

Resources

FCS Support Organizations

FCS Focus has created a free suite of tools designed to ease the diagnosis, management, and understanding of FCS and the FCS lifestyle. Their helpful resources provide insight into FCS & Pancreatitis, Diet & Lifestyle, and provide downloadable resources including a Patient Guide to FCS, FCS CareBook, and FCS Nutrition

LivingwithFCS.org is the site for all FCS patients, caregivers, and family members that offers information, resources, and support. Their website provides information on FCS, nutritional support, genetic testing, rare disease resources, a video library, and current clinical studies.

FCS Foundation: <https://www.livingwithfcs.org/>

FCS Focus: <https://fcsfocus.com/>

Endocrine Society: <https://www.endocrine.org/patient-engagement/endocrine-library/familial-chylomicronemia-syndrome>

National Pancreas Foundation: <https://pancreasfoundation.org/pancreas-disease/fcs/>

Foundation of the National Lipid Association (FNLA): <https://www.learnyourlipids.com/lipid-disorders/familial-chylomicronemia-syndrome/>



The Basics of FCS

You can learn more about the basics of FCS and the diagnosis from several support groups.

https://www.learnyourlipids.com/wp-content/uploads/2020/05/FCS_What_You_Need_to_Know.pdf

<https://pancreasfoundation.org/pancreas-disease/fcs/>

<https://fcsfocus.com/what-is-fcs/what-is-fcs/>

Dietary Needs

FCSfocus provides a guide for eating with FCS (<https://fcsfocus.com/nutrition/eating-with-fcs/>). They discuss strategies for focusing on foods you can eat, help you to identify sources of cravings, and guide you in discovering new options for foods you like. Additionally, they also provide helpful information about eating out and shopping for food (https://www.learnyourlipids.com/wp-content/uploads/2020/05/NLA_FCS_DietSheet.pdf, <https://fcsfocus.com/nutrition/using-food-labels/>).

FCSfocus and the FNLA both provide cookbooks, recipe, and tips to convert fat-containing foods into FCS-friendly dishes (<https://www.learnyourlipids.com/heart-healthy-resources/fcs-cookbook/>, <https://fcsfocus.com/nutrition/adding-flavor-without-adding-fat/>, <https://fcsfocus.com/holiday-recipes/>).

Tracking Resources

FCSfocus has a handy, downloadable diet and fat tracker worksheet to help you monitor your fat intake (<https://fcsfocus.com/nutrition/fat-tracker/>). Simply, write down your nutrition goals for the day in grams or calories, then distribute your daily goal across meals and snacks. During the day, record what you eat and drink, the serving size, and the grams or calories. Add up grams or calories eaten during the meal or snack. This will allow you to compare what you eat to your goals. You can adjust your food intake at the next meal as needed to stay within goal.

The tracker will let you monitor your diet over time and give you the opportunity to share with your doctor or dietitian.

You can find additional tools and tracking resources at <https://fcsfocus.com/get-tools/download-order-tools/>.

