

Familial Hypercholesterolemia 101

What is Familial Hypercholesterolemia?

Familial hypercholesterolemia, or FH, is a genetic disorder that raises low-density lipoprotein cholesterol levels from birth, increasing the risk of strokes or heart attacks.

Familial hypercholesterolemia is one of the most **common** genetic disorders, affecting about 1.3 million Americans. People living with FH face a much higher risk of developing cardiovascular disease at a young age if it goes undiagnosed and untreated.

There are **two types** of Familial hypercholesterolemia:

Heterozygous FH:

The most common form, caused by inheriting one FH gene variant from one parent. Untreated, heart disease can begin before age 30.

Homozygous FH

A rare, more severe form, caused by inheriting FH gene variants from both parents. Untreated heart disease can begin before age ten.

The Importance of Screening

Familial hypercholesterolemia is an inherited condition that has a 50% chance of being passed from parent to child. Over time, LDL cholesterol can cause plaque to accumulate in the arteries, raising the risk of early heart attacks, strokes and other cardiovascular events.

Genetic testing can help confirm a diagnosis as early as age two for children who may have inherited FH. The new **2026 ACC/AHA dyslipidemia guidelines** now recommend measuring LDL-C earlier, taking into account patients' risk level in screenings.

Patients should know their "LDL Safe Zone" if they have been diagnosed with FH. Having an LDL-cholesterol level at or above 190 mg/dL in adults, or 160 mg/dL in children, is a primary indicator of FH.

What Treatment Options Are Available

Familial hypercholesterolemia requires lifelong treatment. Early diagnosis and treatment are recommended to manage cholesterol and reduce cardiovascular event risks. But even if someone with FH does "everything right," they should still actively monitor and work with their cardiologist to manage their cholesterol levels.

Novel treatments for FH show life-changing promises for patients. Under the bipartisan **MINI Act**, genetically targeted technologies, including PCSK9 inhibitors, show real benefits to patients: administered just once or twice a year by a clinician, they can improve adherence—a key challenge for cardiovascular patients—and expand treatment options.

*Clint W., Californian
living with FH*



Call to Action

Given enough time, genetically targeted technologies could be a gamechanger for FH patients and others living with cardiovascular disease. The MINI Act would promote and support medical innovation for people living with FH and similar conditions. It would require medications with genetically targeted technology to have had market approval for at least 11 years before qualifying for price negotiation.

To learn more about high cholesterol management and to hear from patients living with Familial hypercholesterolemia, visit the [Partnership to Advance Cardiovascular Health](#).