

Dear GP,

We are a UK charity dedicated to supporting families affected by Dravet Syndrome.

You have likely been handed this pack as one of your patients has received a diagnosis of Dravet Syndrome. We understand that you may not be familiar with this rare neurological condition.

What is Dravet Syndrome?

Dravet Syndrome is a rare, lifelong and life-limiting neurological condition that causes severe, difficult-to-control seizures. Seizures are often accompanied by intellectual disability and a range of comorbidities such as autism and ADHD, as well as difficulties with speech, mobility, eating and sleep. Heat and sudden temperature changes can bring on a seizure.

We hope this pack will help further your knowledge about Dravet Syndrome and make you aware what challenges your patient and their family may endure now and in the future.

You are welcome to join our professional database to be kept up to date on the latest research and treatments by visiting our website: www.dravet.org.uk.

Dravet Syndrome UK hold a biennial professional conference dates for our next event can be found on our website.

The conference includes a packed agenda of leading voices in Dravet Syndrome to enable discussion of the latest updates, news and medical research. In attending this conference, healthcare professionals can expect to achieve the following:

- Increased understanding of Dravet Syndrome
- Better understanding of how and when to diagnose Dravet Syndrome
- Improved awareness and understanding of current treatments for Dravet Syndrome
- Improved understanding of the associated co-morbidities of Dravet Syndrome and its natural history
- Better understanding of SUDEP and other associated mortality in Dravet Syndrome
- Improved awareness and understanding of emerging treatments for Dravet Syndrome
- Increased understanding of findings in research relating to Dravet Syndrome

We have also enclosed 10 of our 'How we can support your family' leaflets to include in your reception / waiting area for families to take as needed.

Please do not hesitate to contact us if you would like any further leaflets or information.

Yours sincerely,

Dravet Syndrome UK

Hard copies to accompany this letter include

- Family Guide
- Transition Guide
- Could it be Dravet Leaflet
- Professional sign-up flyer to join our mailing list to be kept up to date with all latest news.
- Conference Flyer/Invite
- 10 x How we can support your family for waiting room
- Understanding the mental health toll of caring for someone with Dravet. A guide for professionals.

The letter and full hard copy pack can be ordered in our shop for this to be posted out to you to pass on to your GP practice.