CATS
CORI ACTION TEAM SUPPORT

GSD in the UK and Ireland

GSD Type 3 - *Glycogen Storage Disease*

AGSD UK
Association for Glycogen Storage Disease (UK) Ltd

CATS - CORI ACTION TEAM SUPPORT

CATS is a group of patients and carers who have got together to support those affected by **Cori Disease**. The disease is one of the hepatic **GSD** types and is named after Carl and Gerti Cori who were awarded the Nobel Prize for their work in glycogen synthesis. As well as supporting patients and families, we aim to be active in recognising and promoting the needs of Cori patients with medical staff, through the work of **AGSD-UK**. Members of CATS are spread throughout the UK and have varied experience and interests.

So if you're newly diagnosed, a more established patient, a family member, or an interested party please get in touch and we will do our best to help you. We'll be at the annual AGSD-UK conference but we hope to set up support meetings throughout the year.

Do you have another **Hepatic Glycogen Storage Disease**? We know how difficult it can be for people with a rare disease, so if you have one of the other hepatic types and you'd like to get in touch, please do and we will welcome you to AGSD-UK and try to help.

Whilst we may have different needs we all stick together in our small GSD community.

Ailsa Arthur - Oxfordshire

I have been involved with the AGSD for over twenty years since the diagnosis of my son with Cori's (type 3a) and last year volunteered as a trustee.

Recently, I felt patient and family involvement have become crucial to help further better treatments and support. I am very keen to take an active involvement in getting recognition and awareness of this little known condition out to the public.

We live between Reading and Oxford with our children and far too many cats and dogs.

Nikki Christie - North Warwickshire

I was diagnosed as a baby, roughly six months old.

My consultant at the time thought I had liver cancer as my stomach was so large. After a liver biopsy they discovered I had GSD Type 3a.

Obviously I don't remember, but I had several low blood sugar episodes throughout my childhood. I was told to stick to a high carbohydrate diet, and eat little and often, I was quite often ill, always catching coughs and colds. I played like all the other 'normal' children but was never very fast, and was always the first to run out of energy, still... **Life was good.**

I managed to live a relatively normal teenage life, I was able to do all the things I wanted to do. I travelled; I worked full time and spent time with friends and family... **Life was fun!**

Throughout my late twenties-early thirties, with much careful monitoring and a strict diet of carbs and cornstarch, I had my three beautiful children... **Life was wonderful!**

As I approached my late forties I started to experience more muscle problems, exercising was really hard, walking then became a struggle; even day to day tasks were exhausting... **Life was difficult and challenging.**

So now I am learning to live in my new body; while it doesn't work as well as my old one, my plan is to look forward, concentrating on what I am going to achieve with its new limitations... **Life is different!**

Sylvia Wilson - Suffolk

I have a granddaughter diagnosed with Cori. She lives abroad and it took almost a year to get her diagnosis.

She was the first case her hospital had dealt with. It was a very frightening time for the family and I took to the internet to research the disease.

Having ploughed my way through various German Shepherd Dog sites I eventually came across AGSD-UK. I phoned them up with great trepidation fearing that they would not deal with me as: (a) I was not a parent and (b) my granddaughter didn't live in the UK. I needn't have worried as I was warmly welcomed into the GSD family.

I attended my first conference not sure what to expect but it was such a positive and informative occasion. I would urge everyone to attend if they can.

GSD has been a steep learning curve. I'm interested in genetics and the view that carriers can also display aspects of the disease.

My granddaughter stays with me for several weeks each year, and I've found providing the sugar free diet she needs quite challenging. It helps that I've always been interested in cooking and nutrition so I feel we're all on a healthier diet now because of GSD.

Gary, Andrea and Lauren Thompson - Derbyshire

We are Gary, Andrea and Lauren Thompson. Lauren is 18 years old and our only child. Lauren was diagnosed with GSD type 3 at the age of 11 months after a lengthy stay in hospital.

Lauren has been on varied amounts of cornstarch and overnight feeds most of her life. Over the last two years Lauren has been taking daily doses throughout the day of Glycosade and protein powder. Lauren also came off her overnight feeds and had her gastrostomy mini button finally removed and stoma closed recently.

This year (2018) Lauren is making the transition from the Children's to Adults Hospital. We have had many, many concerns to deal with over the previous years, including working with CAMHS (Child, Adults Mental Health Services) and we have worked together to support and encourage Lauren in how to deal with her issues.

We are looking forward to working with the new CATS team to help others by sharing our own knowledge with who have been diagnosed with GSD type 3.

Checks

The members of CATS are DBS checked. We take your personal information and safety seriously. We do not pass on your details to anyone without your express permission.

AGSD UK Office Contact

Staff are available to help. Tel: 0300 123 2790 Mon - Fri (answerphone outside office hours). Don't forget our annual conference. We can put individuals in touch with others who have the same condition. **Email: cats@agsd.org.uk**

www.agsd.org.uk

Further Resources

Facebook Groups – GSD in the UK and Ireland
Glycogen Storage Disease Type 3 FaceBook page
Children's Liver Disease Foundation
childliverdisease.org Phone 0121 212 3839
Local Citizen's Advice Bureau
www.citizensadvice.org.uk Phone 03444 111 444
Genetic Alliance and Rare Diseases UK
www.geneticalliance.org.uk Phone 0207 831 0883
www.gov.uk
Muscular Dystrophy UK
www.musculardystrophyuk.org and helpline on 0800 652 6352
Regional Neuromuscular Centres
Locate your NHS NM centres, for a referral /advice

Counselling - Need help? Especially at diagnosis or during a life crisis. Locate your NHS counselling service from your GP. There can be a waiting list, so don't delay. There are some local free, independant counselling services. Siblings without a GSD - We know they are affected by illness within the family. Someone in CATS can speak to you about this, for more in depth help, access local family support services

Genetic Counselling - If you were not offered this at diagnosis seek a referral from your consultant to ask about family members being checked and family planning.

Carers - Carers and families often need support too. A free assessment is available at local social services. There are many different local carers services and centres. carersuk.org Phone Mon & Tues 0808 808 7777

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