

FACTS ABOUT DRAVET SYNDROME

What is Dravet syndrome?

Previously known as severe myoclonic epilepsy in infancy (SMEI), Dravet syndrome is a neurological disorder with onset during the first year in an otherwise healthy infant. It was first described by French physician Dr. Charlotte Dravet in 1978.

Is Dravet syndrome under-recognised?

In the UK, Dravet syndrome has previously been estimated at 1 in 40,000 or about 7% of all severe epilepsies, however recent data suggests the true incidence is closer to 1 in 19,000 live births.

What causes Dravet syndrome?

A major contributor to the cause of Dravet syndrome has been found to be mutations of the SCN1A gene, found in around 80% of patients. The gene mutation occurs randomly and is almost always not inherited. Much remains to be understood about the causes of Dravet syndrome and research is ongoing.

What is the course of the condition?

Dravet syndrome typically occurs during the first year of life, presenting with prolonged, recurrent seizures that are often triggered by fever, illness, or sudden temperature change. Over time, other seizure types appear and developmental delays occur in most children. Dravet syndrome develops as the child grows older and is associated with a wide spectrum of related problems, such as learning disability, ataxia and behaviour difficulties.

How is Dravet syndrome diagnosed?

A genetic diagnosis test is now available in the UK from the NHS. Early diagnosis and effective treatment can make a huge difference – it saves unnecessary investigations, reduces seizures and may improve long-term outcomes.

What treatments are available?

Unfortunately there is no cure for Dravet syndrome. Treatments focus on controlling or minimising seizures. 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.

Reference

1. Dravet C *et al.* 'Severe myoclonic epilepsy in infancy (Dravet syndrome)' in Roger J *et al.* (eds) *Epileptic syndromes in infancy, childhood and adolescence* 2005, p81-82



Hope for families with life-limiting epilepsy



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 appropriate support, education and medical research.

If you would like to join our database, please visit the 'Join us' part of website, fill in and submit the online form and we will keep you up to date with upcoming research news, information and family events through mailings and emails.

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Registered charity number: 1128289

www.dravet.org.uk

HOW WE HELP PEOPLE WITH DRAVET SYNDROME AND THEIR FAMILIES

Dravet Syndrome UK operates on a national level and is made up of a team of trustees, world-renowned professional advisors and volunteers. This small team works very closely together to ensure we meet the needs of families affected by Dravet syndrome, whilst working with professionals in the field of neurology on research projects.

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 attending and presenting at relevant professional conferences and meetings. We also provide literature for healthcare professionals, such as the 'Professional Guide to Diagnosis', 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+', organising and facilitating family meet ups, organising regular conferences, 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. These resources are available to view at www.dravet.org.uk.

Visit
www.dravet.org.uk
for more
fundraising ideas
or to find out how
to donate



Hope for families with life-limiting epilepsy

HOW YOU CAN HELP

Dravet Syndrome UK relies on fundraising and donations to continue funding medical research and supporting families.

A very large percentage of Dravet Syndrome UK's income comes from sponsored events. These events can be as small as holding a coffee and cake morning for you and your friends or as large as climbing a mountain or jumping out of a plane. However you choose to fundraise it should be fun and Dravet Syndrome UK will support you as much as we can and provide items such as T-shirts, wristbands and sponsor forms.

Direct donations make a huge difference to the running of Dravet Syndrome UK. Thanks to the generosity of donors the charity is able to fulfil its three aims of funding research, supporting families and raising awareness within the medical profession.

You can donate easily using JustGiving:

JustGiving™

www.justgiving.com/dravetsyndromeuk/Donate

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