

Know your  TGS

Lipid specialists and FCS

A GUIDE TO CERTIFIED LIPID SPECIALISTS FOR PEOPLE
WITH FAMILIAL CHYLOMICRONEMIA SYNDROME (FCS)

Actor portrayal.
Not actual physician
or patient.



LIPID SPECIALISTS AND FCS

Lipid specialists: An important part of your healthcare team

When you have FCS, managing your health means managing your lipids. But what are lipids? And how can a certified lipid specialist help you with them? This brochure will answer those questions and more. You will learn:

- What a certified lipid specialist is and how they train.
- Why working with a lipid specialist is important and how they can help you.
- How to find the right lipid specialist for you as part of a healthcare team.

With this information, you will be better prepared to find help in managing your condition.

*Actor portrayal.
Not actual physicians.*

The information provided here is for educational purposes only and is not intended as medical advice. Always consult with a qualified healthcare professional before making any changes to your diet or lifestyle.

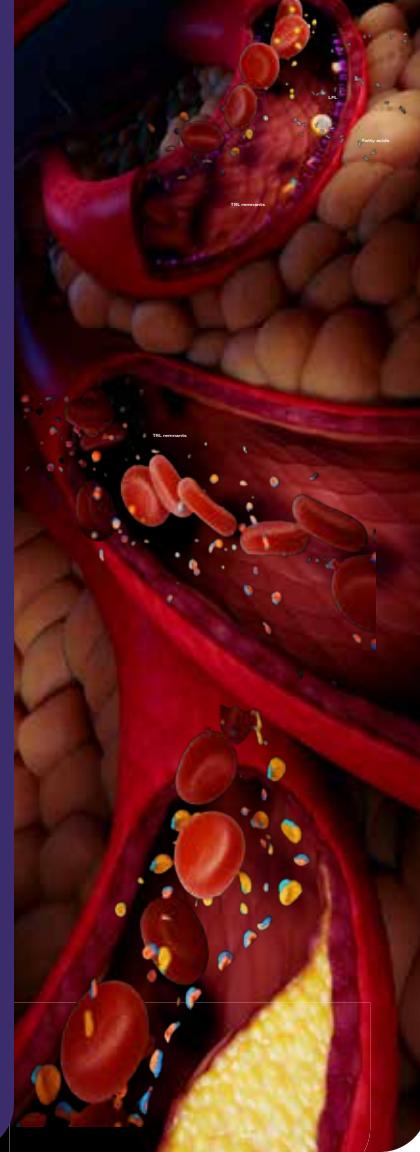
Why should someone with FCS care about lipids?

Lipids are a class of oily or waxy molecules that tend not to dissolve in water. This includes different types of fat.

The most common type of fat in your body is triglycerides. Triglycerides come from the food you eat, such as butter, oil, meat, and nuts. They also form when your body packages extra calories that it does not use right away.

People with FCS have a genetic disorder that severely impairs the body's ability to break down triglycerides. This often causes people with FCS to have extremely high triglyceride levels, called severe hypertriglyceridemia, which can lead to serious complications like pancreatitis.

Since triglycerides are a type of lipid, careful management of triglyceride levels often means people with FCS must work with a certified lipid specialist.



What is a certified lipid specialist?

A certified lipid specialist is a healthcare professional (HCP) with advanced skills in the identification and management of disorders related to lipids in the blood. This includes conditions involving hypertriglyceridemia, such as FCS. Two professional organizations certify this specialization: The American Board of Clinical Lipidology and the Accreditation Council for Clinical Lipidology.





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How are lipid specialists certified?

Once they have completed all the requirements, lipid specialists must pass an exam to become certified by one of two professional organizations:

- The American Board of Clinical Lipidology certifies physicians as Clinical Lipidologist (CL).
- The Accreditation Council for Clinical Lipidology certifies cardiovascular care team members such as pharmacists, physicians, physician assistants, nurses, and dietitians as Clinical Lipid Specialists (CLS).

Can lipid specialists have other specializations?

Lipid conditions often overlap with other medical conditions and organ systems, so some lipid specialists may have other specialties.

Specializing in multiple fields enhances the diagnosis, treatment, and management of lipid-related conditions like FCS.

Other specializations of lipid specialists:

TYPE	SPECIALTY	RELATION TO LIPIDS
Endocrinologist	Hormone-secreting glands and organs like the pancreas	Diabetes and metabolic disorders can influence lipid levels
Cardiologist	Heart and blood vessels	High lipid levels can increase the risk of heart disease and other complications
Gastroenterologist	Digestive system	The digestive system breaks down and absorbs lipids
Registered Dietitian Nutritionist	Diet and nutrition	Help patients make lifestyle changes to manage lipid levels
Geneticist	Genes and heredity	Assist in diagnosing inherited lipid conditions and advise on family risks

How does a lipid specialist help patients with FCS?

- **Evaluates your history,** including reviewing personal and family medical history, symptoms, and lifestyle factors. This helps determine the severity of your condition and potential risk factors.
- **Analyzes blood test results** to help diagnose, track, and manage lipid-related disorders with extremely high triglyceride levels, such as FCS. They also monitor additional markers, such as cholesterol and enzyme levels, to assess overall health.
- **Contributes to an early and accurate diagnosis** by recognizing the specific patterns of FCS and possibly ordering genetic testing to support the diagnosis. An early and accurate diagnosis may reduce the chance of complications like acute pancreatitis.
- **Creates, monitors, and adjusts an individualized care plan** to fit your unique needs and symptoms. This will include strict dietary modifications, such as avoiding fats and simple carbohydrates, as well as strategies to manage symptoms like fatigue, abdominal pain, and brain fog.
- **Collaborates with the healthcare team**, working with your primary care physicians, dietitians, endocrinologists, and other specialists, so you get whole-body care.
- **Provides patient education** about the condition, dietary strategies, lifestyle modifications, and new developments in the field. They can help you understand how to manage symptoms, avoid triggers, and advocate for your health.



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Why should FCS patients have a lipid specialist?

- **The complexity of FCS requires their expertise.** FCS is underdiagnosed, so not a lot of HCPs know about it. Also, it does not respond to common TG-lowering treatments. A lipid specialist has exposure to lipid conditions, so they can support an accurate diagnosis and give you management strategies tailored to your needs.
- **They stay up to date on research.** A lipid specialist stays informed about emerging therapies, clinical trials, and medical advancements, giving you access to the most up-to-date and effective options.
- **You may feel emotionally supported.** Living with an underdiagnosed condition like FCS may leave you feeling frustrated or isolated. Lipid specialists are there to listen and help you navigate challenges, make informed decisions, and connect with additional resources such as support groups and dietitians.
- **They can help you minimize complications.** Consistent monitoring and expert guidance from a lipid specialist may encourage you to make and keep the lifestyle changes needed to prevent serious complications like pancreatitis, which can be life-threatening.
- **They can help you maximize your quality of life.** The goal of FCS management is not only to prevent complications but also to improve your daily life. A lipid specialist may help you reduce symptoms such as abdominal pain, fatigue, and cognitive difficulties, making it easier to carry out daily activities and maintain overall well-being.
- **FCS requires lifelong care.** Since FCS is genetic, it never goes away. You may need long-term monitoring and adjustments to your care plan your whole life.

Why is a team of healthcare professionals important for people with FCS?

When you have a condition like FCS, which may impact multiple aspects of your health, it just makes sense to have a good team on your side.

A team-based approach will help you get the well-rounded, individualized care you need by:

- Providing specialized expertise for different aspects of FCS.
- Coordinating personalized treatment plans based on your specific needs.
- Monitoring symptoms, lab results, and long-term health trends.
- Offering emotional and lifestyle support to improve quality of life.

In addition to the HCPs listed in the specialty chart shown earlier, you will probably have a primary care physician who oversees your overall health, preventive care, and non-FCS-related medical issues. You may also need a mental health professional to support you in coping with the emotional challenges of living with FCS, such as anxiety and stress.

How does a healthcare team work together?

Each specialist plays a unique role, but regular communication can address all aspects of your health in a seamless, effective way. Ideally, a well-connected healthcare team shares information, treatment updates, and patient progress so your care is comprehensive and consistent.

They should:

- Coordinate treatment plans where specialists work together to balance dietary, medical, and lifestyle recommendations.
- Share lab results and health updates so each provider understands your current condition and can adjust care accordingly.
- Make decisions on medication, clinical trial opportunities, and symptom management strategies.



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Who runs your healthcare team?

At the head of that team is the most important team member: **YOU**.

There are many things that only you know about yourself, your health, your lifestyle, your family, your values, and your preferences. All of that knowledge goes into developing a treatment plan that works for you.

You are also the head of the team because, often, nobody will fight for your health and rights like you will.

KnowYourTGs.com has a whole page on your role on your healthcare team, and a guide to self-advocacy, so definitely check those resources out.

How can you find a lipid specialist?

- Referral from a primary care doctor or specialist
- Online directory at the National Lipid Association (NLA) lipid.org/member_map.
- Hospital or academic medical centers with lipid clinics

How can you interview a lipid specialist?

A lipid specialist will work for **you**, so it is fair to interview them for the job. Here are some subjects to explore so you can make sure they are the right fit for you.

Experience & expertise:

- How much experience do you have treating FCS?
- Do you work with other patients with rare lipid conditions?

Diet & lifestyle guidance:

- Do you collaborate with dietitians experienced in FCS?
- What support do you offer for managing strict dietary needs?

Communication & accessibility:

- How can I reach you if I have urgent questions?
- Do you offer virtual appointments?
- Will you work with a care team?
- Will you work with me to create an emergency care plan?

Research & new treatments:

- Are you up to date on FCS research or clinical trials?
- Involved in any?



NOTES

Visit knowyourtgs.com to learn more about about FCS symptoms, acute pancreatitis, genetics and more.

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