

Our Mission

Our mission is to support families and improve outcomes for individuals affected by Dravet Syndrome and other complex genetic epilepsies in Ireland.



Please visit our website

 www.dravetsyndromeireland.org

 info@dravetsyndromeireland.org

Find us on social media



DRAVET SYNDROME

Ireland

Supporting families affected
by rare genetic epilepsies in Ireland



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Dravet Syndrome Ireland
Registered in Ireland, Company No. 669279
Registered Charity No. 20206183



What is Dravet Syndrome?

Dravet Syndrome is a rare and severe form of drug-resistant epilepsy that begins in infancy and affects people for life. It has an estimated incidence of 1:15,700. Dravet Syndrome is more than just seizures and is classified as a developmental and epileptic encephalopathy.

Symptoms of Dravet Syndrome can include:

- Seizures beginning in the first year of life
- Drug-resistant epilepsy with prolonged and/or frequent seizures
- Developmental delays
- Movement and balance issues
- Behaviour issues
- Problems with sleeping

Over 80% of people with Dravet Syndrome have a mutation in the SCN1A gene. The mutation affects the functioning of neurons in the brain, causing seizures and other issues. Early diagnosis is crucial to learning to live with Dravet Syndrome and to managing the condition. People with Dravet Syndrome may experience significant disability, but can live long, happy and fulfilled lives.

What is Dravet Syndrome Ireland?

Dravet Syndrome Ireland is a registered charity that aims to raise awareness and help those living with rare genetic epilepsies in Ireland.

We aim to support families and carers of people living with Dravet Syndrome and other genetic epilepsies and improve the quality of life of those affected. Dravet Syndrome Ireland is a parent-led, volunteer-run organisation and we welcome new members and support.

Receiving a diagnosis of Dravet Syndrome or other severe genetic epilepsy for your child or family member can be a very difficult and overwhelming time. Families can feel alone when facing what is a life-long condition. At Dravet Syndrome Ireland we have also lived this experience and have come together to try to improve the lives of all families coming to terms with the diagnosis.



Membership:

At Dravet Syndrome Ireland we offer family and carer membership. Membership benefits include access to epilepsy monitors for trial, early access to our family events and virtual talks, and updates on latest news and information.

At Dravet Syndrome Ireland we:

- Organise family events to share information from leading clinicians and researchers
- Organise fun days for all the family
- Host virtual talks with guest speakers
- Raise awareness of genetic epilepsies
- Liaise with pharmaceutical companies to advocate for access to EU approved treatments
- Keep our community up to date on the development of new treatments including gene therapies
- Facilitate family network
- Inform families on Social Welfare and other epilepsy-related entitlements
- Support families in need
- Link with other similar organisations across the world
- Grow Dravet Syndrome Ireland to be a voice for families in our community

