FCS focus

An Introduction to Familial Chylomicronemia Syndrome for Patients and their Families

***Aaron,** Living with FCS*

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What's in a name?

FCS is called many different names, including:[1]

- Chylomicronemia syndrome
- Familial chylomicronemia
- Hyperlipoproteinemia type I/IA
- Lipoprotein lipase deficiency (LPLD)
- Familial LPL deficiency
- Familial hyperchylomicronemia
- Burger-Grutz syndrome
- Familial fat-induced hypertriglyceridemia
- Hyperlipidemia type 1 (Fredrickson)

Welcome to FCS focus

Living with familial chylomicronemia syndrome (FCS) can be an isolating experience for both you and your loved ones…but it doesn't have to be this way.

Educate yourself about FCS with the information and tools in this brochure. They are aimed to empower you with the knowledge you need to manage your health.

Be sure to share this information with your friends and family. It's important to establish a strong, supportive community of people who understand FCS and can support you along the way.

What is FCS?

Familial Chylomicronemia Syndrome (FCS) is a genetic condition where the body can't digest fats, such as triglycerides (TGs).[2] It affects only a small number of people worldwide. There are many rare diseases, so many doctors are not familiar with the disorder.[1]

A distinctive sign of FCS is blood that appears fatty or "milky" (see facing page) after a blood draw. This is due to the high levels of fat in the body. People living with FCS often have a history of extremely elevated TGs (greater than 880 mg/dL or 10 mmol/l) and severe abdominal pain. One serious complication of FCS is pancreatitis, which can be life threatening.[1]

You can be your best advocate

There are others who understand your experience and with whom you can connect. Advocate for your health by recognizing your symptoms, creating a dedicated medical team of healthcare providers, and committing to a holistic plan for living with FCS.

Does this sound like you?

- ☐ Do you have a history of high or extremely high TGs (greater than 880 mg/dL or 10 mmol/l) even with medication and following a low-fat diet?
- ☐ Does anyone in your family have a history of high TGs or a genetic lipid disorder?
- ☐ Have you ever been told you have a genetic lipid, TG or fat disorder?
- ☐ Have you been diagnosed with pancreatitis requiring the emergency room or hospitalization?
- ☐ Do you have frequent pain in your abdomen or lower back?

FCS signs and symptoms

Familial chylomicronemia syndrome (FCS) is a genetic disorder, which means it is always with you.[2] The age at which patients first show symptoms and the types of symptoms they experience may vary. Some people may have noticeable warning signs of FCS when they are young. Others may not feel anything until adulthood.[3,4]

First signs and symptoms

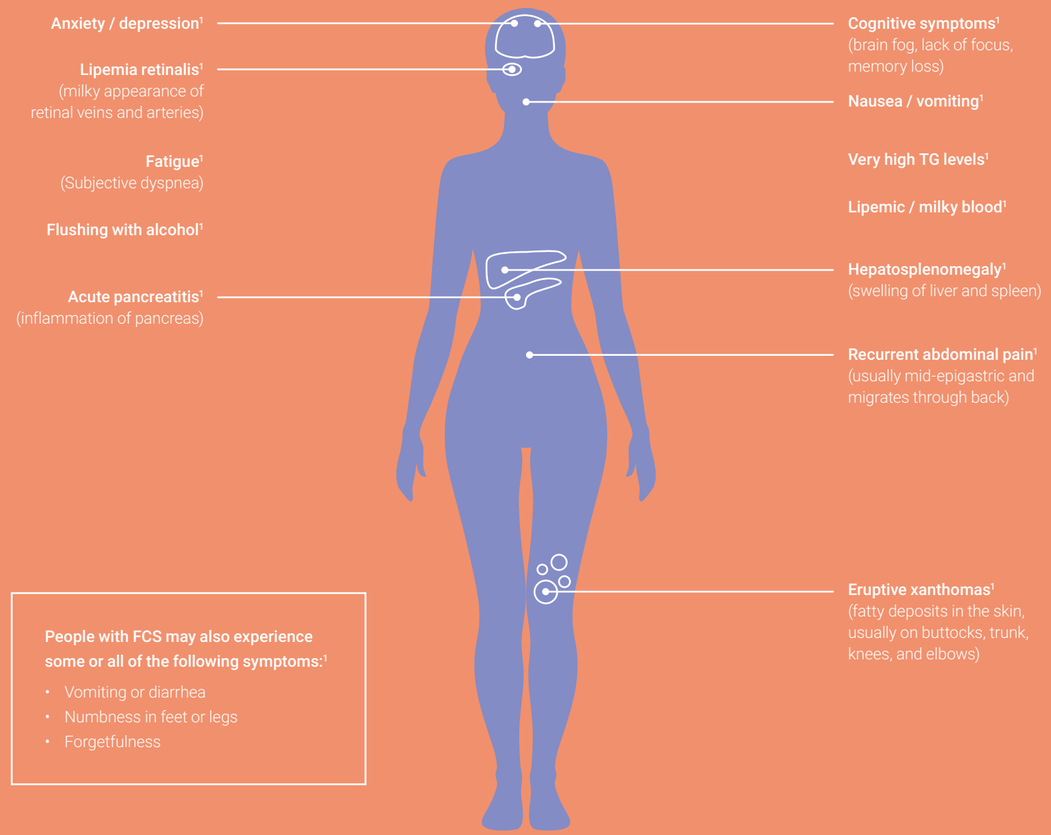
Sometimes, the first clinical sign of FCS is a **blood draw that appears "milky."** The first physical symptom may be **severe abdominal pain.** Triglyceride (TG) levels are considered "normal" when they are less than 150 mg/dL (1.7 mmol/l).[5] People who have FCS have extremely high TGs that may rise up to 10,000 mg/dL (113 mmol/l) or more even after medication and following a low-fat diet.[1]

Dangers of high TGs

Continued buildup of TGs may lead to other health problems, such as **fatty liver disease, enlarged liver, enlarged spleen, and pancreatitis.**[1]

FCS and pancreatitis

The most serious complication of FCS is pancreatitis, which often happens when TGs are very high.[7] The pancreas produces hormones, such as insulin, regulates blood sugar, and helps digest food. The pancreas becomes inflamed when a patient has pancreatitis. It is extremely painful and may worsen quickly. Repeated attacks of pancreatitis may lead to long-term organ damage, insulin-dependent diabetes or even death.[1,3,4,9]



People with FCS may also experience some or all of the following symptoms:[1]

- Vomiting or diarrhea
- Numbness in feet or legs
- Forgetfulness

Lindsey's story

I was diagnosed with familial chylomicronemia syndrome (FCS) when I was five-weeks old so I've lived with this condition my whole life. I cried a lot as a baby, but other than abdominal pain, my FCS was pretty mild throughout childhood.

My day-to-day symptoms got worse during college because I was stressed out all the time. I also began to experience severe fatigue that caused me to miss a lot of class, so I was even more stressed! In total, I've experienced about 30 episodes of pancreatitis for which I was hospitalized. The absolute worst was when I got pancreatitis and was in the hospital during my dad's birthday. I hate worrying my friends and family. They are always concerned and I feel like a burden.

I have had a few medical complications as a result of FCS and have a dull ache and burning sensation in my stomach on a daily basis. I do my best to eat less than 10 grams of fat a day. I like to cook, but this is still a challenge.

FCS has made me a stronger person. As a result of this condition, I am independent and incredibly positive.

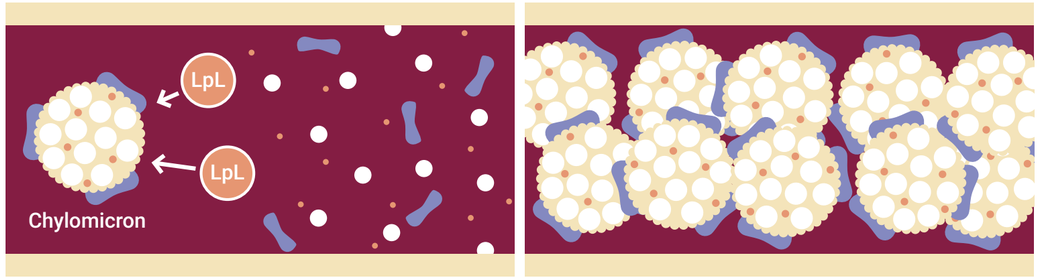
Most importantly, I am an advocate for others like me. FCS will never stand in my way.

Lindsey
is an FCS patient, nutritionist and the co-president of the patient advocacy group the FCS Foundation

People with FCS are not able to digest fats

Fat digestion happens when chylomicrons are cleared from the blood

Foods that are high in fat (i.e., bacon, whole milk, and almonds), or high in sugar (i.e., soda, alcohol, and juices) either have or increase a type of fat called triglycerides (TGs) in the body. After we eat, the TGs in these foods are packaged in structures called **chylomicrons.**[1]



Important: *LPL is the missing piece in familial chylomicronemia syndrome (FCS)*[1]

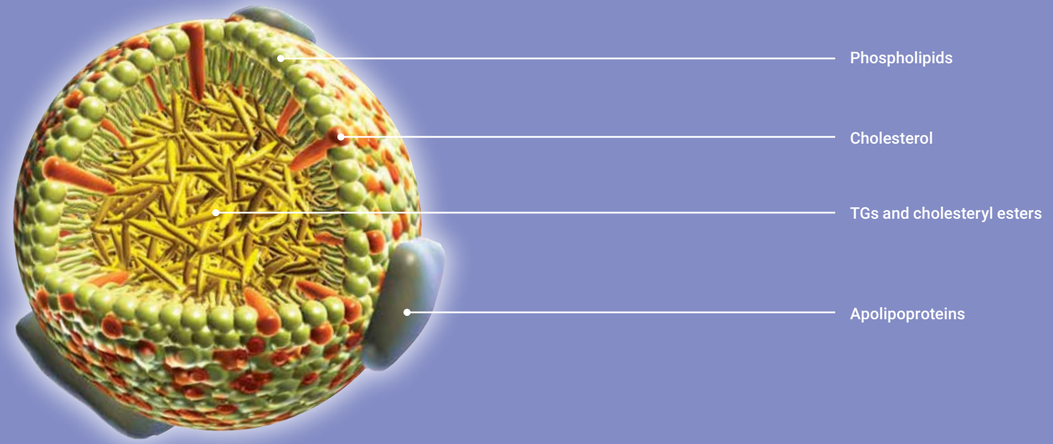
Lipoprotein lipase (LPL) is an enzyme that helps digest fats. It breaks down bulky chylomicrons (see facing page) and processes fat so our bodies can use the byproducts for energy. The image above shows the important role LPL plays in digesting chylomicrons.[1,2,8]

People who have FCS are unable to process TGs because LPL is missing or broken.[1] As a result, fat accumulates in their blood in the form of chylomicrons. This accumulation is called chylomicronemia, illustrated by the image above. [1,2,8]

Chylomicrons

How do you measure chylomicron and TG levels?[1]

Because chylomicrons are made up of mostly triglycerides (TGs), measuring TGs can tell your doctor if you have chylomicrons in your blood. TGs are measured from a blood draw, usually after a period of no eating. Fat levels in the blood of people without FCS increase after eating and return to normal within three to four hours. **If you have FCS, you are unable to digest fats.** This causes sustained high-TG levels. **Severely high levels of TGs, or hypertriglyceridemia (HTG), increase the risk of HTG-induced pancreatitis.**



Chylomicrons are composed mostly of TGs or another type of fat. This design enables fats to travel through the bloodstream during digestion.

Yang's story

I experienced my first symptoms when I was three-months old. I was taken to the hospital because I was incessantly crying, had a rigid body and refused to eat—it was probably my first pancreatitis episode. The doctors were shocked at the high-fat content in my blood, but I did not receive a specific diagnosis. My parents were told to not have any more children and that I would not live long.

The recurrent severe abdominal pain started at 10-years old and continued on and off. I received my first diagnosis of pancreatitis in college, but they did not take blood tests to confirm triglycerides (TGs) as the cause. I experienced more serious and frequent recurrent pancreatitis that prohibited me from finishing my doctoral degree.

I came across a book about a diet and recipes for people with high TGs. In the first chapter, it listed all the possible reasons a patient might have hyperlipidemia, and this included genetic causes.

I wasn't 100 percent sure [it was FCS] because I didn't have skin problems, but it listed recurrent pancreatitis and I had high TGs.

Yang
is an FCS patient and research scientist

Pancreatitis is a serious complication of FCS

Pancreatitis is inflammation that occurs when the digestive enzymes are inappropriately activated inside the pancreas. Why this happens is not well understood. What is important to remember is that **each attack can be severe and life threatening.**[4]

People with familial chylomicronemia syndrome (FCS) may experience recurring episodes of pancreatitis that may cause lasting damage to the pancreas, or chronic pancreatitis.[1,3,4,9]

High triglycerides (TGs), or hypertriglyceridemia, is the third leading cause of pancreatitis.[9] Other more common causes are biliary pancreatitis (gallbladder stones passing into the bile duct triggering pancreatitis) and pancreatitis from excessive alcohol consumption.

How do I diagnose pancreatitis in my patients?
First, the patient presents with severe abdominal pain, like a bomb went off! This is frequently triggered by food but on occasion may be sudden onset. The second finding is a significant elevation of the amylase and/or lipase, at least three times the upper limit of normal. Lastly, I will look for radiological evidence of inflammation in the pancreas (by CT, ultrasound or MRI). Two out of the above three makes a diagnosis of acute pancreatitis.[4]

Anonymous,
– MD, MMSc, pancreatologist

Signs of high TG-induced pancreatitis
The pain in the abdomen can be very severe, requiring you to go to the emergency room for appropriate medical treatment.

Possible signs and symptoms of pancreatitis include:[10]

- Severe upper abdomen pain
- Abdominal tenderness and pain that is worse after eating
- Nausea and vomiting
- Fever

NOTE: Only a medical professional can diagnose pancreatitis. If you are experiencing these symptoms, seek medical care immediately. If pancreatitis due to high TGs is a risk, work with your doctors to put an emergency communication plan in place.

Aaron: "Living with FCS can get really daunting. The cramping, body fatigue, aches, pains, and inflammation. And the stomach problems, that's a huge thing. Day to day, it can grind you down."

Katy: "The spectre of pancreatitis is always there – and it's looming. He has seen what an attack of pancreatitis will do to him, and what it will do to the family. When he comes out after a week in the hospital, it's easily a two week recuperation period just to get him out of bed. The impact on the family, in terms of recovering from his abscence and recovering from that fear, is huge."

Aaron and his wife Katy
– FCS patient, and caregiver

High TG-induced pancreatitis frequently requires emergency care

High TG-induced pancreatitis is serious and is frequently managed under medical supervision. If you are at risk, talk with **your doctor (i.e. lipidologist, endocrinologist or pancreatologist) and have a plan ready.**

What to expect

Healthcare providers usually have standard questions they ask when admitting patients. This overview provides an idea of what to expect.

step 1

What should I bring to the emergency room?

It's helpful to have a packet of information ready to bring along, especially if you have a familial chylomicronemia syndrome (FCS) diagnosis and a history of pancreatitis. Consider bringing the following:

- ☐ **Your medical records.**
- ☐ **A doctor's note.** If you have received an FCS diagnosis, bring a note from your doctor. This will be especially helpful if you have had repeated visits.
- ☐ **Information about FCS.** Your doctors and nurses probably will not know about FCS. Ask your doctor for information you could share if you have to go to the emergency room.
- ☐ **A list of medications you are taking.**

Communicate your medical history to the healthcare provider in the emergency room

Knowing about your FCS diagnosis may prompt your doctor to:

- ☐ Check TG levels upon admission or after a period of fasting.
- ☐ Address your symptoms and start appropriate medical care.

step 2

Tests and diagnosis

To diagnose pancreatitis, doctors will order blood or urine tests to see if you have elevated levels of two digestive enzymes—amylase and lipase.[11] Normal levels of amylase and lipase can occur and may be misleading.[12] This is why it's **CRITICAL** that you communicate an FCS diagnosis to your healthcare providers during all encounters.

Questions you may be asked to confirm a pancreatitis diagnosis:

- ☐ What have you eaten lately?
- ☐ How much alcohol have you consumed in the past few days?
- ☐ What is your pain level?
- ☐ Have you vomited?
- ☐ Is your pain in your abdomen or lower back?
- ☐ Have you experienced pancreatitis before?

step 3

Treatment and management

How is pancreatitis treated?[4]

It may take several days to several weeks to recover from pancreatitis. Standard treatment often includes hospitalization and the following:

- ☐ IV fluids for hydration
- ☐ Pain medication
- ☐ Lowering TG levels through other therapies, if indicated

Note to caregivers: *Your loved one experiencing pancreatitis may have loss of appetite, moodiness and irritability. Knowing the signs will help you offer your loved one support during an episode and recovery.*

step 4

Follow up

Make sure you tell **all** the doctors you see, including your primary care physician, that you had pancreatitis. Follow up with your healthcare team (e.g., lipidologist, endocrinologist or pancreatologist). Be sure you tell your primary healthcare provider about your hospital stay and bring information about FCS to any follow-up visits.

Justin’s story

“It was a long journey to get to a diagnosis because most people are not familiar with familial chylomicronemia syndrome (FCS) and there is very little information available. As a result, people like me are misdiagnosed for months or years. I had to visit many different specialists to finally get an accurate diagnosis, and in the end it was my wife who found a name for my disease. The diagnosis was eventually confirmed by a doctor.

I wish doctors had asked me more questions about my symptoms and tested me for some less common health issues. **I wish I had been referred to a lipid specialist right away.**

There are a lot of rare diseases out there, so you have to ask the right questions and work with the right specialists to get to the right answers.”

Justin
is an FCS patient, volunteer firefighter and operations manager

FCS and other causes of high TGs

Because there are so many other causes of high triglycerides (TGs) and **because familial chylomicronemia syndrome (FCS) is rare, it is often misdiagnosed or not diagnosed at all.**[4]

When examining a patient with high TGs, a doctor will ask questions to rule out common causes, including diet, lifestyle, medications and untreated medical problems. The chart on the facing page shows how, through a process of elimination, they will:[2]

☐ Eliminate common causes of high TGs; and

☐ Collect evidence that supports a diagnosis and recommendations.

Some medications may increase TGs

Several medications, such as estrogen, beta-blockers, and some drugs for mental illness, may increase TG levels. Make sure you share a list of medications you are taking when talking with your doctor.[2]

Women and children require special consideration

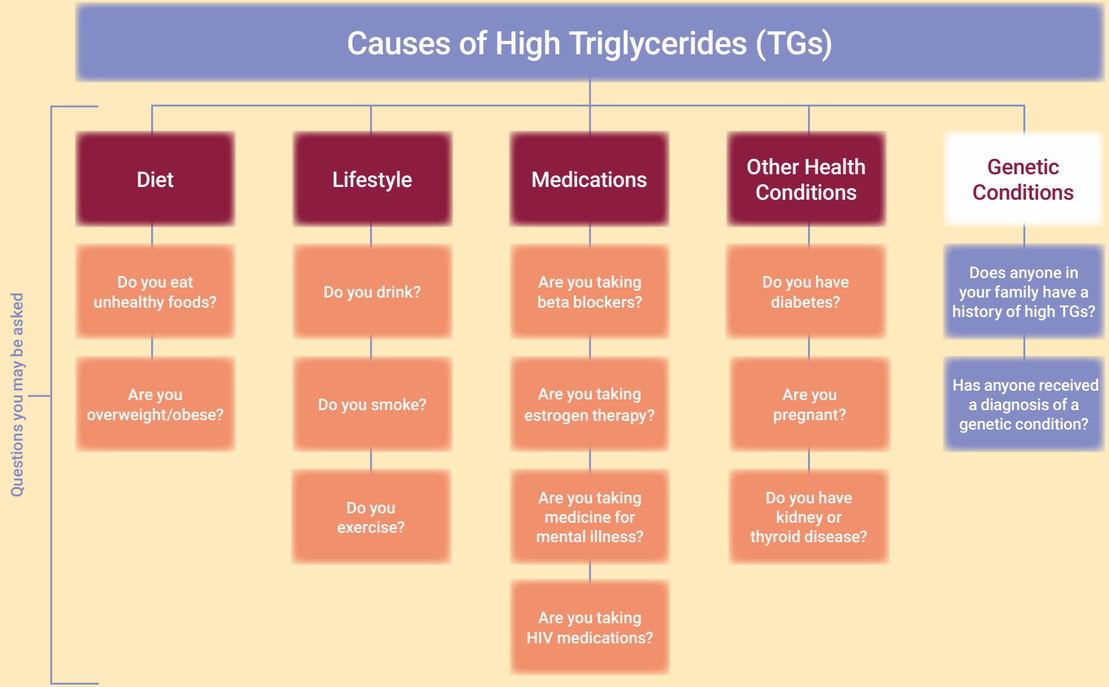
Pregnant women have natural TG fluctuations in their third trimester of pregnancy, but FCS patients may have dangerously high levels of TGs.[2] Speak with a lipidologist if FCS is suspected.

Children may receive an FCS diagnosis in early infancy.[4] Work with a lipidologist and registered dietitian to ensure the child is receiving adequate nutrition and healthcare support.

What is the risk of FCS to my family members?

FCS is a recessive genetic trait, like red hair or blue eyes.That means it can only occur if you inherit a bad gene from both parents.[2] If you have FCS, your family members may or may not have the disorder. If someone else in your family has high TGs, it's important that they also see a specialist (e.g., lipidologist or endocrinologist).

Doctors rule out common causes of high TGs before considering genetic factors[1]



Living with FCS

Familial chylomicronemia syndrome (FCS), like other conditions such as Crohn's or celiac disease, requires a specific lifestyle and diet.[13] And sometimes this can be hard. Learning about foods, fat, carbs and triglycerides (TGs) can help, as can developing good routines and connecting with others.

Successful management means implementing **holistic, healthy lifestyle habits.** Holistic means to treat the "whole person" and not just the physical symptoms of a condition. Choose dietary **AND** lifestyle options that will promote your best health and limit those that will worsen your condition.

A very low-fat diet and abstinence from alcohol are critical first steps of management.[13] Talk to your healthcare provider about other diet and lifestyle strategies to help lower your TG levels.[13]

Medical treatment

Some medications may help lower TGs. Response to TG-lowering medications varies by patient, so be sure to talk to your doctor about your options.[2]

Diet

- ☐ Consult a registered dietitian for nutrition counseling
- ☐ Learn to read food labels to manage your fat and calorie intake
- ☐ Keep a food diary to monitor your eating habits
- ☐ Plan and enjoy your meals at home and in restaurants with food choices recommended by your registered dietitian

Body

- ☐ Exercise 30 minutes, 5 times a week. Always consult your physician before beginning any exercise program
- ☐ Try a fitness class with a friend or family member
- ☐ Track and maintain blood sugar if you have diabetes
- ☐ Eliminate smoking and alcohol

Mind

- ☐ Meditate
- ☐ Keep a mood journal
- ☐ Practice deep breathing exercises to promote a sense of calm
- ☐ Join a support group to share your experience and feelings

Diet and nutrition

Effectively managing your diet is the cornerstone to living with familial chylomicronemia syndrome (FCS)

The good news is you can still enjoy carefully planned delicious foods! A registered dietitian can provide customized advice for food selection to fit your lifestyle. Family members and friends can participate in the counseling sessions. This will help them to provide the support you may need.

What will a registered dietitian discuss?

When you meet with a registered dietitian for the first time, he or she will want to understand YOU, your lifestyle, and your concerns. This info will help them create your targeted nutritional plan. Their counseling will address your education and motivation around the following:

- ☐ Eliminating alcohol and smoking
- ☐ Transitioning to a low-fat diet meal plan
- ☐ Meeting nutritional requirements for essential fatty acids
- ☐ Reducing simple carbs and limiting total carbs
- ☐ Weight management and physical activity
- ☐ Food selection and meal preparation to fit your lifestyle and your taste

What to bring

To make the most of your appointment, bring along:

- ☐ Your most recent **fasting** triglyceride (TG) reading, which means no food or drink (except water) for 12 hours before your appointment and no alcohol for 48 hours
- ☐ A record of **all** food and drinks consumed for three non-consecutive days (two weekdays and one weekend day)
- ☐ Information about FCS

***Important:** Different people may be able to tolerate different foods. It will take time and patience to fully appreciate what an FCS diagnosis means for you, your diet, your lifestyle and your family. Work with a registered dietitian to create a safe plan to slowly introduce or reintroduce different types of foods into your diet.*

FCS-friendly nutrition guidelines*

Food groups	Try this...	...Instead of this
Lean Protein: Focus on lean protein, 3 oz. serving size (size of a deck of playing cards)	• Non-oily white fish, such as cod, skate, sole, canned tuna, or haddock • Most shellfish, including shrimp and scallops • Breast of most poultry, skinned and trimmed of all fat • Steam proteins or cook with Medium Chain Triglyceride oil (MCT, a medical food) • Egg whites • Fat-free dairy products, such as milk, yogurt, and cheese	• Fish high in fat and mercury • Egg yolk • Fatty meat (beef, lamb, pork) • Processed meats (hot dogs, sausage, bologna) • Other saturated and unsaturated fats
Complex Carbs: Focus on whole grains	• Whole grain, such as whole wheat, brown rice • Quinoa • Whole wheat pasta and bread	• Egg pasta and pasta dishes prepared with refined flour, fat, and meat • Most cereal
Vegetables, Nuts, Seeds and Fruits: Eat more colorful vegetables	• Leafy greens, such as spinach and kale • Fill half of your plate with green, red, and yellow vegetables • Colorful vegetables: Red peppers, zucchini, squash • Choose fruits with no added sugar	• Avoid: Edamame, soy nuts, seeds, avocado, olives, coconut, peanuts, and tree nuts
Fat: 10-25 grams a day	• Add/cook with Medium Chain Triglyceride (MCT) oil • Meet requirements for essential fatty acids	• All oils and fats, including olive oil, sunflower oil, canola, soybean oil, butter, lard, margarine, and seed and nut butters • Avoid saturated and unsaturated fats
Simple Carbs: Restrict simple carbs, refined starches and added sugars	• Choose in moderation – strawberries, blueberries, and oranges	• Fruit juices, fruits, candy, soft drinks • Sugar, syrup, honey

* Based on references 13,14

Lynne's story

When you love somebody and see them going through the vomiting and the sickness…it's just heart wrenching. I could also feel his sense of hopelessness, but he was a trooper despite all of this. In some ways, he's my hero. But to be brutally honest, I got mad at the illness and the situation we were in.

My advice to a newly diagnosed patient and their family is to not give up. How you feel today isn't how you are going to feel for the rest of your life.

Also, and importantly, seek out the care of a support group because it is helpful to hear other patients and caregivers share experiences that are similar to yours. You can also talk about your feelings and express your fears.

Fred and his wife Lynne,,
FCS patient and caregiver

You are not alone

Create your team

Familial chylomicronemia syndrome (FCS) is rare and not well understood by most healthcare providers. If you receive a diagnosis of FCS, you may find it helpful to establish and maintain open communication with a team of medical specialists.

Most importantly, you must advocate for your own healthcare, especially when navigating life with FCS.

Type	Role
Primary Care Physician	Often your first point of contact when you are sick. They will refer you to specialists for addressing specific symptoms.
Lipidologist / Endocrinologist / Cardiologist	Lipid experts may be able to provide alternative methods of managing high TGs after other more conventional treatments have failed.
Gastroenterologist / Pancreatologist	GI doctors specialize in diseases affecting the stomach, intestines, and the pancreas. They are called when patients have complicated issues, like pancreatitis.
Registered Dietitian	This specialist will explain dietary requirements of FCS and create customized nutritional plans to minimize symptoms.

Other types of specialists you may see include: ophthalmologists (eyes), hepatologists (liver), geneticists (genes), and cardiologists (heart). Nurses, nurse practitioners, and physician assistants, also play an important role in your care.

A note from Joyce Ross

2016 president of the National Lipid Association, MSN, ANP, CS, CRNP, CLS, FNLA

FCS may not affect many people, but the disruption and devastation of those affected – along with their families – is intense and life altering. Despite the fact that this is a genetic disorder, symptoms may emerge as early as a few days after birth or not until adulthood. I've been distressed to hear patients' stories of struggle to understand their disorder and frustration of finding healthcare providers knowledgeable about FCS. **Sadly, patients are often made to feel that it's their fault**—that they are just not following doctor's orders.

I could relate to these emotions mostly by remembering how in the past patients with the genetic disorder familial hypercholesterolemia (FH) faced similar issues. In my own family, there was little understanding of just how premature cardiac disease occurred in a healthy, active father of five (who had a history of premature cardiac disease in both parents). The good news is that there is now a better understanding of FH diagnosis and treatment. **The goals and dreams are to see FCS understood and that patients will have the same opportunity for appropriate identification, treatment, and a productive life.**

Providers need to be informed as to where to find lipid specialists who are experts in this field and to whom they may refer patients. **Patients and their families** need educational support about FCS to become fully engaged in treatment, including emotional support and dietary requirement information.

Many FCS patients live in isolation, experience employment difficulties and have trouble socializing due to FCS and its consequences. Specifically, they need:

- To understand that FCS is an inability to digest fats
- To understand the association with other diseases
- To have contact with others who understand their world and problems

> "We have come a long way but much more is needed. For the patients and families the message is clear: We hear you, we all hear you, please join in the fight!"

Information and support

Whether you are a patient or a caregiver, there is a worldwide community of people whose lives are affected by familial chylomicronemia syndrome (FCS). They need your input and support.

Information on FCS	Nutritional support	Patient/caregiver support
Know Your TGs www.KnowYourTGs.com	**Foundation of the National Lipid Association** www.learnyourlipids.com	**Action FCS** www.actionfcs.org
National Pancreas Foundation www.pancreasfoundation.org/patient-information	**Academy of Nutrition and Dietetics** www.eatright.org	**Canadian Organization for Rare Disorders** (CORD) www.raredisorders.ca
The Endocrine Society https://www.endocrine.org/patient-engagement/endocrine-library/familial-chylomicronemia-syndrome		**The FCS Foundation** www.livingwithfcs.org
Genetics Home Reference-familial LPLD https://ghr.nlm.nih.gov/condition/familial-lipoprotein-lipase-deficiency		**Living with FCS Facebook** www.facebook.com/fightFCS
HEART UK heartuk.org.uk/health-and-high-cholesterol/triglycerides/lpld		**RareConnect LPLD Community** www.RareConnect.org/community/lipoprotein-lipase-deficiency
		Global Genes globalgenes.org

> “People with FCS are part of the rare disease community; we have differences, but also much in common. One of the most important things patients and caregivers can do is connect with each other over shared experiences, that is when the magic happens in rare disease. When people come together over a shared mission, it sets the stage for individuals to learn, be inspired, develop community, increase awareness, and create real progress. Nothing is more important!”

Nicole Boice, founder and CEO

Global Genes®
Allies in Rare Disease

For more tools and information, go to KnowYourTGs.com

Keep track of your progress: Daily symptom tracker

Take ownership of your health by tracking your symptoms so you can discuss them with your healthcare team.

Daily symptom tracker

Use the checklist below to mark your symptoms and the frequency with which you experience them (i.e., daily, weekly, monthly, or note certain hours of the day). Refer to this resource when speaking to your doctor about symptoms you are experiencing and how frequently they are occurring.

What symptoms have you experienced?	How often are you experiencing this symptom?			
	Daily	Weekly	Monthly	Notes
☐ Neurological: Headaches, forgetfulness, and/or memory loss				
☐ Fatigue				
☐ Irregular yellow patches or nodules on skin (eruptive xanthomas)				
☐ Numbness in feet or legs				
☐ Abdominal or lower back pain				
☐ Diagnosed acute pancreatitis				
☐ Nausea or vomiting				
☐ Diarrhea				
☐ Other				

Lipid panel tracker

A lipid panel is a blood test that measures fat and cholesterol levels in your blood. Healthcare providers use this measurement to determine treatment, and make diet and lifestyle recommendations.

Lipid panel tracker

Use this tool to track and stay informed about your lipid panel blood test results. Tracking your lipid panels will help you understand what your "normal" levels are, and help you have a more productive conversation with your healthcare providers.

Date	Total Cholesterol	HDL	LDL	TGs	Chol/HDL Ratio	Notes
Reference Values[6]	*< 200 mg/dL (< 5.2 mmol/l)*	*> 40 mg/dL (> 1 mmol/l)*	*< 130 mg/dL (< 3.3 mmol/l)*	*< 150 mg/dL (< 1.7 mmol/l)*	*< 3.5 to 1*	

A message from the co-presidents of the FCS Foundation

Living with familial chylomicronemia syndrome (FCS) is nothing short of a challenge. We know this because we have been personally affected by it. FCS is a frustrating genetic condition that causes health problems…even when we are trying our best. Some patients and their families experience pain, discomfort, guilt, and anxiety, every single day due to living with FCS.

We started the FCS Foundation (www.livingwithfcs.org) to help patients and their families find a community of people just like them. Living with a rare disorder can feel extremely isolating. We promote a message of education and support. Patients and their families will benefit from sharing their experience with others who understand and care.

Lindsey Sutton and Melissa Goetz,
co-presidents of the FCS Foundation

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KnowYourTGs.com provides people living with severe hypertriglyceridemia (sHTG) tools, nutritional resources, and education about sHTG. KnowYourTGs.com also features information about genetic causes of sHTG, such as familial chylomicronemia syndrome (FCS).

For more tools and information, go to **www.KnowYourTGs.com**.