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Dravet Syndrome European Federation





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DRAVET SYNDROME EUROPEAN FEDERATION

Our vision

Improving the lives of people living with Dravet Syndrome.

Our mission

The Dravet Syndrome European Federation is dedicated to improving the lives of affected people through collaboration, education, awareness and facilitating research.

Our motto

Together we are stronger.





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ABOUT US

The Dravet Syndrome European Federation (DSEF) is a federation of European organisations active in the field of Dravet Syndrome and driven by patients caregivers.

Together we have built a strong European community of people living with Dravet Syndrome. We are this community's voice and we fight against the impact of Dravet Syndrome.

DSEF is a non-profit organisation founded in 2014. For the list of members, the Board of Directors and our statutes please visit our website.

Our aims

- to improve the quality of life of patients and their family caregivers by promoting and developing medical/social initiatives
- to stimulate research and development into treatments by specialist physicians and researchers
- to raise funds for and promote medical and social research
- to raise awareness of Dravet Syndrome among the public and the medical / social community



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Members

- Alliance Syndrome de Dravet (France)
- Apoyo Dravet (Spain)
- Asociația pentru Dravet și alte Epilepsii Rare (Romania)
- Associação Síndrome de Dravet (Portugal)
- Dravet Italia Onlus (Italy)
- Dravet.PI (Poland)
- Dravet sindrom Hrvatska (Croatia)
- Dravet-Syndrom e.V. (Germany)
- Dravet Syndrome UK (United Kingdom)
- Dravets Syndrome Association Sweden
- Dravet syndrom Norge (Norway)
- Fundación Síndrome de Dravet (Spain)
- Gruppo Famiglie Dravet Onlus (Italy)
- Stichting Dravetsyndroom Nederland/Vlaanderen (Netherlands/Belgium)
- Dravet Sindrom Srbija (Serbia)
- Epilepsforeningen / Dravet Danmark
- Swiss Dravet Syndrome Association (Switzerland)

Board of Directors

Isabella Brambilla, chairman, isabella.brambilla@dravet.eu

Myra de Groot, deputy chairman, myra.degroot@dravet.eu

Renata Heusser, secretary, renata.heusser@dravet.eu

Simona Borroni, treasurer, simona.borroni@dravet.eu

Galia Wilson, galia.wilson@dravet.eu

Chief Scientific Officer

Julian Isla, julian.isla@dravet.eu



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DRAVET SYNDROME

Dravet Syndrome is a Rare Genetic Disease starting in infancy characterised by drug-resistant epilepsy associated with complex neuro-motor development disorders, behavioral delay and intellectual disabilities. Initial seizures are most often prolonged. Development remains on track initially, with plateaus and a progressive decline typically beginning in the second year of life. Individuals with Dravet Syndrome face a higher incidence of SUDEP.

Unless a cure or better treatments for Dravet Syndrome are found, individuals with this disorder face a diminished quality of life. Current treatment options are extremely limited and the prognosis for these children is poor.

OUR SCIENTIFIC ADVISORY BOARD

The Scientific Advisory Board (SAB) was formed in June 2016. It is formed by experts with proven and established expertise, highly qualified, and is in charge for five years. Its main tasks is to support the actions of DSEF, to operate and advise in particular with regard to aspects of a medical, clinical, for those related to the research and to operate and propose in addition to the aspects / initiatives related to better functional and organisational quality of healthcare services provided to patients.

Physicians/scientists; Dr. Helen Cross, Dr. Rima Nabbout, Prof. Bernardo Dalla Bernardina, Prof. Renzo Guerrini, Dr. Lieven Lagae, Dr. Antonio Gil-Nagel and Dr. Ana Mingorance
Representing the DSEF: Isabella Brambilla, Myra De Groot and Julian Isla



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OUR PROJECTS

Research

Several organisations joined their forces and co-financed a new open access mouse model widely used by the scientific community. We also conduct surveys on health and medical issues.



Supporting clinical trials

Our organisation is focused on making clinical trials for Dravet Syndrome happen in Europe, as a way to shorten patients' waiting time for an efficient treatment.



European patient registry

DSEF supports the international Residras platform, a patient registry to capture real data from Dravet patients in Europe to give insights to researches, physicians, industry and patients.



International meetings

We are aiming to create a network of experts to be constantly updated with the newest information in the epilepsy and Dravet Syndrome field, so that dissemination can then go further to all those interested.



In collaboration with ERN-EpiCARE, RARE2030 and EURORDIS



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Let's join forces. Together we can achieve much more!

Become a volunteer
or support our initiatives and donate

Contact

info@dravet.eu

www.dravet.eu



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