AGSD UK
Association for Glycogen Storage Disease

INTRODUCTION

Your Hepatic GSD resources

Living with a hepatic GSD can bring a range of challenges for children and adults affected and their loved ones.

These AGSD-UK information sheets have been designed in partnership with expert professionals and hepatic GSD community members to offer practical help with different aspects of life for anyone affected by this rare and complex condition.

You can choose the sheets that are relevant to you and store them in the folder provided – just get in touch and we'll send you a folder and copies of any sheets you request. Alternatively you can print them off or read and store in an online folder.

We'll continue to add new sheets to the series - if there's a topic you want to see covered just let us know.

Whatever issues you face living with a hepatic GSD, AGSD-UK is here to help. Our offer includes specialist care and advisory services and a range of groups and activities to bring people together and help with living well.

For all queries and support contact:

info@agsd.org.uk

About hepatic GSDs

Glycogen storage disease (GSD) is a rare genetic condition that changes the way the body uses and stores glycogen, a form of sugar or glucose.

Glycogen is a main source of energy for the body and is stored in the liver. When the body needs more energy, certain proteins called enzymes break down glycogen into glucose and send it out from the liver for to the body for use.

When someone has a GSD, a gene mutation means they are missing one of the enzymes that breaks down glycogen. When an enzyme is missing, glycogen can build up in the liver or may not form correctly. This can cause problems in the liver or muscles, or other parts of the body. Hepatic GSDs are ones in which the liver is affected. A swollen liver, sometimes alongside muscle weakness, can be among the first symptoms identified.

Types of hepatic GSD

There are a number of different types of hepatic GSD: types 0 1 3 4 6 and 9. These are classified by the enzyme that is missing in each one. Each has its own symptoms and needs different treatment.

You can find further information on the different hepatic GSDs on the AGSD-UK website.

While there is currently no cure for any of the hepatic GSDs, research and the search for better treatments continue and symptoms can be managed. One of the main aims is to prevent low blood sugar, a symptom that's common to nearly all hepatic GSDs, and careful diet is an important part of life with GSD. For some, regular intake, and use of corn starch, even at night may be needed. Your metabolic team will create a plan with you and working closely with your consultant, nurse, dietician and physiotherapist will help to achieve the best possible management of the condition.

When facing recent diagnosis with a hepatic GSD it can be hard to know where to turn.

Remember AGSD-UK's advice and support services are here for you, and we can help put you in touch with others who have been through similar experiences.

Visit our website **agsd.org.uk** for more information, signposting to further support and details of how to register with us to keep updated on community events.

My son, who is now nine years old, was diagnosed with an extremely rare condition called Glycogen Storage Disease Type 1b when he was just a baby. Every day has presented its unique set of challenges. However, I am determined to navigate this path with resilience, love, and unwavering hope... With the support of my family, the exceptional medical professionals, AGSD-UK, and their wonderful advisors...I know that my children and I can face any obstacle that comes our way.

"...it's OK to have a medical condition like GSD3. Yes, there were problems along the way, but... we have managed well so far in my life."