

ACTION FCS

We are a patient-led charity, working to improve the health and care experiences of everyone affected by FCS.

OUR VISION

Action FCS wants everyone with FCS to live as full and healthy a life as possible.

WHAT WE DO

We raise awareness of FCS and its impact. We provide information and support to everyone affected by it, and we advocate for excellent care and access to new medicines.

FUNDRAISING

As a volunteer-led charity we welcome fundraising initiatives to support our work. Find out about the different ways you can support us www.actionfcs.org/get-involved

Find out more

Email: info@actionfcs.org

Call: +44 7920 715366

Website: www.actionfcs.org

Facebook: [@Action FCS](https://www.facebook.com/ActionFCS)

Twitter: [@ActionFCS](https://twitter.com/ActionFCS)

Instagram: [@actionfcs](https://www.instagram.com/actionfcs)



Familial
Chylomicronaemia
Syndrome

Familial Chylomicronaemia Syndrome

WHAT IS FCS?

People with FCS don't have the enzyme that breaks down fat in their diet, or any enzyme they do have doesn't work properly. When they eat fat it travels around in the blood as triglycerides. These clump together as chylomicrons making the blood milky white, typical of the condition, and causing the many symptoms.

The condition is also known as:

- Lipoprotein Lipase Deficiency (LPLD)
- Hyperlipoproteinaemia
- Fredrickson Type 1
- Familial Hyperlipidemia
- Familial hyperchylomicronaemia
- Hypertriglyceridaemia

LIVING WITH FCS

Symptoms of FCS include:

- Abdominal pain - often severe
- Pancreatitis - which can be life threatening
- Fatigue
- Brain fog
- Xanthoma (fatty spots)
- Depression
- Very high triglycerides, often over ten times the normal level
- Milky white blood

FCS is an ultra-rare genetic condition affecting 1 to 2 people in a million.



THE FCS COMMUNITY

Join the **FCS Community** on Facebook, for patients and the caregivers of people with the condition.

Register for our online events and meetings. For more information www.actionfcs.org/get-involved/events

MORE ABOUT FCS

Diagnosis

Everybody with FCS is born with the condition, but many are not diagnosed until adulthood having experienced unexplained symptoms throughout their lives.

Pregnancy

Pregnancy can be difficult for women with FCS as triglyceride levels rise naturally in the third trimester (6-9 months). Breast feeding supplementation should be discussed with a suitably qualified dietitian.

Managing the symptoms

To reduce the impact of symptoms patients are recommended to eat less than 20g fat per day, avoid added sugar and drink no alcohol.

Living with FCS can be isolating and difficult. See the Action FCS website for tips on managing the restrictions, and recipes to support eating well within the recommendations. www.actionfcs.org



Connecting with others who understand the daily challenges has made a world of difference to my life.



Diabetes

People with FCS are at a higher risk of developing diabetes, which usually occurs in middle age.

For those who develop diabetes, a diet high in sugar and refined carbohydrates can raise the risk of pancreatitis as high blood glucose levels are turned into triglycerides.