH. Can you draw your family on the right? Your nurse or doctor will know your Total or LDL Cholesterol levels. Start with what you know, and add information after sharing this sheet with family members.



DRAW YOUR FAMILY TREE

GRANDPARENTS

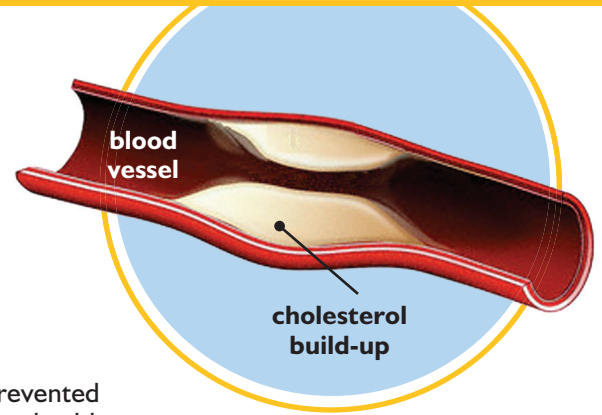
PARENTS

CHILDREN

Familial Hypercholesterolemia (FH)

What causes FH?

Cholesterol is a wax-like, fatty substance that can build up in the walls of blood vessels. In most people, the liver helps remove cholesterol from the blood. In FH, the liver does not remove cholesterol as well, and cholesterol levels can build up earlier than for other people. Over time, the cholesterol build-up can cause events such as heart attacks and strokes. Most people with FH inherit it from one parent. It is uncommon for FH to be inherited from both parents.



Why look for FH?

If FH is found early, serious problems of the heart and blood vessels may be prevented or delayed by making changes such as not smoking, regularly exercising, eating a healthy diet and taking your medications! The American Academy of Pediatrics recommends that if a family has a pattern of early heart attacks or heart disease (before age 55 for men and age 65 for women), a child in that family should have their cholesterol checked after the age of 2 and before age 10.⁴ It is important to find FH and take action at any age, because when treated, the risk of heart disease can be reduced to levels similar to those of the general population!

How do you know if you have FH?

People with FH may look perfectly healthy. FH may not even be found during a health check-up. Nurses and doctors may find FH by a cholesterol test and a review of your family history. They may also order a special blood test to see the specific type of FH you have.

What can you do if you have FH?

TAKE ACTION NOW!

- Tell your family that you have FH and encourage them to have their cholesterol checked too
- Take your medicines as directed – it can become a routine, like brushing your teeth
- Have your childrens' cholesterol checked – this is recommended by the American Academy of Pediatrics

How can you and your family learn more?

Visit a Lipid Specialist.

- A Lipid Specialist, also called a Lipidologist, is a health care provider that specializes in cholesterol problems like FH.

You can find a lipid specialist located near you at:
<http://www.learnyourlipids.com/find-help/>

Learn about FH online:

- **PCNA:** www.pcna.net/clinical/FH
- **Emedicine: Familial Hypercholesterolemia**
<http://emedicine.medscape.com/article/121298-overview>
- **The Foundation of the National Lipid Association:**
Learnyourlipids.com

References:

- ¹ Goldberg A, et al. *J of Clinical Lipidology*. 2011.04.003.
- ² Austin M, et al. *Am J Epidemiol*. 2004;160:407-420.
- ³ Genetic Alliance UK. Available at <http://www.geneticalliance.org.uk/education3.htm>.
- ⁴ Daniels S and Greer F. *Pediatrics*. 2008;122:198-208.

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