

ApoyoDravet

A benchmark in the promotion of patient-centered science and social innovation



ApoyoDravet is a community created by families of patients affected by rare diseases with epilepsy 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 association with declared Public Utility.

Experience, responsibility and solvency

Scientific research

- Direct investment in scientific research projects ApoyoDravet: 494,214 euros.
- Third-party financial contributions to ApoyoDravet projects: 1,600,000 euros.
- Promotional services provided by ApoyoDravet to 46 research centers: more than 800,000 euros in market value (advice, transfers, fundraising, etc.).



(Since 2016)

Experience, responsibility and solvency

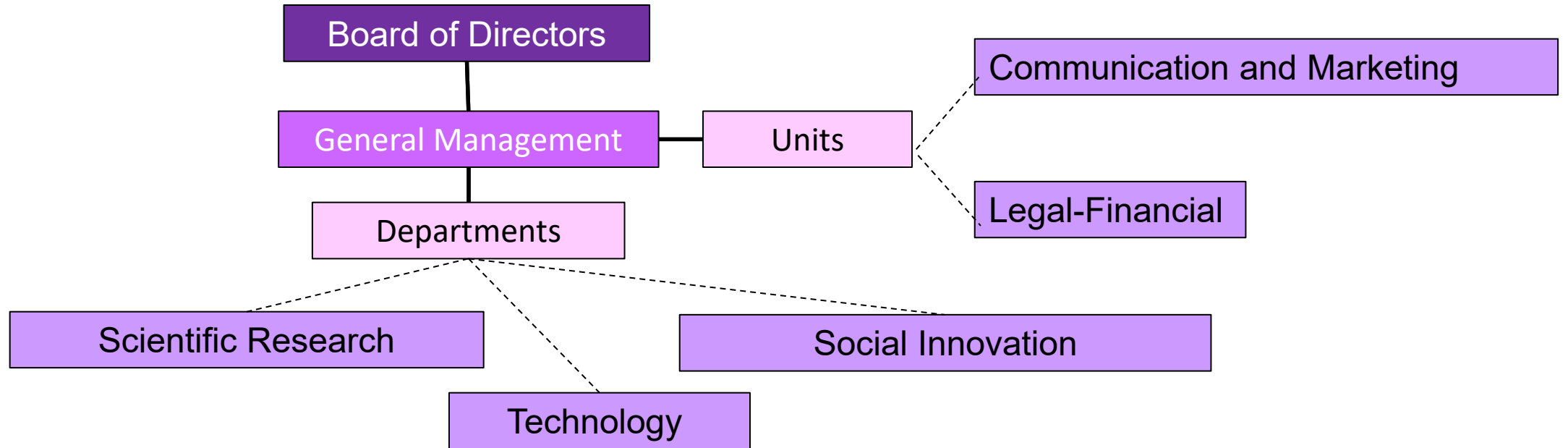
Social innovation

- Direct investment in social intervention: 274,204 euros.

(Since 2016)



Organizational chart



ApoyoDravet

Patient-driven science promotion



Juntos para curar

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Research: Productivity and Impact

INDRE ApoyoDravet

(International Research Network on Dravet and Refractory Epilepsy)

Promotion and acceleration of scientific and technological projects

- 14 groups, more than 50 researchers, 20 projects.
- 15 scientific articles from preclinical and clinical researchers.
- New knowledge on neuroinflammation, cannabinoids, promoter genes and drugs for quality of life.
- 5 new compounds discovered in preclinical phase.



Research: Productivity and Impact

Studies, trials and clinical programs:

- Cannabidiol, cognition, quality of life... Including own clinical studies (7 in 2023).

Research tools developed

- Dravet brain organoid model.
- Drosophila Dravet model.
- Zebrafish Dravet model.
- In silico (computational) platform for drug development for Dravet and rare epilepsies.

Research: Productivity and Impact

Market transfer and business promotion service.

- 1 company promoted. Another company in process (international).

Scientific events: congresses, seminars, meetings, etc.

- Mentions in congresses, awards, references and publications in scientific journals.
- Knowledge transfer and promotion of collaboration.
- Acceleration of projects at the scientific forefront.

Research: Productivity and Impact

Indre ApoyoDravet Congress on Dravet Syndrome and Rare Epilepsies Research:

- The reference of rare and complex epilepsies in Spain.
- The place where the whole community involved is gathered around the scientific network INDRE ApoyoDravet.
- Research centers, hospitals, universities and patients' organizations.
- The last congress was held in May 2024 at Universidad Nebrija (Madrid), co-organiser. Next session in 2026.

[Indre ApoyoDravet](#)



Research: Productivity and Impact

Social Research Unit on Epilepsies (Universidad Nebrija – ApoyoDravet)

Scientific research focused on the quality of life of patients and their families.

- Neuroscientists and social researchers.
- New technologies in data collection.
- Internal projects and ad-hoc projects.
- 3 articles, 1 thesis, 1 validated questionnaire.



Research: Productivity and Impact

Artificial Intelligence Unit:

- Projects and activities for the development and innovation of the application of AI in the field of health and social care.
- Under the aegis and expertise of the company GeneticAI.

Patient-oriented technology

- Serious Games Camp (3 editions).
- Information and training Apps. Virtual reality apps.
- Working group (2 universities, 2 companies, 1 consulting firm).
- Data for a cure (advanced patient data management).
- Intelligent Dravet consultation.
- ApoyoDravet virtual assistant for patients and families.
- Promotion and acceleration of technological projects (crisis alert company, crisis monitoring company).
- Trust value: Traceability of donation data.
- Educational living lab.

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Social innovation and collaboration



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Innovation for Efficient Social Intervention

360º support to patients and families

- Guided Information Service.
- Access to studies, programs and clinical trials.

Cognitive enhancement programs:

- Precision Cognitive Evaluation
- Cognitive teleassistance
- Collaborators: Nebrija Cognition Research Center. Impulso Cognitivo, CogniFIT.
- Neuroscientists and psychologists.



Innovation for Efficient Social Intervention

Inclusive Education in Epilepsies Program

- Information and training advice to schools and intervening parties.
- IEAD kits (educational resources, didactic materials, guides...).
- Teacher training.
- Research and technology.



Awareness and Social Activities:

International Dravet Syndrome Day



23 de junio
Día Internacional del síndrome de Dravet

Conéctate a ApoyoDravet

CONCIENCIA Y PLURIFORME COLABORATIVA EN FAVOR A LOS AFECTADOS POR EPILEPSIAS DRÁVET Y SÍNDROME DE DRÁVET.

#yoApoyoDravet
Séctate una foto con el cartel y compártela en redes sociales

apoyodravet.eu
@ @ @ @

Apoyo Dravet
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Awareness and Social Activities:

DravetTzari (Solidarity Dance Project)



Mountain Ambassadors ApoyoDravet



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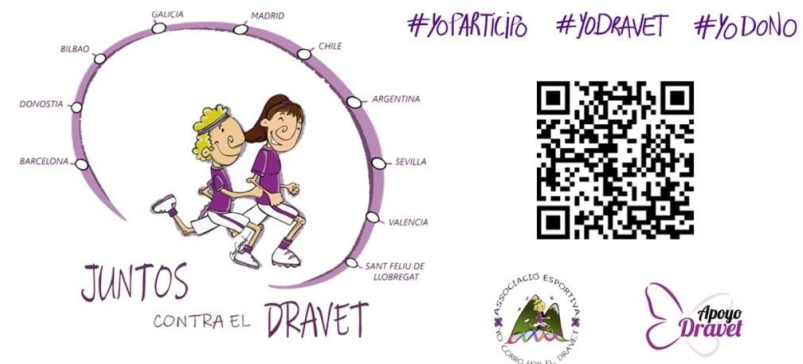


Awareness and Social Activities:

Dravet 2023 Solidarity Run



Solidarity virtual race for research



Collaborative reference

- Vice-presidency of the Spanish Epilepsy Federation (FEDE).
- Member of the Dravet Syndrome European Federation (DSEF).
- Member of Spanish Federation for Rare Diseases (FEDER).
- Collaborative agreements with Fundación Dravet Argentina, Actitud Dravet Argentina, Fundación Dravet Latam, SCN8A Italy...
- Support and management of international scientific projects (collaborating with 5 European patient organizations).
- Collaborative projects with 3 cultural and sports entities.
- In collaboration with País Vasco University on inclusive education projects for the last 3 years.
- Spanish Federation for Rare Diseases (FEDER).

Acknowledgments

- Twice winner of the scientific call of the Spanish Federation for Rare Diseases (FEDER).
- Winner of the technological call of Fundación Quaes.
- Awarded by the Spanish Society of Neurology (Epilepsy category).
- Awarded by Fundación Magtel for social innovation.
- Emprendis Award from the Fundación Ayesa.
- Cited in scientific journal articles and congresses as an example of patient-centered research promotion.
- 41 volunteers, 3 workers, 192 members, 86 affected families.

Always in perpetual motion...

Working on behalf of science, patients and families



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Get involved



- **Become a member.** Not only patients and families affected.
- **Companies.** CSR, donations, sponsorships, agreements...
- **Make your donation.** Solidarity with tax benefits.
- **Become a volunteer.** Contribute your knowledge.
- **Other ways to collaborate.**



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