EUROPEAN
DRAVET SYNDROME
CONFERENCE 2026

ENDORSEMENT BOOKLET

SÍNDROME DE DRAVET
FUNDACIÓN

www.dravetfoundation.eu

19-20 MARCH 2026

MADRID, SPAIN

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Con el Aval Científico de la Sociedad Española de Neurología Pediátrica (SENEP)

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.

EUROPEAN DRAVET SYNDROME CONFERENCE 2026

MADRID, SPAIN

KEY FACTS

Event	European Dravet Syndrome Conference 2026
Date	19th and 20th of March, 2026
Venue	Official College of Nursing of Madrid, Avenida de Menéndez Pelayo, 93, 28007, Madrid (Spain)
Audience	About 200 international participants, including: – 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?	– 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	Simona Giorgi, Scientific Director Dravet Syndrome Foundation Spain C/Toledo, 46, 1º, 28005, Madrid (Spain) +34 622 88 35 58 fundraising@dravetfoundation.eu

2026 AGENDA: DAY 1

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

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

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** *Jacqueline French, NYU Langone School of Medicine* *Stéphane Auvin, Robert Debré Hospital*
	Discussion *Emma James, Encoded Therapeutics and Pediatric Gene Therapy & Medical Ethics (NYU)* *Isabella Brambilla, E+ Alliance*
10:00 – 11:00	**Distinctive Trial Designs for DEE and DS: Are They Needed?** *Jacqueline French, NYU Langone School of Medicine* *Stéphane Auvin, Robert Debré Hospital*
	Discussion *Alexis Arzimanoglou, European Consortium for Epilepsy Trials* *Sandra Silva Arrieta, GRINpatias Association and GRIN Europe*
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** *Rajvinder Karda, University College London*
11:45 – 12:00	**Discussion** *All attendees*
12:00 - 12:45	**Research Talk Session III** *Chair: Massimo Mantegazza*
12:00 – 12:15	**Towards multimodal, personalized in vitro seizure fingerprints** *Susanna Narkilahti, Tampere University*
12:15 – 12:30	**Disrupted temperature-sleep coupling mechanism in a Dravet syndrome mouse model** *Moran Rubinstein, Tel Aviv University*
12:30 – 12:45	**Disruption of Upstream Open Reading Frames by Base Editing Enhances mRNA Translation of SCN genes** *Gaia Colasante, San Raffaele Scientific Institute*
12:45 – 13:00	**Discussion** *All attendees*
13:00 – 14:15	**Networking Lunch & Poster Session**
14:15 – 14:45	**Workshop II:** **Future Directions in DEEs: Omics and Animal Models**
14:00 – 14:15	**Future directions in DEEs: omics and animal models** *Heidrun Potschka, Ludwig Maximilian University of Munich*
14:15 – 14:30	**Discussion** *All attendees*
14:30- 15:00	**Research Talk IV** *Chair: Simona Giorgi*
14:30- 14:40	**Language Development in Dravet Syndrome in the 3 to 6 year stage** *Pedro Sanz de la Rosa, Universidad Complutense de Madrid*
14:40- 14:50	**Musculoskeletal Complications in Dravet Syndrome: The Underrecognized Problem of Scoliosis** *Fien Vandenberk, Antwerp University Hospital and University of Antwerp*

14:50- 15:00	**Discussion** *All attendees*
15:00	**Young Investigators' Best Oral and Poster Presentation Awards, Close & Thank-Yous** *José Ángel Aibar, Dravet Syndrome Foundation Spain* *Nicola Specchio, ILAE Europe* *Jacqueline French, NYU Langone School of Medicine*

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.

CONTACT INFORMATION

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Instagram: @fundaciondravet

Twitter: @FundacionDravet

One dream, one goal

Will you help us?