

Join Our Community

By uniting our community stakeholders - including patient families, clinicians, researchers, and pharmaceutical and biotech companies - into one multidisciplinary community, we can improve the timeline for finding better treatment options and, hopefully, a cure for Dravet syndrome and related epilepsies.

How You Can Participate

- Make a donation
- Host a fundraiser
- Attend a fundraiser
- Join the DSF Parent Network
- Volunteer
- Join our email list
- Share the patient voice and experience
- Participate in research
- Attend our biennial conference
- Share your story on our website
- Follow us on social media



Our Programs

DSF Family & Professional Conference

Our biennial conference brings together families and professionals to learn the latest in diagnosis, best care practices, and current research. It also offers the unique opportunity for patient families to connect in person.

DSF Family Network

The DSF Family Network is a program for parents that includes online support groups and Parent Ambassadors. DSF also hosts Dravet workshops with educational seminars and meetups for families.

Newly Diagnosed Kits

The kit includes a checklist and guide for newly diagnosed families, as well as a medication bag and other materials.

Patient Assistance Grant Program

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

Birthday Buddies

Register your loved one with DS and for their birthday they will receive a birthday card and a small gift from DSF's mascot.

Super Siblings Club

Our Parent & Caregiver Resources and a VIP Sibling Kits offer tools to help sibs understand and cope with having a special needs sibling.

Brainfirst Parenting

Our 9-hour on-demand workshop for behaviors is led by Eileen Devine, LCSW, a neurobehavioral support coach for parents.

Caregiver Connect Grants

Caregiver Connect Grants are small grants that allow caregivers/families to host a regional gathering to bring together patients and their families.

Research Grant & Postdoctoral Fellowship Program

DSF's Research Grant Program offers funding for research directly related to Dravet syndrome and associated disorders, through four types of grant funding mechanisms.

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".



Programs and Family Resources

SUPPORTING FAMILIES
FUNDING RESEARCH
ADVANCING TOWARDS A CURE



www.dravetfoundation.org

What is Dravet Syndrome?

Dravet syndrome (DS) is a rare form of medication-resistant epilepsy that begins in infancy and proceeds with accumulating severity of symptoms that significantly impacts patients throughout their lifetime. DS affects 1:15,700 individuals, and over 80% of patients have a mutation in the SCN1A gene that impairs sodium channel function. DS 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 1-3
- Speech impairment
- Ataxia (unsteadiness) and low endurance
- 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 mortality due to complications from seizures and Sudden Unexpected Death in Epilepsy (SUDEP)
- Dependence in adulthood



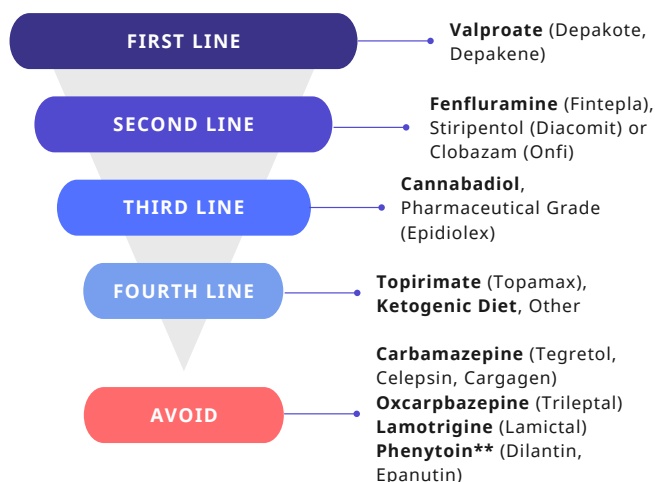
Prognosis & Treatments

DS is 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.

The following are recommended treatments based on the International Consensus on Diagnosis and Management of Dravet syndrome:

Maintenance Antiepileptic Medications



**Phenytoin and Fosphenytoin, while not recommended for daily use, are often used in emergency treatment of prolonged seizures with varying success in patients with Dravet syndrome. Caution is advised.

1. Incidence: Wu YW, et al. Incidence of Dravet Syndrome in a US Population. *Pediatrics* 2015. doi: 10.1542/peds.2015-1807
2. Diagnostic criteria and treatment suggestions: Wirrell EC, et al. The International Consensus on Diagnosis and Management of Dravet Syndrome. *Epilepsia* 2022 doi: 10.1111/epi.17274

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, sibling 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 are We?

Dravet Syndrome Foundation is a 501(c)(3) non-profit organization dedicated to supporting families, funding research, and advancing towards a cure for Dravet syndrome and related epilepsies.

We are proud to be the largest non-governmental funder of Dravet syndrome-specific research, worldwide.

We Understand

- The value of funding innovative research
- The need to keep the patient and family voice at center of everything that we do
- The urgency in finding better treatments
- The benefit of global collaboration
- The importance of transparency to our donors
- The motivation of our donors to make an impact in the fields of Dravet syndrome and related epilepsies