PRESS RELEASE
New Charity- Glut1 Deficiency UK
Launches 28 February 2021 - Rare Disease Day

We are delighted to announce the launch of a new charity, Glut1 Deficiency UK, to further support carers and patients impacted by Glut1 Deficiency Syndrome in UK and Ireland.

This is the culmination of 3 years hard work by a small group of parents, in response to the need for a charity in the UK and Ireland solely dedicated to;

- Increasing awareness of Glut1 Deficiency Syndrome (Glut1DS)
- Improved education for families and health professionals in relation to Glut1DS
- Advocacy for families and patients impacted by Glut1DS
- Support and funding for Glut1DS research

The number of people diagnosed with Glut1 Deficiency Syndrome worldwide is currently thought to number in the hundreds, with just less than a hundred diagnosed in the UK and Ireland. According to the recent International Consensus Paper on Glut1 Deficiency Syndrome, recent studies estimate the true prevalence to be at least 1:24,000, so the vast majority remain undiagnosed.

The trustees, each of whom has a child with a Glut1DS diagnosis, are delighted to have the support of eminent medical experts. These medical professionals have experience treating patients with Glut1DS and have kindly volunteered to form the Medical Advisory Board, ensuring that all the information provided by the charity is medically sound.

“We hope that Glut1 Deficiency UK will provide an inclusive space for our Glut1DS community, providing connection and support to the wide spectrum of those with Glut1DS and their families, with compassion and empathy. With increased awareness and funding for much needed research, we hope for better treatments to improve the lives of all those living with Glut1DS.”

Continued…

If you would like to find out more, we’d love to hear from you. hello@glut1deficiency.org.uk
GLUT 1 DEFICIENCY UK is a registered charity. Charity Reg. Number: 1192599
TRUSTEES of Glut1 Deficiency UK

Trudy Morgan- Chair
Trudy is based in Wales and is Mum to Daniel and Cleo. Cleo was born in 1995 diagnosed with Glut1DS in 2002. Trudy is the current volunteer Glut1 Deficiency Foundation, European Outreach Director.

Sheena Cunniffe - Treasurer
Sheena is based in Scotland and mum to twins Maisie and Ruby. Ruby was diagnosed in 2011 with Glut1DS at age 2.5 years. Ruby is on the Ketogenic Diet and was fitted with a feeding tube in 2019. Ruby is determined and has an infectious smile!

Stefanie Watson – Secretary
Stefanie is based in Scotland and is mum to Adam and Evan. Adam was diagnosed with Glut1DS in 2010 and has been on the classical version of the Ketogenic Diet since that time. Adam is strong and determined and competed and won a medal for cycling in the Special Olympics.

Helen Wilde - Trustee.
Helen is based in England and is Mum to William who was born in 2007. William was diagnosed with Glut1DS in 2010 aged 3.5. Since starting the Ketogenic Diet, William has made great progress in all areas of development and overcome many challenges. Helen is Glut1DS ambassador for Matthew's Friends Ketogenic Dietary Therapies charity.

Meadhbh Connolly - Ireland Representative
Meadhbh is based in Ireland and is mum to Paul who was diagnosed in 2012 with Glut1DS when he was 5. He continues to adhere strictly to the Ketogenic Diet which has eliminated seizures and improved his quality of life.

MEDICAL BOARD of Glut1 Deficiency UK

Professor Sameer Zuberi
Consultant Paediatric Neurologist at the Royal Hospital for Children, Glasgow, UK

Professor Helen Cross
Professor of Neurology Great Ormond Street Hospital for Children London, UK

Professor Dr. Jörg Klepper
Aschaffenburg Children’s Hospital in Aschaffenburg, Germany

Dr Andreas Brunklaus
Consultant Paediatric Neurologist, Royal Hospital for Children, Glasgow, UK

Dr Kathleen Gorman
Paediatric Neurologist Temple Street Children’s University Hospital, Dublin Ireland

Victoria Whiteley
Advanced Clinical Practitioner, Royal Manchester Childrens Hospital, UK

Janette Buttle
Lead Dietician Royal Hospital for Children, Glasgow, UK

CONTACT US AT
hello@glut1deficiency.org.uk

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