



CDG UK and other support networks



CDG UK

CDG UK is a charity set up by the parents of affected families in order to provide support networks in the UK. Our first objective is to raise awareness of this extremely rare group of diseases and to reach out to other families who are affected by it. As more health professionals have become aware of CDG, more children and adults are being diagnosed in the UK. We know that a rare diagnosis can be isolating, and we wish to extend a hand of friendship to others facing the same.

We provide information and resources via our website and by newsletters, and we arrange an annual family day, where CDG families can meet up informally to discuss issues that only CDG families can! We work closely with our patron, Dr Grunewald of Great Ormond Street Hospital, and Donna Krasnewich of the National Institute of Health,  to contact check and distribute our information, and to keep updated on the latest developments in the world of CDG. Our website is: www.cdg-uk.org. CDG UK also has a Facebook group for UK families and our Twitter handle is @UK_CDG. Please get in contact if you would like to sign up to the newsletter or join the Facebook group cdgukcontact@gmail.com.

The Future

Our second objective is to raise funds for research into this group of currently untreatable diseases. According to Professor Jaak Jaeken, the first professional to identify CDG, 'the rewards are many, but the workers are few'. In other words, there is a vast amount still to learn about CDG and so much more that can be done in terms of diagnosis and possible therapies, but there are very few researchers and doctors working in this area at the moment. With funding, we wish to change this, by collaborating with researchers and health professionals with one end goal: a cure for CDG.

We are delighted to let you know that you can now directly support CDG UK when you wear your jeans for Jeans for Genes Day annually in September. While signing up your workplace or school on the Jeans for Genes Day website, click on the box shown after this paragraph and select CDG UK. Then, 50% of what is raised by your organisation directly benefits CDG UK, the national charity supporting patients and families with Congenital Disorders of Glycosylation.

Click here if you are affiliated to one of our partners

Please choose one from the list* CDG UK

Support Networks

Also on Facebook, is the CDG Global Alliance. This is a private group where families from all over the world communicate and share their stories. This is a very active and supportive forum, and members are very responsive to any questions you post. There are also CDG professionals who are members of the group giving expert advice. CDG Care, a USA based organisation run this group: www.cdgcare.com.

Other countries also have CDG organisations, and a list of these can be found at www.rareconnect.org/en/community/cdg/members. The Portuguese organisation is especially active in Europe and organises the CDG World Conference every two years in a different European city (www.apcdg.com).

Back in the UK, there are several umbrella organisations for genetic disorders:

- Metabolic Support UK (previously CLIMB) a charity supporting those affected by inherited metabolic disorders: www.metabolicsupportuk.org
- Genetic Disorders UK, a good source of information and support: www.geneticdisordersuk.org
- Genetic Alliance UK, which encompasses Rare Disease UK and SWAN UK (for undiagnosed patients): www.geneticalliance.org.uk
- The European Reference Network for Hereditary Metabolic Disorders is also a good source of information: www.metab.ern-net.eu





Dr Stephanie Grunewald

Dr Stephanie Grunewald is a doctor in the Metabolic Medicine Department at Great Ormond Street Hospital (GOSH) in London and is an expert in CDG. She is also the patron of CDG UK. If you would like to be referred to her at GOSH, you can ask your doctor to do this. She attends the CDG World Conferences, and has close links to CDG UK. You can read her bio on the CDG UK website: www.cdg-uk.org/dr-g.

Birmingham Children's Hospital is home to the UK's first rare disease centre where children and young people with rare diseases can access highly coordinated multidisciplinary and multi-specialty rare disease clinics together with peer support and consistent access to research, information and treatment: bwc.nhs.uk/rare-diseases.



Photo Credit, Barbara Asboth: <http://www.1in17.uk/2018/06/finn-congenital-disorders-of.html>



For more information, please visit:

www.cdg-uk.org

Or contact us at:

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