

Dear Family Member,

I have been diagnosed with familial hypercholesterolemia (FH). FH is a genetic disorder characterized by high cholesterol levels in the blood and early heart disease. Based on my diagnosis, you are at risk for also having FH. You could have FH without any physical signs or symptoms and may feel and look healthy. If diagnosed, FH can be treated through lifestyle changes (not smoking, regular exercise and a healthy diet) and medication. You can determine if you have FH by seeing your doctor and having a fasting lipid profile. This is a panel of blood tests that provides information about cholesterol levels. Individuals with FH have high levels of low-density lipoprotein (LDL) cholesterol. Genetic testing for FH is available, however, is generally not needed for diagnosis or management but may be useful in some cases.

FH is passed down through families in an autosomal dominant manner and can be inherited from a parent. All first-degree relatives (parents, siblings, children) of an affected person with FH have a 50% chance of also having FH. If you do have FH, each of your children has a 50% chance of having it as well. If you do not have FH, you would be at the general population risk for developing high cholesterol, and your children are not at risk to have inherited FH.

Genetic Counseling

Genetic counselors are healthcare professionals who can help you understand the inheritance of FH and what this diagnosis means for you and your family. Genetic counselors can also facilitate genetic testing and interpret results. To locate a genetic counselor in your area, ask your doctor or use the search tool available on the website for the National Society of Genetic Counselors, www.nsgc.org.

Learn More About FH

- The FH Foundation (<http://www.thefhfoundation.org/>)
- FH Journeys (<http://www.fhjourneys.com/>)
- National Lipid Association (<http://www.lipid.org/>)
- Preventive Cardiovascular Nurses Association (<http://pcna.net/patients/familial-hypercholesterolemia>)

Next Steps

- Ask your family doctor or primary care physician to check your cholesterol
 - A diagnosis of FH is probable if:
 - LDL is greater than 170 mg/dL in adults 20 years of age and older
 - LDL is greater than 155 mg/dL in children and adolescents less than 20 years of age (Williams RR et al. *Am J Cardiol.* 1993;72(2)171-176)
- Take a copy of this letter with you when you meet with your doctor
- If you are diagnosed with FH, share this letter with your at-risk parents, siblings and children