HOW WE HELP PEOPLE WITH DRAVET SYNDROME AND THEIR FAMILIES

Dravet Syndrome UK operates on a national level and is made up of a small team of trustees, staff and a world-renowned Medical Advisory Board (Chaired by Professor Helen Cross OBE, President of the ILAE). The team works very closely together to ensure we meet the needs of families affected by Dravet Syndrome, educate professionals to improve the management and outcomes, and to fund medical research focused around the needs of families.

Dravet Syndrome UK has three primary aims:

1 Funding medical research

There is an urgent need for more research into the causes and complexities of Dravet Syndrome. Dravet Syndrome UK operates a specific research fund, into which people can donate or direct their fundraising as well as a percentage going directly into the research fund.

2 Raising awareness and understanding within the professional community

This encompasses a wide range of activity, including bringing together leading experts in the field at our biannual Professional Conference and networking, attending and presenting at relevant meetings worldwide, as well as providing literature for healthcare professionals, such as our 'Could it Be Dravet?' guide, which aims to aid earlier and more accurate diagnosis of Dravet Syndrome.

3 Supporting families emotionally, practically and financially

Dravet Syndrome can be a very isolating condition, which is why family support is an integral part of the charity. The charity supports families in a number of ways, such as 'The Night-time Monitoring Scheme', 'DSUK Assistance Fund 16+', hosting our family weekend away at Centre Parcs, organising our biannual Parent/Carer conference, running and moderating a private online forum and providing support to families.

We also endeavour to provide families with helpful resources that will enable them to access the best possible care for their child and have the most up to date information on the condition. Our resources, along with further information on Dravet Syndrome can be found at www.dravet.org.uk.

MEDICAL ADVISORY BOARD

HOW YOU CAN HELP

Dravet Syndrome UK relies on the generous support of our community, corporate partners and donations from grant making trusts to ensure we continue to support families, educate professionals and fund medical research.

Each year we need to raise **£320,000** to keep providing our vital services - we couldn't do it without your help.

Whether you choose to fundraise by holding a coffee morning, climbing a mountain or jumping out of a plane, we'll support you every step of the way. As well as sending you a fundraising pack, we can provide DSUK branded t-shirts, banners, sponsor forms and guidance to ensure your fundraising for DSUK is a huge success.

If you'd like to make a one-off donation, or set up a regular gift to DSUK, please visit https://www.justgiving.com/dravetsyndromeuk

Thanks to all of our amazing donors for your continued support.

Visit **www.dravet.org.uk** for more fundraising ideas, to make a donation and to read about the incredible impact of your support.

DRAVET Syndrome UK

Hope for families with life-limiting epilepsy

FACTS ABOUT DRAVET SYNDROME

What is Dravet Syndrome?

Dravet Syndrome is a rare neurological condition that encompasses treatment-resistant epilepsy, intellectual disability and a spectrum of associated conditions (known as comorbidities), which may include autism, ADHD, challenging behaviour and difficulties with speech, mobility, eating and sleep.

Is Dravet Syndrome under-recognised?

Dravet Syndrome occurs in around 1 in 15,000 live births in the UK. It is one of the most common genetic epilepsies but is often undiagnosed (especially in adults) or misdiagnosed as another type of epilepsy.

What causes Dravet Syndrome?

Dravet Syndrome is a genetic condition caused by a mutation to the SCN1A gene in over 85% of patients. In around 90% of cases the gene mutation arises spontaneously and is not inherited from parents.

What is the course of the condition?

While the first signs of Dravet Syndrome occur during infancy, it is a life-long condition. In addition to treatment-resistant epilepsy, all children and adults with Dravet Syndrome have complex needs and are likely to require 24/7 care for life.

How is Dravet Syndrome diagnosed?

Dravet Syndrome is a clinical diagnosis that can be confirmed by a genetic test, freely available on the NHS. Early diagnosis and effective treatment can make a huge difference – saving unnecessary investigations, reducing seizures and potentially improving long-term outcomes.

What treatments are available?

In the future, genetic therapies may be available to treat the underlying causes of Dravet Syndrome. Anti-epileptic drugs are used, but these are not always effective in people with Dravet Syndrome. Comprehensive testing and support is required for the multiple challenges that people with Dravet Syndrome and their families face.

DRAVET Syndrome UK

Hope for families with life-limiting epilepsy

Dravet Syndrome UK is an independent UK charity dedicated to improving the lives of those affected by Dravet Syndrome through support, education and medical research.

By joining our Dravet community you will gain access to the comprehensive range of emotional, practical and financial support services that we provide to families affected by Dravet Syndrome.

To join, visit www.dravet.org.uk/join-us/

For further information and guidance please contact us on the details below or follow us on social media.

@DravetSyndromeUK | @DravetUK

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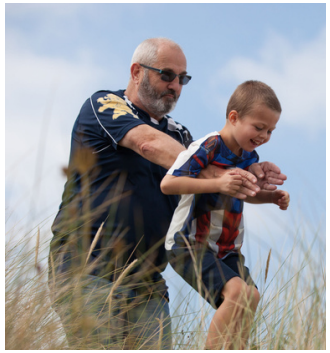

www.dravet.org.uk