

Genetic Testing for Familial Chylomicronemia Syndrome (FCS)



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Yang, Living with FCS



Your guide to FCS genetic testing

Since FCS is a rare genetic disorder, patients with symptoms or a clinical diagnosis of FCS may benefit from a test that checks to see if they have one or more of the genes that causes FCS.^{1,2}

The FCS Genetic Testing program, sponsored by Ionis Pharmaceuticals, offers confidential genetic testing to eligible patients.

Working in partnership with Genome Medical, a telehealth genetics practice, the FCS Genetic Testing program also provides information, support, and resources during the testing process.

To learn about genetic testing and FCS, read this brochure and visit [KnowYourTGs.com](https://www.knowyourtgs.com) for more information.

What are genes?

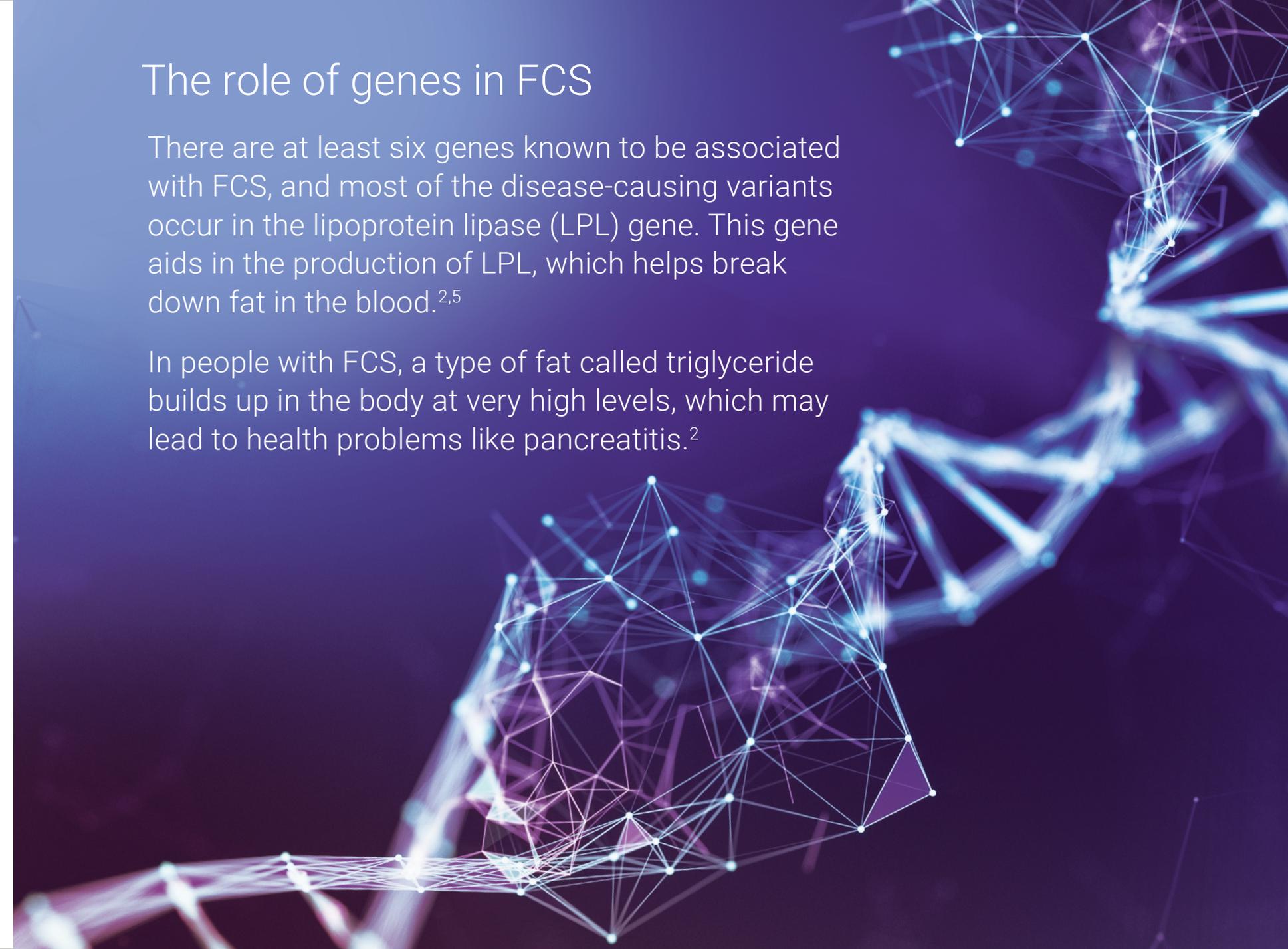
Genes contain DNA and are responsible for making all the different proteins in your body. Each protein has a specific job. Changes to DNA are called *variants*. Some variants may cause disease (also known as *mutations*), whereas other variants may not.^{3,4}

Our genes are inherited from our parents. We receive half of our genes from our mother and half of our genes from our father.⁴

The role of genes in FCS

There are at least six genes known to be associated with FCS, and most of the disease-causing variants occur in the lipoprotein lipase (LPL) gene. This gene aids in the production of LPL, which helps break down fat in the blood.^{2,5}

In people with FCS, a type of fat called triglyceride builds up in the body at very high levels, which may lead to health problems like pancreatitis.²



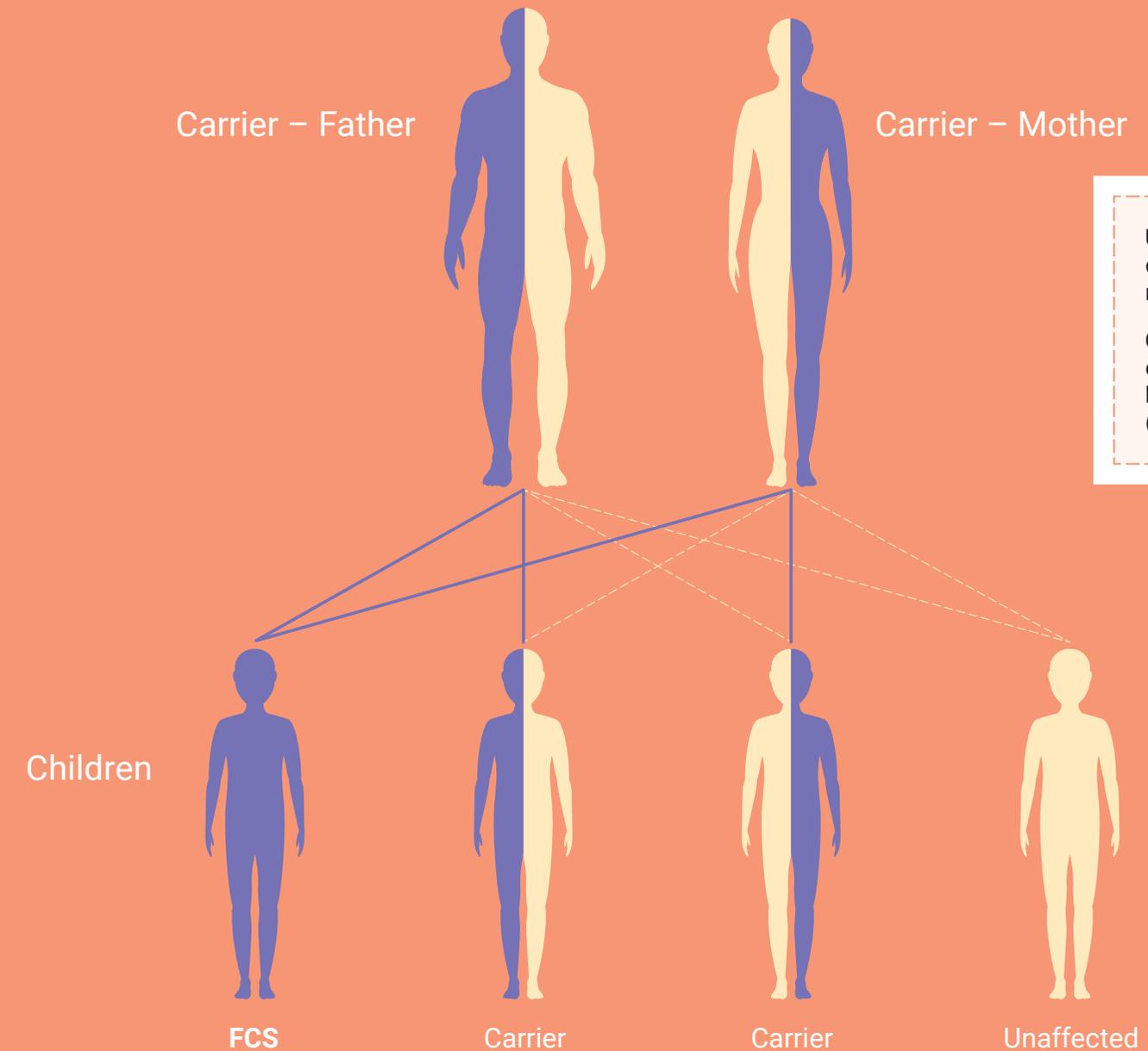
Inheriting FCS

For someone to have FCS, they must inherit two disease-causing genes, one from each parent. This type of inheritance is called autosomal recessive inheritance.²

A person who inherits only one disease-causing gene is called a carrier.⁶

The diagram on the right shows how FCS is inherited. When two parents are carriers, each child they have together has a:

-  **1 in 4 (or 25%) chance to have FCS.** This means the child has two *mutations*, one passed down from each parent.
-  **1 in 2 (or 50%) chance to be a carrier of FCS.** This means the child has one *mutation* and the child will not have FCS. They are more likely to have higher triglyceride levels.²
-  **1 in 4 (or 25%) chance to be unaffected.** This means the child does not have FCS and is not a carrier.



Benefit of genetic testing for FCS

Genetic testing looks for variants in a person's genes that may cause FCS. Healthcare professionals may use genetic tests for two main reasons:

1 Supporting an FCS diagnosis

Genetic testing can help people suspected of having or clinically diagnosed with FCS see if they have disease-causing variants in FCS-related genes.¹

2 Guide treatment and management

Finding out that FCS is the right diagnosis is important because it may help healthcare professionals make lifestyle recommendations and referrals to experts, such as a lipid specialist.⁷



Rick, Living with FCS

Eligibility for testing

The FCS Genetic Testing program is sponsored by Ionis Pharmaceuticals and available to certain qualifying patients. Talk with your healthcare professional to see if you qualify for the program. You qualify if you have:

- Extremely high (severe) triglyceride levels (more than 880 mg/dL or 10 mmol/L), on two fasting blood tests in a row.
- No other known causes of high TG levels.

Get your questions answered

The FCS Genetic Testing program has partnered with Genome Medical, a medical practice specializing in telehealth genetic services, to provide information and genetic counseling throughout the genetic testing process.

Call +1 888.478.1494 to learn more.

How to get genetic tested for FCS

- ❑ Make an appointment with a healthcare professional (HCP)* to discuss genetic testing.
- ❑ Share the [KnowYourTGs.com/diagnosing-fcs/genetic-testing](https://www.knowyourtgs.com/diagnosing-fcs/genetic-testing) webpage with your HCP. Your HCP will check if you qualify for the confidential FCS Genetic Testing program.
- ❑ If you qualify, your HCP can order a genetic test at: https://www.preventiongenetics.com/sponsoredTesting/Ionis_FCS. Testing involves either a saliva sample, an oral swab, or a blood draw.
- ❑ All tests can be done at your doctor's office, or a saliva kit or oral swab kit can be mailed directly to your home.
- ❑ If a saliva kit or oral swab kit is sent to your home, the kit will arrive a few days after ordering. Follow instructions for collection and how to mail the kit to the lab.
- ❑ Testing takes about 3-4 weeks. When results are available, talk with your HCP. You may be scheduled to talk with a genetic counselor about your results and what they mean.
- ❑ To learn more about FCS genetic testing, visit [KnowYourTGs.com/diagnosing-fcs/genetic-testing](https://www.knowyourtgs.com/diagnosing-fcs/genetic-testing) or call the Genome Medical hotline **+1 888.478.1494**.

*Doctors, nurses, physician assistants, and genetic counselors are examples of healthcare professionals who may be able to order genetic tests in your state.

What to expect on your results report

Genetic testing usually shows one of three results:

1 POSITIVE

A positive can occur in two ways:

- A. **Expected to have FCS.** The test found two disease-causing variants in one of the genes that cause FCS. These variants are likely an explanation for some of your symptoms of FCS.
- B. **Carrier of FCS.** The test found one disease-causing variant in one of the genes that cause FCS.

2 NEGATIVE

The test did not find a variant in any of the genes known to cause FCS.

3 VARIANT OF UNCERTAIN SIGNIFICANCE

One or more variants were found in the genes tested, but the lab does not have enough information to determine if the variant(s) causes FCS or not.

Note: If you are not found to have a disease-causing variant but you have a diagnosis of FCS by your doctor, this result does not change your diagnosis.

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FCS Genetic Testing is provided by Ionis Pharmaceuticals®.

[KnowYourTGS.com](https://www.knowyourtgs.com) provides people living with severe hypertriglyceridemia (sHTG) tools, nutritional resources, and education about sHTG. [KnowYourTGS.com](https://www.knowyourtgs.com) also features information about genetic causes of sHTG, such as familial chylomicronemia syndrome (FCS).

Learn more at [KnowYourTGS.com](https://www.knowyourtgs.com)

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