

Familial Hypercholesterolemia (FH) in Children

What is it?

Familial Hypercholesterolemia (FH) is a genetic disorder that results in very high levels of blood cholesterol that you inherit. As an adult this can lead to an increased risk of early heart disease (men before age 55 and women before age 65). FH is caused by changes in a gene that lowers the body's ability to remove low-density lipoprotein (LDL) the "bad" cholesterol from the blood. This makes the levels of LDL very high. In most types of FH, a parent with FH has a 50% chance of passing the gene to their child. If someone is found to have FH, their parents, siblings, and children should also have their cholesterol checked.

Children with FH have high LDL levels that can cause heart disease at an early age. They often have other family members with high cholesterol, early heart disease, or heart attacks. For many people, high LDL levels are the result of eating a diet that is high in saturated fat, being overweight, having diabetes, or not getting enough exercise. Children with FH can be normal weight, have a good diet, exercise enough, and still have a high LDL level.

Why is FH a problem for my child?

FH results in rapid atherosclerosis, often starting before 10 years of age. Atherosclerosis is when fat, cholesterol, and other substances build up in the walls of arteries and forms plaque. Over time, this build up can block the arteries and cause early heart disease, heart attacks or strokes. In a child with FH, the build up can narrow the arteries and

make them stiffer. This makes it harder for blood to flow through them. Clots may form in these narrowed arteries and block blood flow. Pieces of plaque can break off and move to smaller blood vessels, blocking them. The blockage stops blood and oxygen from reaching parts of the body. This can result in damage or tissue death. This is a common cause of heart attack and stroke. If not treated, these people have an increased risk for early heart disease. In 50% of men and 25% of women these heart issues start by age 50.

How common is FH?

Worldwide, FH happens in about 1 in 200-300 people. In some areas of the world, FH can occur in 1 in 100 people. In children FH is a "silent" disease and does not cause any symptoms.

How is FH diagnosed?

FH can only be diagnosed with a blood test. We suggest checking cholesterol levels in all children at 9-11 years of age. If treated at an early age it can help stop build up and reduce plaque. Early treatment of FH in adults has been shown to reduce their risk for future heart disease.

Treatment

Eating a healthy diet low in saturated fat and cholesterol can lower LDL. For most children with FH, this is often not enough. Your child will need to take medicine to lower their LDL. Most children need to make these changes throughout their lives.

The most common medicines that lower cholesterol are called statins. They help to decrease the amount of cholesterol made in the liver. Statins have been used with success to treat adults with high cholesterol. Statins cannot be taken when pregnant because they may cause birth defects to the unborn baby. If your child takes a statin, part of the treatment is to check cholesterol levels and do other blood tests on a regular basis.

Some children with FH need more than one type of medicine to lower their LDL cholesterol level.

Familial Hypercholesterolemia Websites:

The FH Foundation:

www.Thefhfoundation.org

www.Youtube.com/fhjourneys

Patient information from the National Lipid Association:

www.Learnyourlipids.com

Make Early Diagnosis to Prevent Early Death (MEDPED): www.medped.org

Who to Call

AFCH Pediatric Preventive Cardiology
Clinic for more information or questions.
608-263-6420

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 © 4/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#7466