

Dear Family Member,

I have been diagnosed with familial hypercholesterolemia (FH). FH is a genetic disorder that causes high cholesterol levels in the blood resulting in a 20-times increase in risk for premature heart disease (including heart attack) if left untreated. Based on my diagnosis, you are at risk for FH. You could have FH without any physical signs or symptoms and may feel and look healthy. If diagnosed, FH needs to be treated through medication and lifestyle changes (not smoking, regular exercise and a healthy diet). The good news is that **HEART DISEASE due to FH CAN BE PREVENTED if you TAKE ACTION** and have your high cholesterol treated by a health care provider who knows about this condition. Knowing your cholesterol level gives you the power to act.

If you already have high cholesterol or heart disease, ask your health care provider if you might have FH. If you do not know whether you have high cholesterol, you can see your health care provider and have a fasting lipid profile. This is a standard blood test that provides information about cholesterol levels. Individuals with FH have high levels of low-density lipoprotein (LDL) cholesterol, also known as the “bad cholesterol”. Genetic testing for FH is available and can be useful to assist in diagnosis and identify other family members who may also have FH.

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 a person with FH have a 50% chance of also having FH. FH affects people of all ages and high cholesterol levels need to be treated in children as well as adults. Diagnosis of FH in childhood allows for early intervention and treatment and improves chances to prevent heart disease. Therefore we recommend all children at risk for FH have their cholesterol levels checked for the first time between the ages of two and eight years old.

### Next Steps

- Take a copy of this letter with you when you meet with your health care provider.
- Ask your health care provider to check your cholesterol.
  - A diagnosis of FH is probable in a family member of an affected individual with FH if:
    - Untreated LDL is greater than 170 mg/dL in adults 20 years of age and older.
    - Untreated 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).
  - Initial screening of children at risk for FH should take place between 2 and 8 years of age.
- If you are diagnosed with FH, share this letter with your at-risk parents, siblings and children.
- If your cholesterol levels are normal:

- All children should have their cholesterol levels checked by their pediatrician between the ages of 9 and 11, and again between 17 and 21 (AAP guidelines, 2014).
- All adults should have their cholesterol checked every 5 years by their primary care provider (ACC/AHA guidelines, 2013).

### **Genetic Counseling**

Genetic counselors are health care 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 learn more about genetic counselors, visit the website for the National Society of Genetic Counselors, [www.nsgc.org](http://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>)

### **Find FH Professionals**

Genetic Counselors: [nsgc.org/findageneticcounselor](http://nsgc.org/findageneticcounselor)

FH Specialists: [thefhfoundation.org/find-fh-specialist](http://thefhfoundation.org/find-fh-specialist)

The clinic that evaluated me, \_\_\_\_\_,  
would also be happy to evaluate you. You can reach them by calling \_\_\_\_\_.

Sincerely,