

# **Talking with Your Family About Familial Hypercholesterolemia (FH)**



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## Getting Started

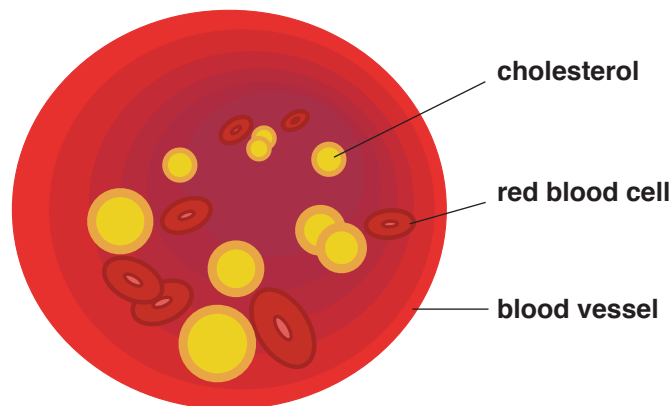
You can play an important role in improving your family's health. Familial hypercholesterolemia (FH) runs in families, but some of your family members may not know about their risks. This booklet will give you the tools to talk to your family about FH.

# Get the facts about FH

## What is familial hypercholesterolemia?

Familial hypercholesterolemia, or FH, is a genetic condition that causes lifelong, high levels of LDL cholesterol in families.

FH significantly increases your risk for early-onset heart disease if left untreated.



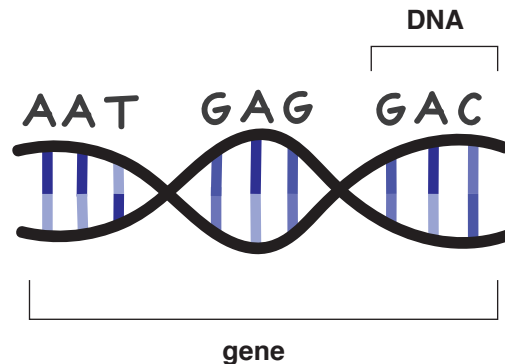
## What is cholesterol?

Cholesterol travels in our bodies in little droplets known as lipoprotein particles. The two main types of lipoproteins are high-density lipoprotein (HDL) and low-density lipoprotein (LDL), each of which carries cholesterol. HDL cholesterol is also known as “good” cholesterol. LDL cholesterol is also known as “bad” cholesterol.

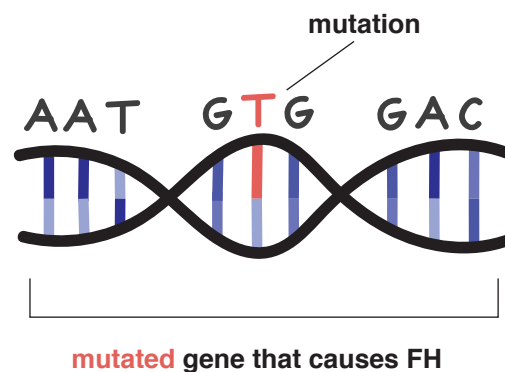
**Too much LDL cholesterol in our bodies increases our risk for health problems like heart disease, heart attacks, and stroke.**

## What causes FH?

FH is something people are born with and it is passed down through families in genes. Our genes are like an instruction manual for our body. Genes are made up of letters called DNA that tell our bodies how to work properly.



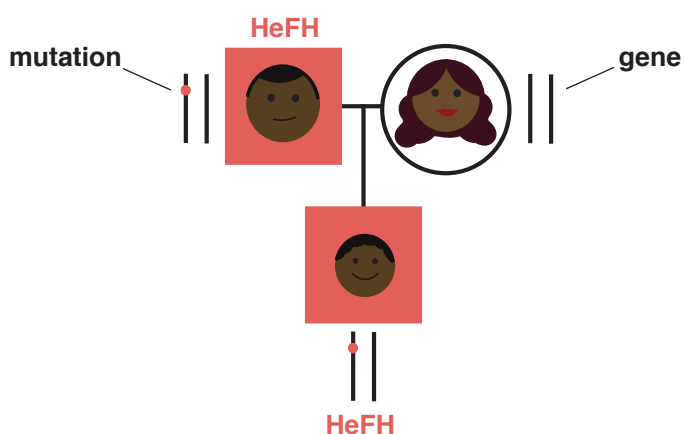
We have thousands of genes in our body and each one has a different job to do. FH is caused by a mutation, or change, in a single gene. When there is a mutation in a gene our body can't read these instructions. This means the gene can't do its job.



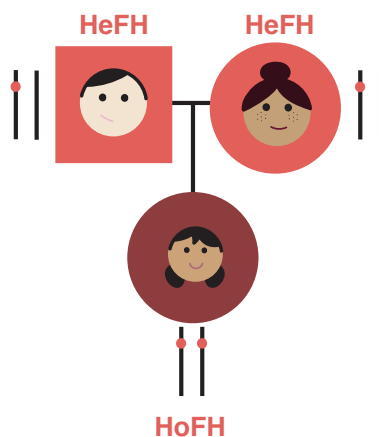
In FH, one of the genes that helps your body maintain normal amounts of LDL cholesterol has a mutation and doesn't work properly. This can cause cholesterol to build up in your blood vessels.

For most genes, we have two copies of each gene. One copy is inherited from your mom and one copy is inherited from your dad.

People with **heterozygous FH (HeFH)** are born with a mutation in only one copy of the gene. They inherited this mutation from either one of their parents. **HeFH is the most common form of FH.**

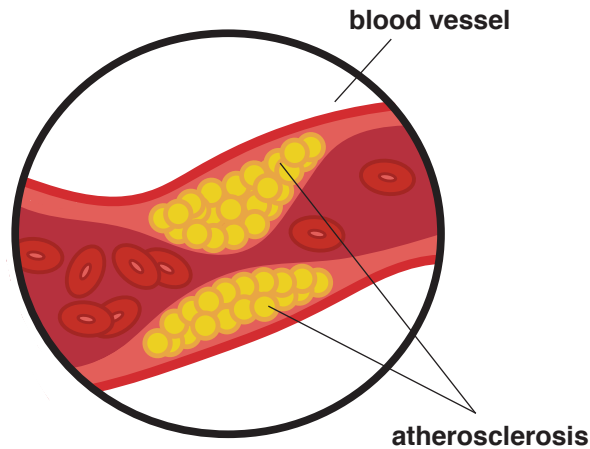


People with **homozygous FH (HoFH)** are born with a mutation in both copies of the gene. They inherited a mutation from both of their parents. HoFH is a more severe form of FH that is less common.



## How does this affect my health?

When cholesterol builds up and hardens in your body it is called plaque. Plaque buildup, or **atherosclerosis**, causes the blood vessels to narrow. This can decrease blood flow to your heart and other body parts.



Atherosclerosis increases your risk for heart disease, heart attacks, and stroke if left untreated.

Untreated FH makes it more likely for people to have these serious health problems at a younger age.



### **Heart disease:**

A group of conditions that affect heart health. These conditions cause the heart not to work properly.

**Heart attack:** Blood flow to the heart is blocked. The heart cannot take up oxygen when the blood supply is blocked.



### **Stroke (ischemic):**

Blood flow to the brain is blocked. The brain cannot take up oxygen from the blood.

## How do I know if I have FH?

FH is an invisible disease. Some people may seem healthy and not know that they are at risk for heart disease or stroke. Some people with FH may have LDL cholesterol levels that are close to normal. Family members with FH can also have different LDL cholesterol levels that can range from 130-400mg/dl.

People with FH (or who may potentially have FH) should talk with a physician lipid specialist:

<https://thefhfoundation.org/find-fh-specialist>

## Potential signs of FH:

- Personal or family history of high LDL cholesterol levels (>190mg/dl)
- Personal or family history of early heart disease or heart attacks (before age 50 in men, before age 60 in women)
- Family history of FH
- Corneal arcus: white, grey, or blue ring in the colored central part of the eye (before age 45)
- Xanthomas: bumps on the tendons of ankles or knuckles

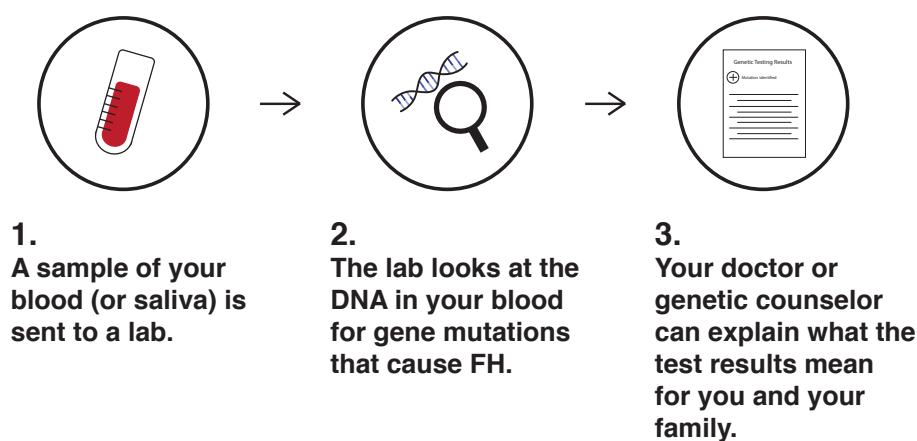
**FH can be diagnosed by a healthcare provider using information such as:**

- Personal health history
- Family health history
- Cholesterol levels (blood test)
- Genetic test results (blood or saliva test)

## What is genetic testing?

Genetic testing is a type of test that can look for changes in the genes that cause FH. Genetic testing can help confirm a diagnosis of FH.

If you want to learn more about genetic testing, you can talk to your doctor or a genetic counselor. They can help you understand if genetic testing is right for you.



## What is a genetic counselor?

Genetic counselors are healthcare professionals who are trained to help families at risk for genetic conditions.

They can help families make decisions about genetic testing and discuss how this information may be useful for their health.

To find a genetic counselor near you, visit:  
<https://www.nsgc.org/findageneticcounselor>

To learn more about how a genetic counselor can help you and your family, check out this website:  
<http://aboutgeneticcounselors.com/>





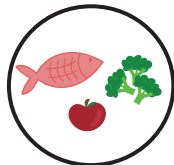
## What can I do about my FH?

FH will always be a part of your life. You can't change your genes, but you can take action now to lower your cholesterol levels and decrease your risk for heart disease.

Almost all people with FH will need to take medication called statins to lower their cholesterol levels. Women who are pregnant, planning to become pregnant, or breastfeeding should not take statins. Non-statin treatment is also available for people who cannot tolerate statins or if their cholesterol is not lowered enough from taking statins. You should talk to a lipid specialist about your treatment: <https://thefhfoundation.org/find-fh-specialist>

**In combination with this medication, you can decrease your risk for heart disease and stroke by:**

**Eating a healthy diet**



**Exercising regularly**



**Managing stress**



**Avoiding smoking**



**Treating hypertension and diabetes**



## How is FH Different?

High cholesterol can be caused by lifestyle factors such as diet, smoking, and diabetes in some people. However, FH is not caused by these lifestyle factors.

**Even if you live a healthy lifestyle, you may still need to take medication to lower your cholesterol levels.**

**What makes FH different than high cholesterol mainly caused by lifestyle factors?**

- FH is caused by a mutation (change) in a gene
- High cholesterol levels can start from birth
- FH is a lifelong condition
- Heart disease is more likely to happen at a younger age

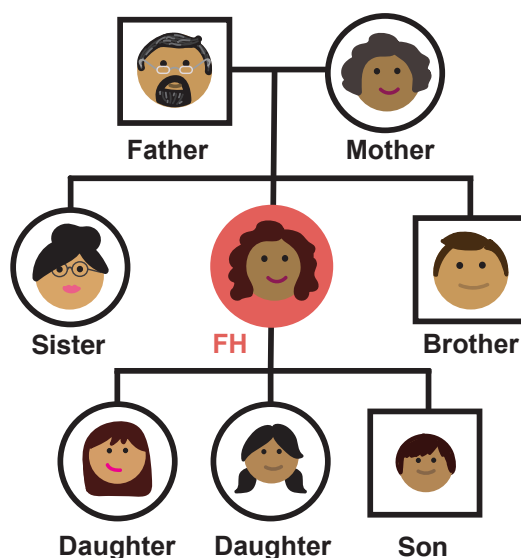
## Why is it important to know if I have a diagnosis of FH?

- Your cholesterol will be **managed more aggressively**
- You will need **treatment at a younger age** to prevent heart disease
- You can **tell your family** about their risk

# Is my family at risk for FH?

“Family” can mean many things to different people. When talking about who is at risk for FH, family are those people who are biologically-related (blood-related) to you. Genes are something you share with your family. Just like your eye color and hair color, you can also share risks for health conditions.

Did you know you share half your DNA with your first-degree relatives? If you have heterozygous FH (HeFH), your **mother, father, sisters, brothers, sons, and daughters each have a 50% chance, or a 1 in 2 chance** of sharing the mutation that causes FH.

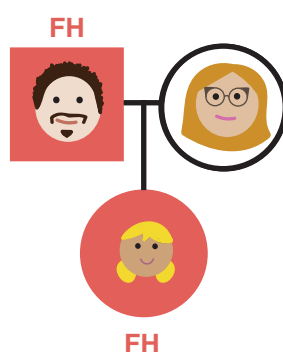


**Other family members like cousins, aunts, uncles, nieces, nephews, grandparents, and grandchildren may also be at risk for having FH.**

# How does FH affect my child?

If you have heterozygous FH (HeFH), **each of your children has a 50% or 1 in 2 chance** of inheriting the mutation that causes FH. You can't control which genes you pass onto your children, but you can make sure they get the right care to stay healthy.

In FH, early treatment is key to prevent heart disease. The first step is to find out if your child has FH. Your child's cholesterol levels can be checked as early as age 2.



Without treatment, children with FH can have high cholesterol levels even if they seem healthy. This exposure to high cholesterol levels starting at a young age increases their risk for heart disease.

It is recommended that children with FH start taking medication between the ages of 8 and 10 years to lower their cholesterol levels. If your child has FH, talk with his or her doctor about when your child should start taking medication.

Remember, exercising regularly and eating healthy is important at any age for a healthy life.

# Why is it important to talk to my family about FH?

**Some of your family members might have FH without even knowing it.** It is important that your family members know their risks so they can make decisions about their health.

Even if your family members are already being treated for high cholesterol, letting them know about your diagnosis of FH can help their doctor make the best decisions for their treatment.

## Why should my family members be tested for FH?

Testing can identify which family members have FH so they can be treated properly to decrease their risk for heart disease. Testing may point out other family members who may be at risk for having FH.

For example, your brother is tested and finds out he has FH. His children should also be tested because they each have a 50% chance of having FH.

# How do I talk to my family about FH?

It is normal to feel nervous about talking with your family about FH. You don't need to be an expert to talk about FH with your family. You can choose the best way for you to share this information with your family.

**Here are some ways you can communicate with your family:**

**Send an email**



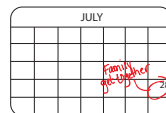
**Write a letter**



**Make a phone call**



**Plan a get together**



**Share this booklet!**

## **What can I do to prepare?**

### **Learn about your FH**

Looking over the information in this booklet can help you feel more comfortable talking about FH with your relatives. Reading about FH can also help you better understand how it affects you and your family's health.

### **Gather your materials**

If you feel comfortable sharing them, copies of any genetic test results and doctor's letters about FH can be helpful for your family members to have when they talk to their doctor.

You can black out any identifying information like your name, birthdate, and medical record number.

There are a few websites listed on page 16 that you can share with your family members so they can learn more about FH.

### **Talk to your doctor**

Your doctor or other healthcare provider may have some helpful tips on how to talk to your family. Genetic counselors can also provide support and tips for sharing this information with your relatives.

### **Find a support person**

Is there someone in your family who keeps in touch with your relatives? This person may be able to help you share this information with the rest of your family.

### **Act it out**

Acting out what you want to say with your family members can make you feel more comfortable and help you prepare. Ask a friend, support person, or a healthcare provider if you can practice with them.

## What should I talk about?

It is important to let your family know they are at risk for FH and there is something they can do about it. Tell your family members to let their doctor know about their family history of FH.

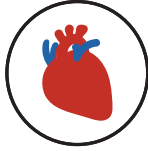
<b>Key points to share with your family:</b>	<ul style="list-style-type: none"><li>— FH is hereditary (runs in families)</li><li>— FH is different than high cholesterol caused by lifestyle factors</li><li>— FH increases your risk for heart disease</li><li>— FH can be treated</li></ul>
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## Here are some ways to start the conversation:

- Have you had your cholesterol levels tested recently?
- I want to talk to you about a condition I have...
- Have you ever heard of FH?
- Has your doctor said anything about high levels of cholesterol that run in families?

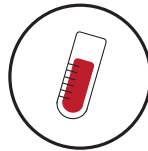


# Common concerns



## **What if my family members are already being treated for high cholesterol?**

FH is treated more aggressively and earlier than high cholesterol caused by lifestyle factors. It is important that your family knows if they have FH so they can get the proper treatment. Information about your family history can be helpful for everyone in the family to know. There may be other family members at risk for FH who are not being treated.



## **How do my family members get tested for FH?**

Your family members should tell their doctor about their family history of FH. Their doctor can take a “lipid profile”, which is a blood test to check their cholesterol levels. Most healthcare clinics should have this type of test available. The National Lipid Association Expert Panel on Familial Hypercholesterolemia has guidelines for testing, diagnosis, and treatment of FH.



## **What if I do not keep in touch with people in my family?**

If having a phone call or an in-person conversation is not right for you, sending an email or a letter may be a good way to share this information. Sending the “Dear Family Member” letter can be a great way to let your family members know about their risk. Find the letter at: <https://thefhfoundation.org/media/FH-Family-Letter.pdf>



## **What if my family does not want to talk about FH?**

Your family members may have different beliefs about health. Some people may not want to know about their risk for FH or they may not be ready to talk about it. Some people may get angry or upset. You can respect their space, but let them know you are there if they are ready to talk.

### **You can share these resources with your family:**

**The FH Foundation** is a research and advocacy organization focused on FH. The website has more information about FH and ways to become involved. Check out their website at: <https://thefhfoundation.org/>

**The National Society of Genetic Counselors** created a “Family Member Letter” that explains FH and how your family can talk to their doctors. You can find this letter at: <https://thefhfoundation.org/media/FH-Family-Letter.pdf>

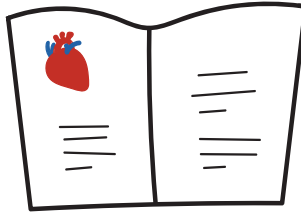
If you or your family members are interested in talking with a genetic counselor, you can find one near you at: <https://www.nsgc.org/page/find-a-genetic-counselor>

There are doctors who specialize in treating patients with FH. To **find an FH specialist** go to: <https://thefhfoundation.org/find-fh-specialist>

### **Find this booklet online:**

<http://www.med.umich.edu/1libr/CVC/TalkingToFamilyAboutFHBooklet.pdf>

# Review



- **FH is a condition you are born with that causes high levels of LDL cholesterol and increases your risk for heart disease and other health issues**
- **Many people may not know they have FH**
- **If you have FH, tell your family members about their risk for FH so they can get tested**
- **FH can be treated and you can reduce your risk for heart disease and stroke**

Disclaimer: This document contains information and/or instructional materials developed by Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

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