Questions to Ask Your Healthcare Provider When Diagnosed with Familial Chylomicronemia Syndrome (*FCS*)

The National Pancreas Foundation

If you've been diagnosed with Familial Chylomicronemia Syndrome (FCS), here are some suggestions of what to ask your healthcare provider to better understand your condition and manage it effectively.

Understanding the Condition:



1. In plain terms, could you explain to me what exactly FCS is, and how does it affect my body?
2. How is FCS different from other reasons for high triglycerides or hyperlipidemia?
3. What caused my FCS? Is it due to a specific gene mutation? How do I know what my mutation is?
4. Are my family members at risk? Should they be tested?

Symptoms and Complications:

1. What symptoms should I be aware of, and how can I manage them? When these symptoms come up, what specialist would you recommend I see?
2. Can you explain to me what pancreatitis is and why it is so painful? How can I reduce my risk of pancreatitis?
3. Are there any other complications I should be concerned about?
4. How does FCS impact other aspects of my health (*e.g., liver, heart, pancreas*)? Should I have additional testing for my liver, heart, and/or pancreas before something goes wrong? Should I have baseline testing?

Diet and Lifestyle:



1. What specific dietary changes should I make to manage my triglyceride levels?
2. Are there any foods I must completely avoid? Who can I talk to about an FCS diet?
3. How does my exercise impact my triglyceride levels? What types of exercise are safe?
4. Where can I find resources?

Treatment and Medications:

1. Are there any medications available to treat FCS? What are the potential side effects of any prescribed treatments?
2. Are there any clinical trials or new therapies on the horizon for FCS?
3. How often do I need to monitor my triglyceride levels?
4. Is there anyone else that should be on my care team (*endocrinologist, lipidologist, pancreas specialist, dietician, etc.*)?
5. What is my current triglyceride level and what should I aim for my triglyceride level to be?

Daily Management and Support:



1. Are there any patient organizations I can reach out to for information and/or support?
2. How do I connect with others who are going through this same situation?
3. Is there support available for my family/spouse/child?

Mental Health:

1. Being diagnosed with a rare genetic disease is very challenging. Is there someone you would recommend I talk to about living with a rare disease that has impacted every area of my life?
2. Does stress contribute to pancreatitis flares?

Pregnancy:



1. Can I carry a baby to full-term and stay healthy if I have FCS?
2. Can hormones affect my triglyceride levels and send me into a pancreatitis attack?