If you or someone in your family has very high LDL cholesterol and it hasn’t improved with diet, other lifestyle changes and medication, ask about familial hypercholesterolemia (FH). FH is a condition that leads to very high levels of low-density lipoprotein (LDL) cholesterol, also known as the “bad” cholesterol.

FH usually runs in families. People with FH often have a genetic variant (a mistake in a gene). This change makes it hard for the body to remove cholesterol, a wax-like and sticky substance. As a result, extra cholesterol is in the bloodstream. This starts in childhood - often before 10 years of age.

Over time, cholesterol builds up in the arteries and veins, causing them to narrow or even become blocked. This can lead to chest pain, heart attacks and strokes early in life. Taking extra steps to lower LDL cholesterol is really important.

Answer the following questions and talk with your care team. The information can help decide if you need testing or might benefit from talking with a genetic counselor.

**Your LDL cholesterol**

Is your LDL cholesterol very high? (Over 190 mg/dL for adults and over 160 mg/dL for kids.)

☐ Yes  
☐ No  
☐ I don’t know

If you know your most recent LDL cholesterol level, write it here: ________ mg/dL

Has your LDL cholesterol stayed high even after you’ve tried exercising more, eating heart healthy, not smoking, and/or taking medication(s) to lower your cholesterol?

☐ Yes  
☐ No  
☐ I don’t know
Family history and patterns of early heart disease

Has someone in your family (a brother, sister, parent, or child) had any of the following at a young age (usually before age 55 for males and 65 for females):

- Heart disease
- Surgeries or procedures to open blocked arteries
- Heart attack
- Stroke
- I don’t know

Has anyone in your family been told they have familial hypercholesterolemia? Or were they told that their high cholesterol or heart disease was likely due to their genes or something they were born with (even if they didn’t put a name with the condition)?

- Yes (If yes, who: ____________________________________________________ )
- No
- I don’t know

Potential signs, which tend to be common in people with a certain type of FH

When you look at your hands and ankles, are there raised skin-colored bumps around your:

- Knuckles
- Elbows
- Knees
- Back of ankle, heel (Achilles tendon)
- No, I don’t notice any

These fatty deposits are called xanthomas.

Do you notice (or has your eye doctor talked about):

- Yellowish areas around your eyes
- Bumps on your eyelids (xanthelasmas)
- A whitish gray ring or half-moon around the cornea

These can also be signs of cholesterol buildup.