

HoFH

**Homozygous
Familial
Hypercholesterolemia**



Could your extremely high levels of bad cholesterol (LDL-C) be putting you at risk for a heart-related event?

You could be living with an ultra-rare inherited disease called Homozygous Familial Hypercholesterolemia (HoFH)

Know the signs of HoFH so you can talk to your healthcare provider about a possible diagnosis and treatment options.

Understanding HoFH

Approximately 1 in 300,000 people are affected by HoFH. Many of them are not diagnosed, or are only diagnosed later in life.



HoFH is an inherited condition that makes it difficult for your body to clear bad cholesterol (LDL-C)

Having HoFH means you have extremely high levels of bad cholesterol (LDL-C), reaching or exceeding levels **5x higher than target** (>10 mmol/L with HoFH vs 1.8 mmol/L target for adults with no cardiovascular risk).

You could be living with an ultra-rare inherited disease called **Homozygous Familial Hypercholesterolemia (HoFH)**

Recognizing HoFH can help you potentially get diagnosed and treated early



BAD CHOLESTEROL (LDL-C) LEVELS

Extremely high levels of bad cholesterol that can be difficult to control



GENETIC CONDITION

HoFH is inherited from your parents



VISIBLE SIGNS

Cholesterol buildup:

- Around the joints and on the tendons (xanthomas)
- In the eyes (corneal arcus) and around the eyelids (xanthelasmas)

Untreated, HoFH can cause cardiovascular events, even at a young age. Events include:



Damage to the heart



Stroke

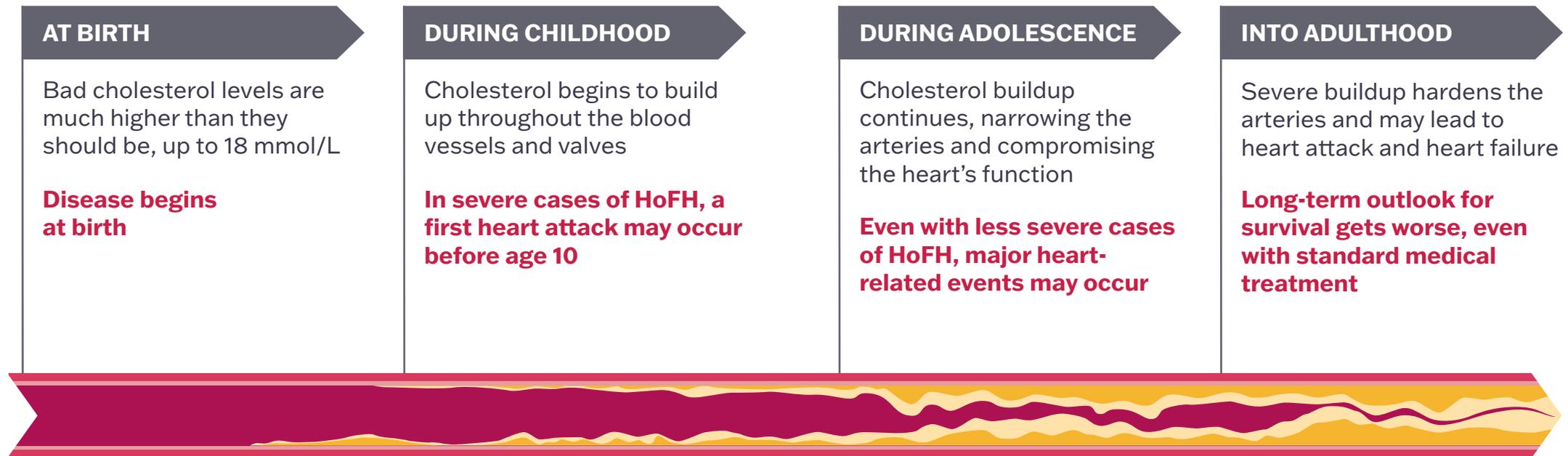
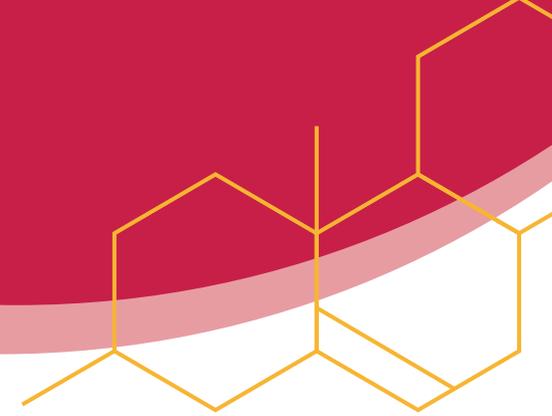


Heart attack

Knowing the signs of HoFH can help you get a diagnosis and start treatment right away

It's important to diagnose HoFH early because the risks can get worse over time

Living with high levels of bad cholesterol (LDL-C) from HoFH can increase heart-related issues



The earlier you receive a diagnosis, the earlier you can start treatment to help lower your bad cholesterol levels



2023 ESC/EAS LDL-C Reduction Target Recommendations

Children:

<3 mmol/L

Adults:

<1.8 mmol/L

Adults with ASCVD:

<1.4 mmol/L

HoFH can have a serious effect on both your body and mind



HoFH is often underdiagnosed or misdiagnosed



Family history



A physical exam



A blood test

In addition to heart-related risks, HoFH can affect you:



Physically:

Cholesterol buildup can cause joint pain and make moving painful



Emotionally:

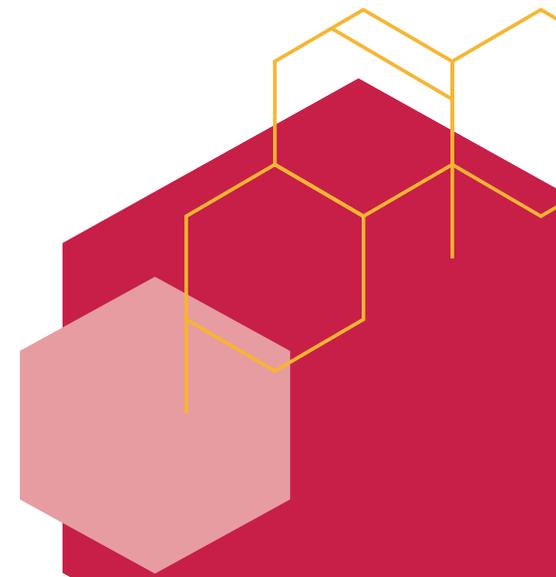
You could experience feelings of shame, fear, and being alone
You could feel isolated because movement is painful and makes it hard to be active socially

Once diagnosed, talk to your family members about HoFH

HoFH is an **inherited disorder**. There is a 1 in 4 chance that your siblings have HoFH and a 1 in 2 chance they have HeFH.

If you suspect that you or a family member might have HoFH, consult your healthcare provider to screen for it

Guidelines suggest healthcare providers use a process called reverse cascade screening to see if your family members could have FH.



Treating HoFH early can lower serious risks to your health

Here are a few things you can do:



Recognize HoFH early to help lower the risk of heart-related events, such as a heart attack



Get diagnosed as early as possible to begin the right treatment plan



Treat to lower bad cholesterol (LDL-C) levels to help lower heart-related risks

Treatment options for HoFH may include:

- Lifestyle changes (diet, exercise, etc)
- Medicines (statins, PCSK9 inhibitors, others)
- Emerging therapies
- Filtering out bad cholesterol (apheresis)
- Liver transplant (extreme cases)



If your HoFH is undertreated, you may be at a more than 12x higher risk* for death from a heart-related event.

Talk to your healthcare provider about getting a diagnosis and creating an LDL-C treatment plan that is right for you

*Risk varies with patient characteristics, total cholesterol, and prior treatment. PCSK9=proprotein convertase subtilisin/kexin type 9.

HoFH may seem overwhelming, but you are not alone

Many tools and resources are available to help you along the way

The familial hypercholesterolemia (FH) community is active and supportive, and can help you throughout your HoFH journey.

Use these resources to learn more about HoFH and connect with the FH community:

FH Canada:

<https://www.FHcanada.net>

Family Heart Foundation:

<https://familyheart.org/>

2023 EAS Consensus on HoFH:

<https://eas-society.org/publications/consensus/>

EAS Familial Hypercholesterolaemia Studies Collaboration (FHSC):

<https://beta.clinicaltrials.gov/study/NCT04272697>
<https://fheurope.org/about-hofh/homozygous-familial-hypercholesterolaemia/>

Worldwide experience of HoFH, retrospective cohort study published in The Lancet:

<https://eas-fhsc.org/publications/>

These organizations are an incomplete listing of rare disease advocacy groups. The list is meant for informational purposes only and is not intended to replace your healthcare professional's medical advice. Ask your doctor or nurse any questions you may have about your disease or treatment plan.

Untreated, HoFH can cause heart attacks and even death before age 30

Lower your risk with an early diagnosis

Know the signs and symptoms of HoFH so you can start managing your condition:



Extremely high levels of bad cholesterol (LDL-C)



Heart attack or heart-related event at a young age



Family history of heart attacks at a young age and/or family history of FH



Cholesterol buildup in joints and eyes

Talk to your doctor about a diagnosis; with the right early diagnosis, you can take action to lower your bad cholesterol (LDL-C) with a treatment plan tailored to your condition



Scan the QR code to learn more at [HoFHdisease.ca](https://www.HoFHdisease.ca)

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MRCP-UX858-00008 06/2023