

# Familial Chylomicronemia Syndrome

## WHAT YOU NEED TO KNOW



### What is FCS?

- ◆ FCS stands for Familial Chylomicronemia Syndrome, a condition of very high triglycerides (*a type of fat*) in the blood.
- ◆ The enzyme lipoprotein lipase (*protein that causes a chemical reaction*) that breaks down triglycerides from the diet is absent or does not work well, causing triglyceride levels in the blood to build up.
- ◆ High triglycerides in the blood cause episodes of pancreatitis, a painful and potentially life-threatening inflammation of the pancreas.



### How can my healthcare provider diagnose FCS?

#### Genetic Testing

- ◆ FCS is genetic (inherited), and genetic testing is recommended to confirm diagnosis.

#### Recognition of Symptoms\*

- ◆ Triglyceride levels in the blood  $\geq 885$  mg/dL ( $\geq 10$  mmol/L) or  $\geq 1000$  mg/dL ( $\geq 11.2$  mmol/L), confirmed on multiple occasions. Usually triglycerides are elevated in the thousands.
- ◆ No reason to explain the high triglycerides other than genetics. For instance other conditions can cause high triglycerides like poorly controlled diabetes, a diet high in sugar or fat, low thyroid hormone or kidney disease.
- ◆ Episodes of pancreatitis, often starting in childhood.
- ◆ Triglyceride levels remain high despite taking the standard medications for triglycerides (*fibrates, fish oil which can be dietary supplements or prescription omega-3*).
- ◆ Breakouts of yellowish or white bumps over elbows, buttocks, feet, and trunk (*seen when triglycerides are over 2000 mg/dL*).
- ◆ Stomach pain, confusion, trouble breathing, and numbness or tingling in hands and feet.

\* Note that not all symptoms listed here are present in all FCS patients



### What can I do for my FCS?

- ◆ Follow a very low-fat diet (<20g a day). You should see a registered dietitian (RD) for help with this (*also see FCS cookbook at [LearnYourLipids.com](http://LearnYourLipids.com)*).
- ◆ Seek out a specialist who is trained in managing blood lipids (*Lipid Specialist*).
- ◆ Stay informed on possible new medications which can lower triglycerides in FCS patients. The first FDA-approved medication for FCS, olezarsen, is now available. It is an APOC3 inhibitor that lowers triglycerides and reduces pancreatitis risk. Plozasiran, another APOC3 inhibitor, is currently under review process by the FDA. These studies are listed on [ClinicalTrials.gov](http://ClinicalTrials.gov)
- ◆ A trained specialist can help you get on new medications that reduce triglyceride levels and the risk of pancreatitis for people with FCS.