

*DSF Annual Research Roundtable*

Our annual meeting allows researchers, geneticists, neurologists and other professionals with an interest in Dravet syndrome and related epilepsies to establish a "research roadmap." By helping this consortium of specialists to establish a collective plan, DSF will be better positioned to fund research projects offering the most promising breakthroughs at the fastest pace possible. The meeting takes place each year on the evening before the commencement of the American Epilepsy Society (AES) Conference.

*International Patient Assistance Grant Program*

This program offers grants to patients with Dravet syndrome and associated epilepsies for necessary medical expenses associated with these conditions that are not covered through private insurance or other assistance programs.



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*Raising hope & changing lives through research*



## WHAT IS DRAVET SYNDROME

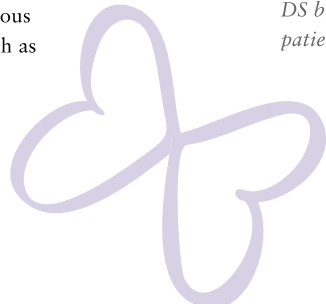
Dravet syndrome is a rare and catastrophic form of epilepsy that begins in infancy and is characterized by multiple and frequent seizure types. All seizure types are remarkably resistant to currently-available medical therapies. There is no cure for Dravet syndrome, and the prognosis for the child is poor. Dravet syndrome is on the severe end of a spectrum of ion channel epilepsies believed to be caused by SCN1A gene mutations which include: Generalized Epilepsy with Febrile Seizures (GEFS); Generalized Epilepsy with Febrile Seizures Plus (GEFS+); Intractable Childhood Epilepsy with Generalized Tonic-Clonic Seizures (ICEGTC); and Severe Myoclonic Epilepsy Borderline (SMEB).



Individuals with Dravet syndrome face a higher incidence of SUDEP (sudden unexplained death in epilepsy) than the general epilepsy population and have other associated conditions that also need to be properly managed.

These conditions may include:

- behavior and developmental delays
- movement and balance issues
- growth and nutrition issues
- sleeping difficulties
- chronic upper respiratory infections
- sensory integration disorder
- disruptions of the autonomic nervous system (which regulates things such as body temperature and sweating)



## WHO WE ARE

Dravet Syndrome Foundation is a 501(c)(3) non-profit organization whose mission is to aggressively raise research funds for Dravet syndrome and related epilepsies; to increase awareness of these catastrophic conditions; and to provide support to affected individuals and families.

We understand:

- The need to fund innovative research
- The urgency in finding better treatments
- The motivation of our donors to make an impact in the fields of Dravet syndrome and related epilepsies
- The importance of transparency and accountability of our organization and the researchers that we fund
- The need for global collaboration in order to find a cure

## JOIN OUR COMMUNITY

By uniting families and professionals in a global collaboration, we can improve the timeline for finding better treatments and a cure.

How you can help:

- Make a donation
- Host a fundraiser
- Volunteer
- Join our email list
- Enroll your child in the IICEPR

*"Dravet syndrome related research, like many types of basic research, is relevant to all forms of epilepsy, in particular the wide spectrum of pediatric epilepsies for which current treatments are not adequate. As such, support for this research is critical and is not limited to children suffering with DS but is applicable to nearly 3 million epilepsy patients worldwide."*

Scott C. Baraban, PhD  
Professor & William K. Bowes Endowed  
Chair in Neuroscience Research UCSF  
DSF Scientific Advisory Board Member

## OUR PROGRAMS

### *Research Grant Program*

This program offers grants for research directly related to Dravet syndrome and associated epilepsies. Our research grants fund initial research hypotheses that have not been fully explored. The results extracted from this type of research will help bring untested research to the point that it can qualify for larger governmental funding. Research applications will be judged principally on novelty of the hypotheses, innovative approaches with a direct relevance and application to Dravet syndrome and associated epilepsies, scientific quality, strength of approach, and likelihood of success. All research grants are reviewed and approved by DSF's accredited Scientific Advisory Board.

### *International Ion Channel Epilepsy Patient Registry*

This registry (co-funded by DSF & ICE Alliance) is owned by University of Michigan Department of Neurology and Miami Children's Hospital Brain Institute, but is available to all interested researchers. It will collect basic information and genetic test results of individuals with Dravet syndrome and related epilepsies worldwide. The establishment of this registry will 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.

[www.icepr.org](http://www.icepr.org)

