Apoyo Dravet

We are a community
and a creator of communities

Finding a Cure Together

Dravet Syndrome and Rare Epilepsies

apoyodravet.eu

About ApoyoDravet

ApoyoDravet is a community of people affected by rare epilepsies and Dravet syndrome. It acts as a **collaborative platform** that connects patients and family members with volunteers and other contributors (including scientists, doctors, psychologists, educators, technicians and others).

It promotes scientific research, medicine, technology and innovation as a part of social intervention seeking to improve the **quality of life** of patients, their families and their social circles.

ApoyoDravet is a **non-profit organization** with declared public utility. It is a member of the Spanish Rare Diseases Federation (Federación Española de Enfermedades Raras, FEDER), the Spanish Epilepsy Federation (Federación Española de Epilepsia, FEDE), the Dravet Syndrome European Federation (DSEF) and the Ibero-American Dravet Syndrome Support Federation (Federación Iberoamericana de Apoyo Contra el Síndrome de Dravet).

Departments

Scientific Research

ApoyoDravet's efforts seek to **accelerate scientific research** projects, driving the advancement and practical application of science in the field of rare epilepsy diseases. In this context, it heads a collaborative network of researchers (the INDRE network), to whom it offers advising services, the promotion of knowledge and technology transfer, and assistance financing projects.

The association currently supports **14 research groups** and more than 50 researchers working at the cutting edge of technology in fields such as genetic techniques, cellular therapy, machine learning, artificial intelligence, nanotechnology, drug development, neuroinflammation and brain organoids, among others.

Its initiatives include:

- the International Research Network on Dravet Syndrome and Refractory Epilepsy (INDRE).
- the Epilepsy Social Research Unit [Unidad de Investigación Social sobre Epilepsias].
- ApoyoDravet's clinical studies, trials and programs.
- conventions and scientific conferences.
- its cognitive intervention platform.

Social Innovation

ApoyoDravet's social innovation initiatives seek to promote **inclusion in social and educational** contexts and to improve the assistance and home care available to patients, thus contributing to improving the quality of life of the family members of the person affected.

At the cutting edge of assistance in the field of rare epilepsies, all of ApoyoDravet's social programs are based on **innovation** and putting scientific and technological knowledge to use in order to carry out effective social interventions. These include:

- supporting those affected and the people surrounding them.
- cognitive evaluation and intervention.
- inclusive education.
- sensitization, raising awareness and social activities.

Patient-centric Technology Department

ApoyoDravet has a program for promoting and accelerating technology-based projects seeking to improve the quality of life of patients and their families by developing **new tools** for doctors, researchers and other people involved in the efforts.

ApoyoDravet by the Numbers

17 research groups, more than 50 researchers, more than 20 projects.

Universities, hospitals, research centers, biotech companies.

More than 200 private donors and 14 business and institutional contributors.

Clinical studies, trials and programs carried out by the association itself and in collaboration with other bodies.

13 social innovation projects.

ApoyoDravet by the Numbers

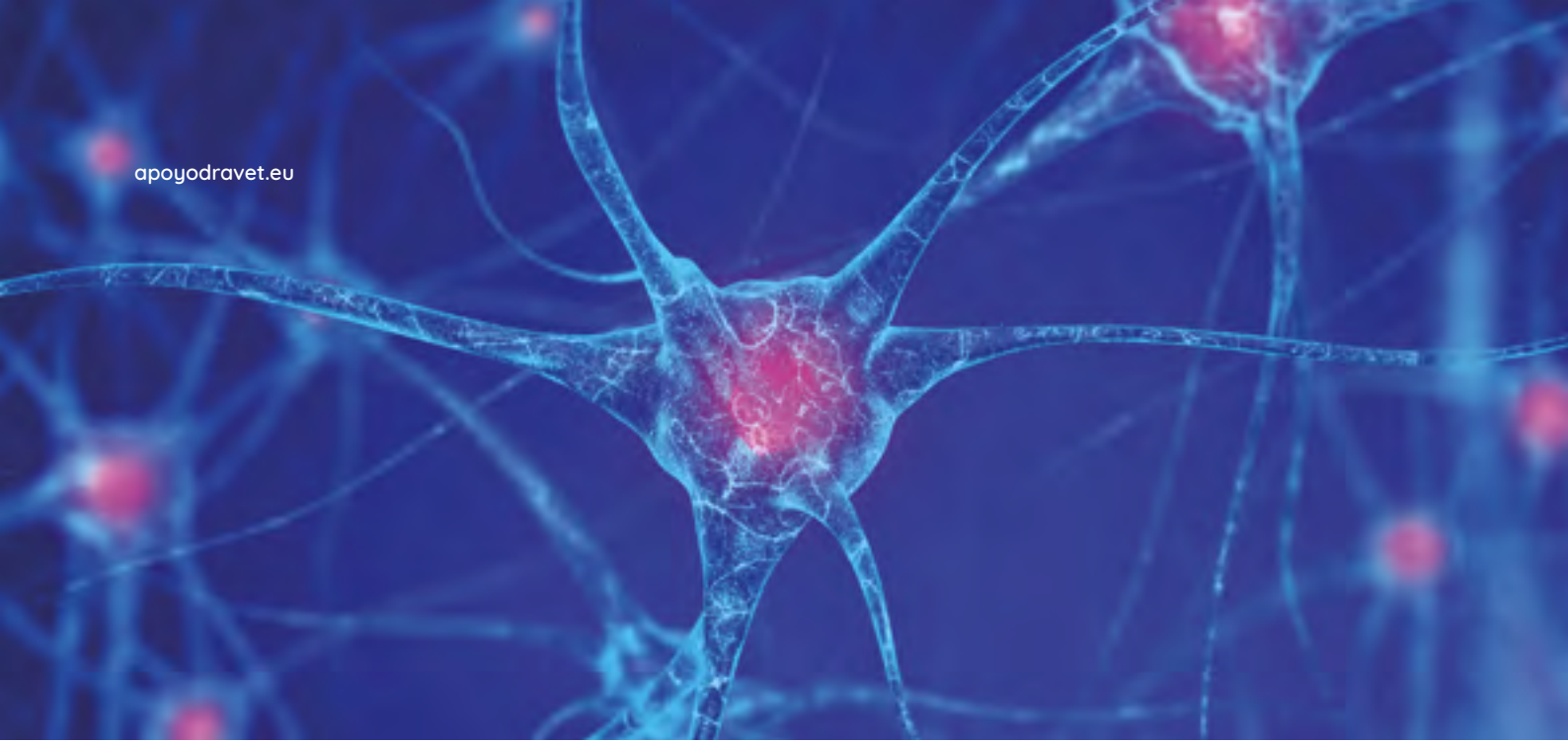
Since 2016

Investment in scientific research

€450.954

Investment in social intervention

€220.954



Rare Epilepsies

A variety of rare diseases and syndromes involve epileptic seizures. The presence of increased neuronal activity in those affected is correlated with severe brain dysfunction that comes with serious consequences as a result of **epileptic encephalopathy**.

Refractory epilepsies are types of epilepsy in which seizures cannot be adequately controlled using current anti-seizure medication. Refractory epilepsy is estimated to be present in 30% of people with epilepsy.

Rare and complex epilepsies make up a range of syndromes and epilepsies characterized by their high degree of severity and mortality and significant presence in infants, in whom controlling the disease is exceedingly difficult.

While multiple diseases share the commonality of involving epileptic seizures, it is not appropriate to speak of a single type of **epilepsy** but rather different epilepsies with different causes and features. As a result, different treatments are required even though patients tend to have similar needs and require similar care.

For information purposes, examples of some epileptic encephalopathies, epileptic syndromes or diseases could include **Dravet** syndrome, **West** syndrome, **tuberous sclerosis, Lennox-Gastaut** syndrome, **PCDH19** gene mutation, **Rett** syndrome, **Rasmussen** syndrome, **GLUT1** deficiency syndrome and more.

Scientific and medical advances in the field of rare epilepsies can offer tangible benefits for improving quality of life, in the ultimate goal of curing patients of a variety of related diseases.

Dravet Syndrome

Dravet syndrome is a rare neurological disease mainly consisting of uncontrolled epileptic seizures, cognitive impairment and serious alterations in behavior, with high levels of **disability**.

It is a genetic disease that appears in previously asymptomatic infants under the age of 1. There are no effective treatments for it.

It is estimated that 1 in every 20,000 people suffers from Dravet syndrome, with a high rate of underdiagnosis.

It is also important to note that Dravet syndrome has one of the **highest mortality** rates among so-called epilepsy syndromes.

Structure and Team

Management

ELENA CALVO
President

JULIO ANDRÉ HIDALGO
Treasurer

RAQUEL OMEDES
Secretary

Dirección

ANTONIO VILLALÓN
Managing director

JULIO ANDRÉ HIDALGO
Finance director

Profesionales

DR. LUIS MIGUEL ARAS
Investigation

IOSUNE GARCÍA
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