

EUROPEAN
DRAVET SYNDROME
CONFERENCE 2026
ENDORSEMENT BOOKLET



SÍNDROME DE DRAVET
FUNDACIÓN
www.dravetfoundation.eu

19-20 MARCH 2026
MADRID, SPAIN



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SUMMARY

The **Dravet Syndrome Foundation Spain** is pleased to host the **2026 European Dravet Syndrome Conference**, scheduled for **Thursday, March 19 and Friday, March 20**, in **Madrid, Spain**.

Following the success of the 2025 edition—which brought together top-tier researchers, clinicians, and families impacted by Dravet syndrome—we are excited to announce the next chapter of this important event. The 2026 conference will aim to deepen collaboration and accelerate progress in the understanding and treatment of Dravet syndrome across Europe and beyond.

This in-person gathering will once again welcome a **global audience of healthcare professionals, scientists, regulatory authorities, and pharmaceutical industry representatives**, all united by a shared commitment to combating epilepsy.

Attendees can expect a comprehensive program featuring the latest developments in Dravet syndrome care, including updates on newly approved therapies and promising treatments currently in development. The conference will offer a valuable opportunity to stay informed, exchange insights, and engage in meaningful dialogue with international experts in a dynamic and collegial setting.

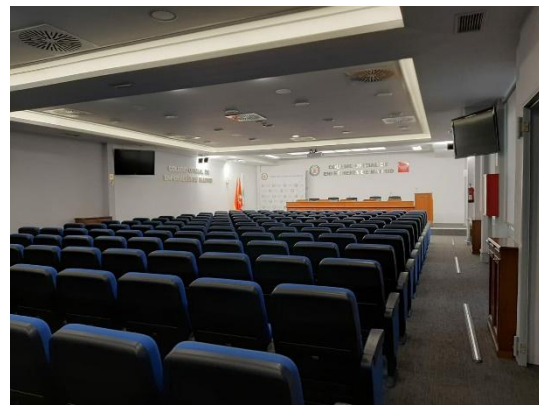
We warmly invite all stakeholders in the healthcare and biomedical research ecosystem—policy makers, academic researchers, pharmaceutical companies, SMEs, patient advocates, regulatory bodies, and public-private partnerships—to participate in this key event.

Registration is free of charge but required for logistical purposes.



The European Dravet Syndrome Conference 2026 will take place at the **Official College of Nursing of Madrid** (Spain), located in the former factory of the American sewing machine company Singer, an emblematic building of the 20th century.

Breaks and lunch will take place in the **Nursing History Museum** of the Official College of Nursing in Madrid, which is the only nursing museum in all of Spain, receiving visitors from all over the world.



Main entrance, hall and museum of the Illustrious Official College of Nursing of Madrid (Spain)



WHAT IS DRAVET SYNDROME?

Dravet syndrome (DS), also known as Severe Myoclonic Epilepsy in Infancy, is a **rare and severe developmental and epileptic encephalopathy** affecting 1 in 16,000 live births.

In more than 80% of patients, Dravet syndrome is caused by a **de novo pathogenic variant in the SCN1A gene**. These mutations result in the reduction of the voltage-gated sodium channel subunit Nav1.1. Variants in other genes such as *GABRG2*, *GABRA1* or *STXBP1* have also been linked to Dravet syndrome.

DS is characterised by a **drug-resistant epilepsy**, and by a number of severe **comorbidities**. Among these there are **cognitive, psychomotor and language impairment**, as well as **behavioural disorders**.

The first symptom of Dravet syndrome is typically a convulsive seizure appearing in the first year of life, in a previously healthy baby. Further **seizures are frequent and often prolonged**, sometimes evolving into status epilepticus, although the seizure types depend on age.

During the second year of life, the **neurodevelopmental impairment** becomes evident. **Comorbidities**, such as sleep disturbances, growth and eating difficulties, and frequent respiratory tract infections, are shared by almost all Dravet syndrome patients.

Dravet syndrome has a **15% mortality rate**, with 50% of cases due to **SUDEP** (Sudden Unexplained Death in Epilepsy).

Will you help us?



More information about Dravet syndrome can be found on our website here: <https://www.dravetfoundation.eu/sobre-dravet/> (click "Translate" at the bottom-right corner to get the English version).



ABOUT DRAVET SYNDROME FOUNDATION SPAIN

Dravet Syndrome Foundation Spain is a non-profit organisation that promotes, encourages, and connects the world's leading research centres for Dravet syndrome and related diseases. It is based on the principle of collaboration: a model uniting patients, investigators, clinicians, regulators, and sponsors in the search for an effective therapy. The main goal of Dravet Syndrome Foundation Spain is to remove the barriers that prevent research on Dravet syndrome from advancing, and to find effective therapies that mitigate and even cure the disease.

Dravet Syndrome Foundation Spain was established in 2011 by a group of struggling parents who did not resign themselves to following the dictates of the disease that was attacking their children. They support patients and their families, while searching for a cure and better treatments for Dravet syndrome by providing investigators working in basic, applied and clinical sciences with tools and financial support.



"We are an organisation that aims to find an effective treatment for Dravet syndrome"

In recognition of our work, Dravet Syndrome Foundation Spain has received numerous awards and honours, including the Epilepsy Award from the Spanish Society of Neurology, acknowledging our work in the promotion of scientific, institutional, and social neurological activities.

To learn more about Dravet Syndrome Foundation Spain, please visit our website:

<https://www.dravetfoundation.eu/>.



KEY FACTS

Event	European Dravet Syndrome Conference 2026
Date	19 th and 20 th of March, 2026
Venue	Official College of Nursing of Madrid, Avenida de Menéndez Pelayo, 93, 28007, Madrid (Spain)
Audience	<p>About 200 international participants, including:</p> <ul style="list-style-type: none">– Specialised investigators and clinicians– The pharmaceutical industry and other sectors in healthcare– SMEs and mid-sized enterprises– Patient representatives– Regulators and policymakers– Representatives of other public-private partnerships– Research-funding organizations– Students and early career scientists
Why getting involved?	<ul style="list-style-type: none">– ONLY international conference on Dravet syndrome held in the European Union– Direct contact with global and key opinion leaders in the field to raise awareness of your company's mission, expand your network, and build a reputation– Numerous sponsoring opportunities to get recognised– Industry exhibition for more visibility and interaction
Website	Coming soon at www.dravetconference.com
Contact	<p>Simona Giorgi, Scientific Director Dravet Syndrome Foundation Spain C/Toledo, 46, 1º, 28005, Madrid (Spain) +34 622 88 35 58 fundraising@dravetfoundation.eu</p>



2026 AGENDA: DAY 1

08.30 – 09:00	Welcome & Registration
09:00 – 09:15	Opening Statements & Introduction to the Program <i>José Ángel Aibar, Dravet Syndrome Foundation Spain</i> <i>Alexis Armazinoglou, ERN EpiCARE</i> <i>Nicola Specchio, ILAE Europe</i> <i>Lieven Lagae, KU Leuven</i> <i>Jacqueline French, NYU Langone School of Medicine</i>
09:15 – 11:00	Advances in Dravet Syndrome: A 5-Year Retrospective <i>Chair: Jacqueline French, NYU Langone School of Medicine</i>
09:15 – 09:30	What Have We Learned from Natural History Studies <i>Nicola Specchio, Bambino Gesù Children’s Hospital</i>
09:30 – 09:45	Beyond SCN1A: New Genes, Mosaicism, and Regulatory Elements <i>Franck Kalume, University of Washington</i>
09:45 – 10:00	Therapeutic Landscape in Dravet Syndrome: Approved Drugs and Treatment Algorithms <i>Antonio Gil-Nagel, Ruber International Hospital</i>
10:00 – 10:15	Evolution of Treatment Goals: From Seizure Control to Comprehensive DEE Management <i>Rocio Sánchez-Carpintero</i>
10:15 – 10:30	Update on the Research Pipeline for Dravet Syndromes <i>Vicente Villanueva, University Hospital La Fe</i>
10:30 – 10:45	Shaping the Future of Epilepsy Care: The Role of European Networks <i>Alexis Arzimanoglou, Sant Joan de Déu Barcelona Children’s Hospital</i>
10:45 – 11:00	Discussion <i>All attendees</i>
11:00 – 11:30	Networking Coffee Break & Poster Session
11:30 – 13:00	Dravet Syndrome in Adulthood and Mortality <i>Chair: Danielle Andrade, University of Toronto</i>
11:30 – 11:45	Clinical and Neuropathological Insights into Adult Dravet Syndrome <i>Danielle Andrade, University of Toronto</i>
11:45 – 12:00	Understanding the Emotional Toll of SUDEP Risk on Families <i>José Ángel Aibar, Dravet Syndrome Foundation Spain</i>
12:00 – 12:15	Communicating SUDEP and Mortality: Strategies for Supporting Caregivers <i>Kette Valente, University of São Paulo</i>
12:15 – 12:30	A Mother’s Journey Through Dravet Syndrome: Love, Loss, and Legacy <i>Océane Silvestri, mother of Matilda</i>
12:30 – 13:00	Discussion <i>All attendees</i>
13:00 – 14:30	Networking Lunch & Poster Session
14:30 – 15:30	Research Talk Session I <i>Chair: Alexis Arzimanoglou, Sant Joan de Déu Barcelona Children’s Hospital</i>
14:30 – 14:45	Early chronic Kv3.1 modulation improves phenotypic alterations in a mouse model of Dravet syndrome <i>Albina Farkhutdinova, Hertie Institute for Clinical Brain Research, University of Tübingen</i>
14:45 – 15:00	Cell Type–Specific Effects of Increased Persistent Sodium Current on Neuronal Firing <i>Manon Dobrigna, Institute of Molecular and Cellular Pharmacology, Université Côte d’Azur</i>
15:00 – 15:15	Functional excitation-inhibition ratio as a marker for indicating anti-seizure medication efficacy <i>Georgii Krivoshein, Leiden University Medical Center</i>
15:15 – 15:30	Discussion <i>All attendees</i>
15:30 – 16:00	Networking Coffee Break & Poster Session
16:00 – 17:15	Biomarkers and Predictive Tools for Precision Diagnosis in DEEs <i>Chair: Lieven Lagae, KU Leuven</i>
16:00 – 16:15	Predicting Phenotypic Trajectories from Early Seizure Onset <i>Lieven Lagae, KU Leuven</i>
16:15 – 16:30	Predictive Markers for Diagnosing Dravet Syndrome – The Earlier the Better <i>Andreas Brunklaus, University of Glasgow</i>
16:30 – 16:45	MicroRNAs and Epigenetic Signatures: Unlocking New Diagnostic Tools <i>Petra Bencurova, RCSI University of Medicine and Health Sciences</i>
16:45 – 17:00	Exploring the role of artificial intelligence (AI) in Dravet Syndrome: A use case in translational research <i>Satya Sahoo, Case Western Reserve University</i>
17:00 – 17:15	Discussion <i>All attendees</i>



17:15 – 18:00	Research Talk Session II <i>Chair: Else Tolner, Leiden University Medical Centre</i>
17:15 – 17:25	Ribozyme-mediated RNA trans-splicing as a therapeutic strategy for Dravet syndrome <i>Maria de los Angeles Garduño Robles, Center for Applied Medical Research (CIMA), University of Navarra</i>
17:25 – 17:35	Expanding the Genetic and Phenotypic Spectrum of Dravet Syndrome <i>Jair Tenorio, Institute of Medical and Molecular Genetics (INGEMM) at La Paz University Hospital, CIBERER</i>
17:35 – 17:45	Efficacy of a Novel Gene Replacement Therapy Against Dravet Syndrome Behavioral Comorbidities <i>Samantha Hanson, Seattle Children's Research Institute</i>
17:44 – 18:00	Discussion <i>All attendees</i>
18:00	Wrap up day 1 <i>José Ángel Albar, Dravet Syndrome Foundation Spain</i>

2026 AGENDA: DAY 2

08:30 – 09:00	Welcome & Registration
09:00 – 11:00	Expert Panel Discussions
9:00 – 10:00	Rethinking Control Groups, Maintaining Blinding in DEEs Clinical Trials <i>Jacqueline French, NYU Langone School of Medicine</i> <i>Stéphane Auvin, Robert Debré Hospital</i>
	Discussion <i>Emma James, Encoded Therapeutics and Pediatric Gene Therapy & Medical Ethics (NYU)</i> <i>Isabella Brambilla, E+ Alliance</i> <i>Ryan Arnold, Stoke Therapeutics</i>
10:00 – 11:00	Distinctive Trial Designs for DEE and DS: Are They Needed? <i>Jacqueline French, NYU Langone School of Medicine</i> <i>Stéphane Auvin, Robert Debré Hospital</i>
	Discussion <i>Alexis Arzimanoglou, European Consortium for Epilepsy Trials</i> <i>Sandra Silva Arrieta, GRINpatias Association and GRIN Europe</i> <i>Tolga Uz, Lundbeck</i>
11:00 – 11:30	Networking Coffee Break & Poster Session
11:30 – 12:00	Research Workshop I: Innovative Therapeutic Strategies: From Antisense Oligonucleotides to Gene Therapy
11:30 – 11:45	Introduction to the topic <i>Rajvinder Karda, University College London</i>
11:45 – 12:00	Discussion <i>All attendees</i>
12:00 – 12:45	Research Talk Session III <i>Chair: Massimo Mantegazza, Institute of Molecular and Cellular Pharmacology, University Cote d'Azur, CNRS & Inserm</i>
12:00 – 12:15	Towards multimodal, personalized in vitro seizure fingerprints <i>Susanna Narkilahti, Tampere University</i>
12:15 – 12:30	Disrupted temperature-sleep coupling mechanism in a Dravet syndrome mouse model <i>Moran Rubinstein, Tel Aviv University</i>
12:30 – 12:45	Disruption of Upstream Open Reading Frames by Base Editing Enhances mRNA Translation of SCN genes <i>Gaia Colasante, San Raffaele Scientific Institute</i>
12:45 – 13:00	Discussion <i>All attendees</i>
13:00 – 14:00	Networking Lunch & Poster Session
14:00 – 14:30	Workshop II: Future Directions in DEEs: Omics and Animal Models
14:00 – 14:15	Introduction to the topic <i>Heidrun Potschka, Ludwig Maximilian University of Munich</i>
14:15 – 14:30	Discussion <i>All attendees</i>
14:30 – 15:00	Research Talk Session IV <i>Chair: Simona Giorgi, Dravet Syndrome Foundation Spain</i>
14:30 – 14:40	Language Development in Dravet Syndrome in the 3 to 6 year stage <i>Pedro Sanz de la Rosa, Universidad Complutense de Madrid</i>
14:40 – 14:50	Musculoskeletal Complications in Dravet Syndrome: The Underrecognized Problem of Scoliosis <i>Fien Vandenberk, Antwerp University Hospital and University of Antwerp</i>
14:50 – 15:00	Discussion <i>All attendees</i>
15:00	Young Investigators' Best Oral and Poster Presentation Awards, Close & Thank-Yous <i>José Ángel Albar, Dravet Syndrome Foundation Spain</i> <i>Nicola Specchio, ILAE Europe</i> <i>Jacqueline French, NYU Langone School of Medicine</i>



ADVERTISING AND DISSEMINATION

The European Dravet Syndrome Conference 2026 will be advertised:

- On our social networks (>97K followers in Facebook, Twitter, LinkedIn, and in Instagram).
- Via direct e-mail to Dravet syndrome families.
- Via direct e-mail to our professional contact distribution list (including relevant medical and scientific societies, centres, enterprises, clinicians and investigators involved in neurology and epilepsy research from all around the world).
- To the non-expert public through press releases.
- Via announcements from our public and private key stakeholder partners.

ENDORSEMENT

With the great support of:



With the scientific endorsement of:



CONTACT INFORMATION

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One dream, one goal



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