

Join Our Community

By uniting families, clinicians and researchers into one multidisciplinary community, we can improve the timeline for finding better treatments and, hopefully, a cure for Dravet syndrome and related epilepsies.



How you can participate:

- Make a donation
- Host a fundraiser
- Volunteer
- Join the DSF Parent Network
- Join our email list
- Enroll your child in a patient registry
- Participate in research
- Attend our biennial conference

Contact Us

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Our Programs

Research Grant & Postdoctoral Fellowship Program

DSF's Research Grant Program offers two year grants for research directly related to Dravet syndrome and associated epilepsies. DSF's Postdoctoral Fellowship Program provides one year of support for individuals engaged in postdoctoral study relating to Dravet syndrome. All research grants are reviewed by DSF's Scientific Advisory Board.

Could it be Dravet? Campaign

Our *Could it be Dravet?* Campaign targets physicians and other medical professionals and is aimed at raising awareness of Dravet syndrome and related epilepsies to assure early and appropriate diagnosis and treatment.

DSF Family Network - dsffamilynetwork.org

The DSF Family Network is a program for parents in the U.S. that includes regional online support groups and Parent Ambassadors. These regional groups offer the opportunity for parents to share local updates regarding doctors and therapy options; to receive information on local events and fundraisers; and to be able to share knowledge about the resources available in your state and region. DSF will host an annual *Day for Dravet* workshop in each region with educational seminars and meetups for families.

DSF Family & Professional Conference

Our biennial conference brings together families and professionals to hear about the most current information available in the field of Dravet syndrome, including diagnosis and approaches to care, as well as updates on the latest in research. It also offers the opportunity to socialize and connect with others who are on the same medical journey. It takes place on even-numbered years in different locations across the United States.

International Ion Channel Epilepsy Patient Registry - iicepr.org

This registry collects basic information and genetic test results for individuals with Dravet syndrome and related epilepsies worldwide. This registry will help expedite clinical trials, improve communication of ideas among interested researchers, and assure rapid distribution of any new information that may benefit patients and their families.

DSF Annual Research Roundtable

This annual meeting brings together researchers, geneticists, neurologists and other clinicians with an interest in Dravet syndrome to share and discuss the latest research, to form collaborations with one another, and to help make advances along our "roadmap to a cure." The meeting takes place each year on the evening before the annual American Epilepsy Society Meeting.

Patient Assistance Grant Program

This program offers funding to patients with Dravet syndrome and related epilepsies for necessary medical and educational items that are not covered through private insurance or other assistance programs.



Raising Hope and Changing Lives through Research



What is Dravet Syndrome?

Dravet syndrome (DS) is a rare, catastrophic form of epilepsy that affects 1:15,700 - 1:20,900¹. Approximately 80% of children diagnosed with DS have a mutation in their *SCN1A* gene that results in improper sodium ion channel function in their neurons.



Dravet syndrome is a clinical diagnosis that can be made with or without a confirmed mutation in the *SCN1A* gene. It is characterized by:

- Frequent, often prolonged seizures that usually begin in the first year of life and are resistant to treatment
- Mild to severe developmental and behavioral delays typically appearing between ages 1 and 4
- Speech impairment
- Ataxia (unsteadiness) and low endurance
- Common seizure triggers including heat, temperature change, physical exertion, photosensitivity, pattern sensitivity, and illness
- Learning plateaus and/or regression
- Difficulty sleeping
- Autonomic dysfunction (difficulty regulating body systems including temperature, sweating, circulation, etc.)
- Increased risk of Sudden Unexpected Death in Epilepsy (SUDEP) and mortality due to complications from seizures
- Dependence in adulthood

DS is thought to be at the severe end of the spectrum of *SCN1A* related epilepsies including Generalized Epilepsy with Febrile Seizures (GEFS) and Generalized Epilepsy with Febrile Seizures Plus (GEFS+).



Prognosis for children with Dravet syndrome is variable. Children will not outgrow this disorder, but there is hope that earlier diagnosis and proper treatment will improve outcomes.

Beneficial Treatments

- Sodium valproate (Depakote, divalproex sodium)
- Clobazam (Onfi)
- Stiripentol (Diacomit)
- Topiramate (Topamax)
- Levetiracetam (Keppra)
- Ketogenic diet

Treatments to Avoid

- Oxcarbazepine (Trileptal)
- Carbamazepine (Tegretol)
- Fosphenytoin[†] (Dilantin)
- Lamotrigine (Lamictal)
- Other sodium channel blockers

[†] Phenytoin and fosphenytoin may be used in emergency settings but daily use is usually contraindicated.

dravetfoundation.org

Families Need Support

Because individuals with DS often require frequent therapies and multiple visits to specialists to address the co-morbidities associated with DS, parents and caregivers can become overwhelmed by the amount of care and assistance required to properly care for their loved one. Respite care is difficult to find because the patients have significant health concerns. Support from family and friends can include a listening ear, help with meals, respite care, and simple visits that show you care. Support from doctors, schools, and therapists includes understanding that DS extends far beyond seizures and impacts multiple areas of the patient's and family members' lives.

Who we Are

Dravet Syndrome Foundation is a 501(c)(3) non-profit organization dedicated to aggressively raising research funds for Dravet syndrome and related epilepsies, while providing support to affected individuals and families.

We Understand:

- The value of funding innovative research
- The urgent need to find better treatments
- The motivation of our donors to make an impact in the fields of Dravet syndrome and related epilepsies
- The importance of transparency to our donors
- The benefit of global collaboration



1. Incidence, diagnostic criteria, and treatment suggestions taken from the North American Consensus Project: Wirrell EC, et al. Optimizing the Diagnosis and Management of Dravet Syndrome: Recommendations From a North American Consensus Panel. *Pediatr Neurol.* 2017 Mar;68:18-34.e3. doi: 10.1016/j.pediatrneurol.2017.01.025. Epub 2017 Feb 4. PubMed PMID: 28284397.