

MARCH
2023

PRACTICAL INFORMATION DRAVET SYNDROME SCIENTIFIC AND FAMILY DAYS 2023

DRAVET SYNDROME FOUNDATION SPAIN



SÍNDROME DE DRAVET
FUNDACIÓN

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**Official College of
Nursing of Madrid**

**DRAVET
SYNDROME
CONFERENCE**

**Thursday,
March 23
08:30 am**

**EDSAT
MEETING**

**Friday,
March 24
08:30 am**

**Rafael Ybarra
School**

**ANNUAL
FAMILY
MEETING**

**Saturday,
March 25
08:30 am**



**SÍNDROME DE DRAVET
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**SÍNDROME DE DRAVET
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AGENDA 1/2

DRAVET SYNDROME CONFERENCE

08.30 – 09.00	Welcome & Registration
09.00 – 09.15	Opening statements & Introduction to the program Charlotte Dravet Raquel Yotti, Secretary-General for Research, Ministry of Science and Innovation of Spain Jorge Andrada, President, Official College of Nursing of Madrid Lieven Lagae, Scientific Committee, Dravet Syndrome Foundation Spain José Ángel Aibar, President, Dravet Syndrome Foundation Spain
09.15 – 09.45	Dravet syndrome perspectives Chair: Charlotte Dravet
	Dravet syndrome by a parent Lauraine Mckenna, Patrick's mom
	Dravet syndrome: From one century to another! Charlotte Dravet
09.45 – 11.15	Coexisting comorbidities in Dravet syndrome Chair: Lieven Lagae, KU Leuven
	Early diagnosis and intervention and its long-term impact on comorbidities Andreas Brunklaus, Royal Hospital for Children, Glasgow
	Cognition in Dravet syndrome Lieven Lagae, KU Leuven
	Neuropsychiatric disorders in Dravet syndrome Susana Boronat, Hospital Sant Pau Barcelona
	SUDEP in Dravet syndrome. Can it be mitigated? Franck Kalume, University of Washington
	Defining therapeutic success in Dravet syndrome Ángel Aledo-Serrano, Hospital Vithas Madrid La Milagrosa
11.15 – 11.45	Networking Coffee Break & Poster Session
11.45 – 13.00	Dravet syndrome in adults Chair: Danielle Andrade, University of Toronto
	The Dravet syndrome patient journey: The Spanish journey Estibaliz Barredo, University Hospital Gregorio Marañón
	Comorbidities in adults with Dravet syndrome Vicente Villanueva, Hospital La Fe
	Transition taking comorbidities into account Danielle Andrade, University of Toronto
	Undiagnosed adults with Dravet syndrome. What can be done? Sarah Weckhuysen, University of Antwerp



AGENDA 2/2

DRAVET SYNDROME CONFERENCE

13.00 – 14.30	Networking Lunch & Poster Session
14.30 – 15.30	What's coming next in Dravet syndrome? 1/2 Chair: Rajvinder Karda, EGA Institute for Women's Health at UCL
	Update on the research pipeline for Dravet syndrome Vittoria Spinosa, Dravet Syndrome Foundation Spain
	The open access Dravet syndrome research kit Verónica Rivero Hernández, Dravet Syndrome Foundation Spain
	A high-throughput method for screening for new drugs for the treatment of genetic epilepsies Lorianne Masuoka, Epygenix Therapeutics
	Clinical update on soticlestat (TAK-935) for the treatment of Dravet syndrome Vicente Villanueva, Hospital La Fe
15.30 – 16.00	Networking Break & Poster Session
16.00 – 16.45	What's coming next in Dravet syndrome? 2/2 Chair: Verónica Rivero Hernández, Institute for Research, Development and Innovation in Health Biotechnology of Elche (IDiBE, UMH)
	Advanced therapies approaches for Dravet syndrome Rubén Hernández, CIMA Universidad de Navarra
	Preclinical development of RT101, a novel approach for normalizing SCN1A expression levels Jordane Dimidschstein, Regel Therapeutics
16.45 – 17.00	The power of patient groups in drug development Vittoria Spinosa, Dravet Syndrome Foundation Spain
17.00	Close & thank-yous

This meeting has been endorsed by:



EpiCARE



**EUROPEAN
PAEDIATRIC
NEUROLOGY
SOCIETY**

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**Official College of
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**EDSAT
MEETING
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**SÍNDROME DE DRAVET
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AGENDA 1/2

EDSAT MEETING 2023

EUROPEAN DRAVET SYNDROME ADVANCED THERAPIES

08.30 – 09.00	Welcome & Registration
09.00 – 09.10	Opening statements & Introduction to the program José Ángel Aibar, President, Dravet Syndrome Foundation Spain
09.10 – 09.55	Research Talk Session I Targeting GABA-switch can rescue behavioral defects but not seizures in Scn1a+/- DS mice Massimo Mantegazza, Côte d'Azur University & CNRS
	Validation of θ-γ PAC as potential EEG biomarker to assess efficacy of the anti-seizure treatment Else Tolner, Leiden University Medical Center
	Boosting a homeostatic response as therapeutic approach in Scn1a+/- Dravet syndrome mice Evgeniia Rusina, Institute of Molecular and Cellular Pharmacology, CNRS
09.55 – 10.40	Workshop 1: Existing ASMs for Dravet syndrome and related epilepsies
	Introduction to existing ASMs for Dravet syndrome and related epilepsies Heidrun Potschka, Ludwig-Maximilians-University Munich
	Dynamic group discussions on existing ASMs for Dravet syndrome and related epilepsies All attendees
10.40 – 11.10	Poster Session & Networking Coffee Break
11.10 – 11.30	Research Talk Session II
	Strategies to reduce inflammation of adenoviral vectors in a Dravet syndrome mouse model Rubén Hernández, CIMA Universidad de Navarra
	Constitutive restoration of Nav1.1 levels in GABAergic neurons ameliorates Dravet syndrome phenotype Martina Mainardi, San Raffaele Scientific Institute
11.30 – 12.30	Workshop 1: Pros and cons of the different advanced therapy strategies for Dravet syndrome
	Introduction to the pros and cons of the different advanced therapy strategies for Dravet syndrome Gabriele Lignani, UCL Queen Square Institute of Neurology Rubén Hernández, CIMA Universidad de Navarra
	Dynamic group discussions on the pros and cons of the different advanced therapy strategies for Dravet syndrome All attendees

AGENDA 2/2

EDSAT MEETING 2023

EUROPEAN DRAVET SYNDROME ADVANCED THERAPIES

12.30 – 14.00	Poster Session & Networking Lunch
14.00 – 14.45	Expert Panel: New insights into the neuropathophysiology of Dravet Syndrome Chair: Massimo Mantegazza, Côte d'Azur University & CNRS
	Initial pathological mechanism and remodeling (secondary modifications) Massimo Mantegazza, Côte d'Azur University & CNRS
	Secondary modifications studied with proteomics and metabolomics Heidrun Potschka, Ludwig-Maximilians-University Munich
	Can upregulation of Nav1.1 overcome secondary modifications? Gaia Colasante, San Raffaele Scientific Institute
	Open discussion on the topic Sarah Weckhuysen, University of Antwerp
	Dynamic group discussion Speakers and attendees
14.45 – 15.15	Poster Session & Networking Break
15.15 – 16.00	Research Talk Session III
	A human cortical assembloid model of Dravet Syndrome Clara Zourray, UCL Queen Square Institute of Neurology
	Sleep and temperature dysregulation in a Dravet syndrome mouse model Saja Fadila, Tel Aviv University
	Local reactivation of Scn1a gene in a reversible mouse model of Dravet syndrome Gaia Colasante, San Raffaele Scientific Institute
16.00	Best Oral and Best Poster Presentation Awards, close & thank-yous José Ángel Aibar, Dravet Syndrome Foundation Spain

The background of the entire poster is a photograph of several hands of different skin tones reaching upwards, palms facing forward. The image is overlaid with a semi-transparent purple filter.

Rafaela Ybarra School

ANNUAL FAMILY MEETING 2023

**Saturday,
March 25
08:30 am**



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AGENDA 1/2

ANNUAL FAMILY MEETING 2023

08.45 - 09.15	Welcome to families
09.15 - 09.45	Opening statements & Introduction to the program José Ángel Aibar, Dravet Syndrome Foundation Spain
09.45 - 10.00	Presentation of new families Amparo Bastos, Dravet Syndrome Foundation Spain
10.00 - 10.20	Dravet Syndrome Foundation Spain: A catalyst for Dravet syndrome research José Ángel Aibar, Dravet Syndrome Foundation Spain
10.20 - 10.40	The Dravet syndrome research kit Verónica Rivero Hernández, Dravet Syndrome Foundation Spain
10.40 - 11.00	My (other) child does not have Dravet syndrome: When there are siblings without the disease Itziar Alonso-Arbiol, University of the Basque Country
11.00 - 11.30	Break
11.30 - 12.00	DANCE project: Evaluation of neuropsychiatric disorders associated with Dravet syndrome Susana Boronat, Hospital de la Santa Creu i Sant Pau
12.00 - 12.30	Improving the transition from pediatric to adult care Danielle Andrade, University of Toronto
12.30 - 13.00	Dravet syndrome research pipeline Vittoria Spinosa, Dravet Syndrome Foundation Spain
13.00 - 13:30	Clinical update of clemizole (EPX-100) for the treatment of Dravet syndrome Lorianne Masuoka, Epygenix
13:30 - 14:00	Clinical update of soticlestat (TAK-935) for the treatment of Dravet syndrome Manuel Toledo, Hospital Vall d'Hebron

AGENDA 2/2

ANNUAL FAMILY MEETING 2023

14.00 - 16.00	Lunch
16.00 - 16.30	Sleep disorders in Dravet syndrome V́ctor Soto, Hospital Infantil Universitario Niño Jeśs
16.30 - 17.15	The role of the school nurse Natividad Ĺpez Langa, AMECE
17.15 - 17.35	Psychosocial Support Program of the Dravet Syndrome Foundation Spain Carla Bonafé, Neuropsicóloga
17.35 - 18.00	Break
18.00 - 18.30	The experience of a mother and psychologist Ares Regué, Neuropsychologist and mother of Athenea
18.30 - 18.45	Dravet Awards 2023 José Ángel Aibar, Dravet Syndrome Foundation Spain
18.45 - 19.00	Close & thank-yous

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OFFICIAL COLLEGE OF NURSING OF MADRID

ADDRESS: Avenida de Menéndez Pelayo, 93, 28036, Madrid

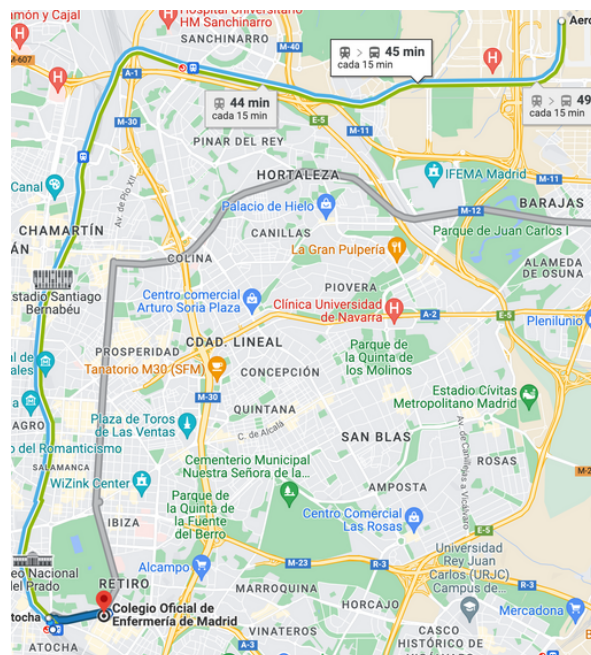
METRO STATION:
Menendez Pelayo:
Line 1

BUS STOP:
Mariano de Cavia:
Bus 14, 32, 63



AIRPORT TO OFFICIAL COLLEGE OF NURSING OF MADRID

RENFE C1 or C10 to *Atocha* and then the **BUS** 14 or 32 to stop *Mariano de Cavia*



ATOCHA STATION TO OFFICIAL COLLEGE OF NURSING OF MADRID

BUS 14 or 32 to stop *Mariano de Cavia* or walking for 11 minutes.



How to get to Rafaela Ybarra School

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SÍNDROME DE DRAVET
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RAFAELA YBARRA SCHOOL

ADDRESS: Avenida de Rafaela Ybarra, 73,
28026 Madrid

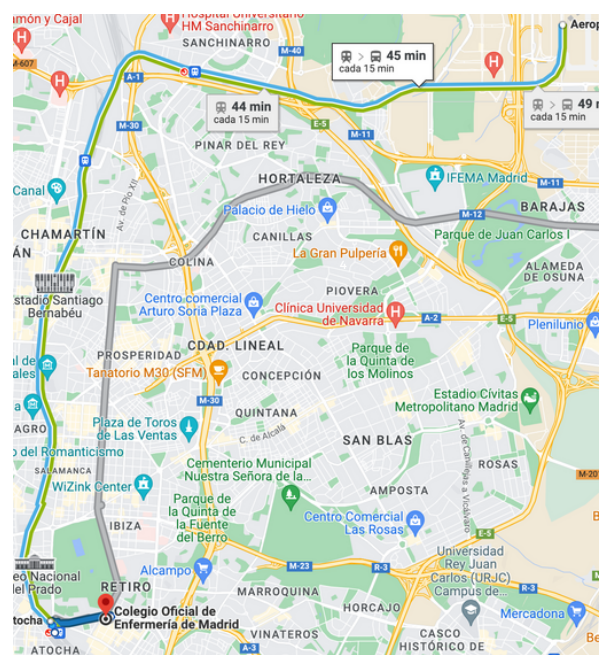
METRO STATION:
Plaza Elíptica - Line 6

BUS STOP:
Rafaela Ybarra/Marina Vega - Bus 6



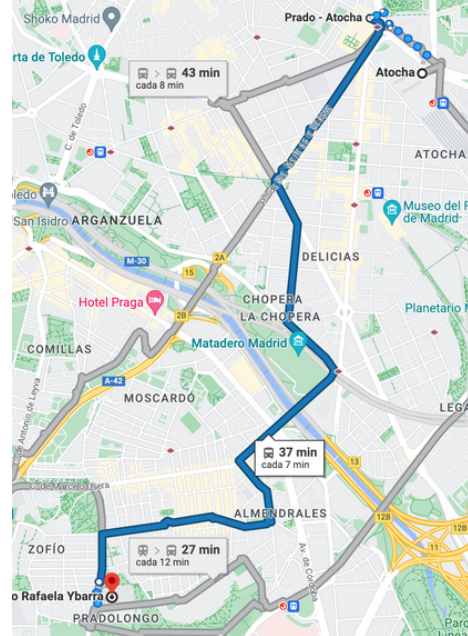
AIRPORT TO RAFAELA YBARRA SCHOOL

RENFE C1 or C10 to *Atocha Station* and then change for **RENFE** C5 to stop *Doce de Octubre*; finally walking.



ATOCHA STATION TO RAFAELA YBARRA SCHOOL

Walking for 6 minutes to stop *Prado/Atocha* to take the **BUS** 6 to the stop *Rafaela Ybarra/Marina Vega*



EMERGENCY CONTACT

112 : Which is a single number for assistance in the event of any type of emergency:

- Health [ambulance].
- Fire extinguishing [fire brigade].
- Rescue or public safety [police].

CONTACT

During the conference you can contact us at:



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