

InFOCUS

Investigation of Findings and Observations Captured
in Burden of Illness Survey in **FCS Patients**

Opportunity to Participate in an Important Research Study

Has a doctor ever told you that you have very high triglyceride levels?

Do you have:

- A history of acute pancreatitis?
- A family history of very high triglycerides?
- Recurrent abdominal pain requiring hospitalization / emergency department visits?

Burden of Illness Study in Familial Chylomicronemia Syndrome (FCS)

If you are **18 years or older** and answered **YES** to any of these questions, you may be eligible to participate in a new market research study being conducted by Trinity Partners, a healthcare research and consulting company.

The purpose of this study is to help doctors and others better understand the effects of a condition called **familial chylomicronemia syndrome (FCS)**, also known as **lipoprotein lipase deficiency (LPLD)** or **type I hyperlipoproteinemia**. This research will give you the opportunity to describe your experiences living with FCS and the impact it has on many aspects of your life. The results of this study will be published in a medical journal and will be used to increase awareness and understanding of FCS among physicians, healthcare payers, and the public. This information may also be helpful to many people living with FCS as well as their families and care partners.

As a participant in this study you can help to:

1. Identify how FCS affects different aspects of your life.
2. Document your experiences related to symptoms, co-morbidities, health complications, hospital visits, etc.
3. Assess how effectively FCS can be managed by modifications in diet and lifestyle.

The study is expected to launch in June 2016 and will be conducted with participants from several countries including the US, UK, Canada and the Netherlands. Participants will complete a short online questionnaire (~45 minutes). All information provided will be CONFIDENTIAL. At the completion of the survey, participants can choose to be notified of the results of the study when they are published.

FCS is a very rare condition, and our goal with this landmark study is to have as many participants as possible from around the world. We ask that you please strongly consider participating in this effort to help understand FCS, and that you encourage others to take part. **Every voice counts!**

HOW TO PARTICIPATE IN THIS STUDY:

If you think you may be eligible for this research, please visit: www.fcsinfocus.com for instructions on how to get started. You do not have to take part in this survey and you may stop participation at any time. There are no costs and all personal information remains confidential.

If you have any questions about the study, please contact Caroline Crowson at ccrowson@trinitypartners.com. This study has been reviewed by The University of Mississippi's Institutional Review Board (IRB). If you have any questions, concerns, or reports regarding your rights as a participant of research, please contact the IRB at (662) 915-7482 or irb@olemiss.edu.