

Familial Hypercholesterolemia (FH) Genetic Counseling and Testing

Familial hypercholesterolemia (FH) is a condition that causes very high levels of blood cholesterol. The disease starts in childhood. FH causes a higher risk of early heart attack or stroke.

FH is caused by changes in one of a few genes. These genes tell your body how to process LDL (“bad”) cholesterol. When there is a defect in one of these genes, your body cannot remove LDL from the blood. This causes very high levels of LDL.

In most types of FH, a parent with FH has a 50% chance of passing the gene to their child. If you have FH, your parents, siblings, and children should also be checked.

Genetic Counseling

A genetic counselor is someone who can help you learn more about how a genetic illness affects you and your family. They look at how family and health history may impact the disease. They can help you decide which genetic test you need, and how to make the best choices for your healthcare.

All patients with FH are offered genetic counseling. This will help you figure out who in your family needs regular screening and medicine. This is **vital**. Early treatment can help prevent early heart disease.

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person’s health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 12/2020. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8178.

Genetic Testing

The testing looks at four genes that relate to FH:

- LDLR,
- LDLRAP
- PCSK9
- APOB

Testing looks at your genetic code and compares it to a normal genetic code. It shows if there is a difference between yours and the normal versions of these genes.

To Find Out More

National Society of Genetic Counselors
www.nsgc.com

The FH Foundation
www.thefhfoundation.org

Who to Call

AFCH Pediatric Preventive Cardiology
Clinic
608-263-6420
www.uwhealth.org/kidscholesterol