PRESENTATION OF THE RESULTS
OF THE UNSEEN STUDY

“DRAVET SYNDROME”

D’Unseen
Ethnographic insights
into Dravet Syndrome

BIOCODEX
healthcare with passion and conviction

SUMMARY

PROJECT OVERVIEW 01

In 2024 the laboratory Biocodex launched multi-country ethnographic research about the experiences of families impacted by Dravet Syndrome to understand more about the everyday lived realities of Dravet families. This project was made possible thanks to you.

Your participation in the project was invaluable. Thank you for sharing your experiences with us. Biocodex is working on a scientific publication based on this research, projected for the second half of 2025 and on developing strategies to assist families impacted by Dravet Syndrome. In the meantime, we wish to share here with you the context of the project and some of the study's major findings.

InProcess

The goal of the study was to explore the social context of Dravet Syndrome to **find ways to improve patients' and caregivers' quality of life. To undertake this research, Biocodex hired the strategic design firm InProcess.** InProcess is made up of cultural and medical anthropologists and designers who work together on projects spanning across sectors from transportation, healthcare, consumer goods, and public services.

In this project, we used an **ethnographic approach**, meaning we conducted qualitative research that allowed us to speak with and learn directly from medical experts, patient associations, healthcare experts, and families impacted by Dravet Syndrome.

METHODS AND RESEARCH PARTICIPANTS

02

This study was overseen by a Steering Committee.
The committee members include :
Rima Nabbout*1, Liam Dorris*2,3, Marion Danse*4, Nadine Benzler*5, Nicolas Specchio*6, and Luis Miguel Aras*7.

Our methods included :

- **Desk research and interviews** with medical experts in order to have a foundational scientific understanding of Dravet Syndrome;
- **Interviews with families** in France, Spain, and Italy;
- **Interviews with healthcare centers** in France, Spain, Italy, Germany, and the UK;
- **Interviews with patient associations** in France, Spain, Italy, Germany, and the UK.

In total

44

people were interviewed

(outside of the 2 initial interviews for the foundational scientific understanding).

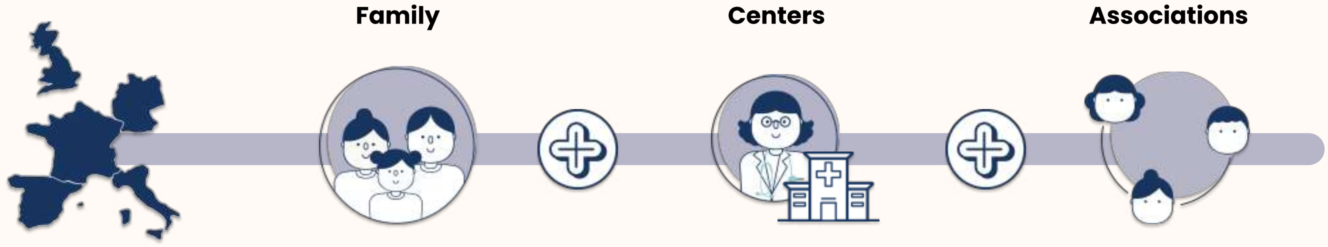
Field study

Fieldwork across 5 countries

Family

Healthcare Centers

Associations



UK
Italy
Spain
France
Germany

5x
1x Italy
1x Spain
3x France

5x
1 per country

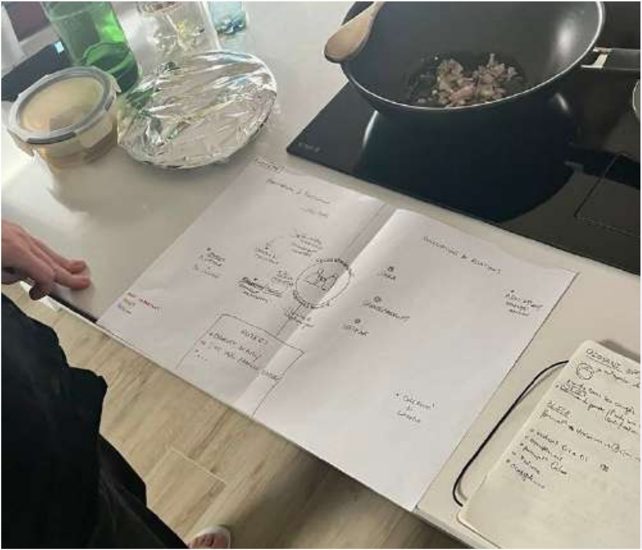
*in Remote for UK and Germany

5x
1 per country

Here is who we spoke with:

Families

5 families (7 parents) with children with Dravet Syndrome ranging in age from 2 ½ to 10 ½. The level of symptoms and disability present varied among the children, with one child having seizures approximately every three weeks and another approximately two times a year. Some children attended mainstream schools, others specialized schools for children with greater disability needs. We spoke with families with a diversity of income levels and families whose geographical distance from their healthcare center also varied.



Associations

We interviewed **16 patients' representatives** from associations in France, Spain, Italy, Germany, and the UK. The associations we spoke with were:

- Dravet Syndrome UK (UK)
- Alliance Syndrome de Dravet (France)
- ApoyoDravet (Spain)
- Dravet Syndrome e.V. (Germany)
- Gruppo Famigle Dravet (Italy)

Healthcare centers interviewed

We interviewed **21 individuals** from healthcare centers in France, Spain, Italy, Germany, and the UK. The healthcare centers we spoke with were:

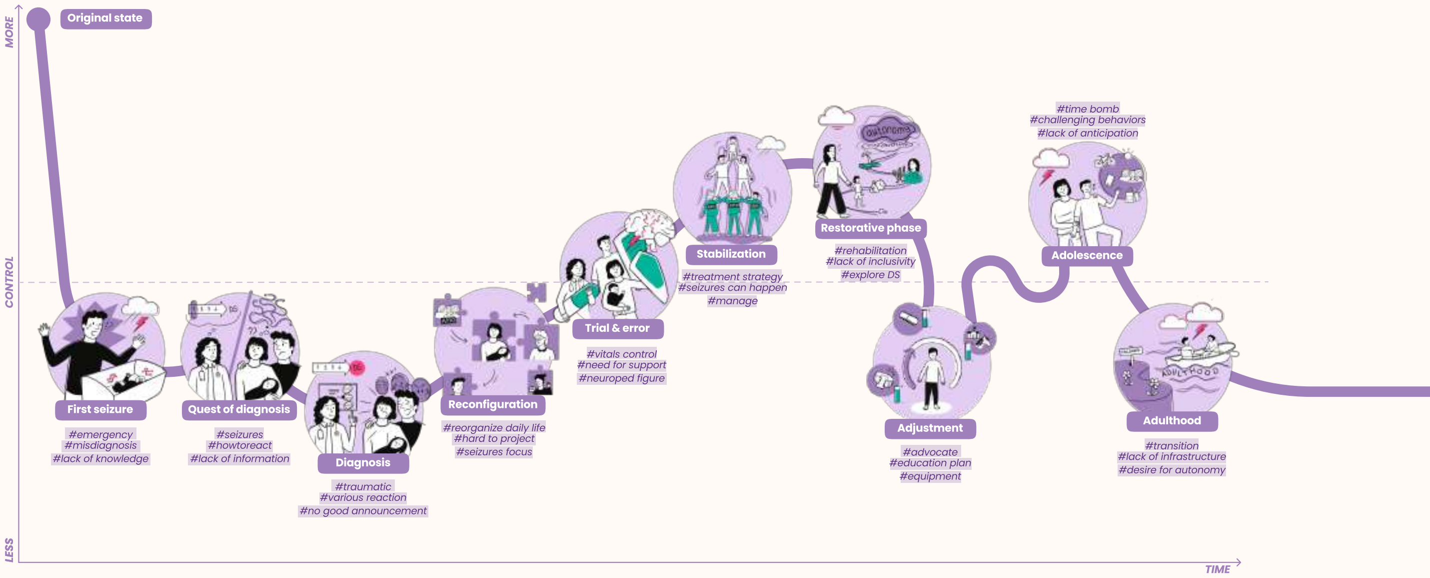
- Great Ormond Street Hospital (UK)
- CHU Toulouse (France)
- Sant Joan de Déu (Spain)
- Epilepsiezetrum Klein Wachau (Germany)
- Ospedale della Donna e del Bambino (Italy)

WHAT WE LEARNED

03

This ethnographic research provided valuable insights about the critical systems of support around families as they navigate a challenging medical journey, the various ways parents relate to their child's medical condition, the factors that can either motivate or prevent families from joining patient associations, and how these associations are similar and different across Europe.

What immediately stood out to us is that despite geographic, cultural, and medical differences among families, all families experience what we call **the emotional odyssey of being a parent of a child with Dravet Syndrome.**



> This **"emotional odyssey"** revealed a previously unseen, holistic narrative, interweaving medical, personal, and familial perspectives, combining the patient's lived experience, the family's emotional journey and the medical journey.

We found that the emotional odyssey begins with a quest for a diagnosis that begins after a child's first seizure.

This search for a diagnosis, which for some families is extremely long and for other families happens relatively quickly, marks the beginning of a period where families feel a near complete loss of control. The announcement of the diagnosis is a traumatic event for parents as it launches families into the world of Dravet Syndrome. In addition to confronting ongoing seizures, there is a massive reconfiguration of family life. Beginning at the moment of diagnosis, families go through a process of reinvention as each parent goes through their own personal journey of accepting their child's diagnosis. Parents are forced to take immediate practical actions without necessarily having the time to process the diagnosis. This can be an extremely difficult period for couples who may process the news differently from each other and who are subjected to enormous stress. It is also a period where the family is launched into a previously unknown medical and social universe, and where the future becomes hard to imagine.

The next stage of the emotional odyssey is a period of stabilization.

Stabilization and restorative phase.

Regardless of how Dravet Syndrome presents in each child, eventually the frequency and intensity of the seizures comes to be considered reasonable and stable by the neuropediatrician. This moment is preceded by the adoption of the right treatment strategy for the particular child in terms of dosage and molecules. Once the right treatment strategy is implemented, caregivers know that seizures can still happen but are better equipped to respond to them. This period marks some sense of stabilisation after the sensation of a **total loss of control** felt during the early days of the illness. This period of relative stability is disrupted when children reach the adolescence stage. As one of the participants in this study remarked, **"adolescence is a powder keg."**

During this period the form of seizures may change, occurring during sleep, for example. Behavioral issues can become more pronounced or appear for the first time. Adolescents can express a **desire for autonomy and defiance** towards their condition and treatment. Our research showed that this step of **the journey is not always anticipated by parents.**

Transition to adulthood

The transition to adulthood is equally challenging for families.

Adulthood implies the **transition to a new medical system**, where a neurologist, specialized in epilepsy but not in behavioral and/or developmental issues, takes charge of the patient. It's a **difficult change** for both caregivers and patients, as patients must move to a new healthcare center. As the child reaches adulthood this confers a new legal status. In France, for example, parents must put their child under a legal guardianship so that the child will be covered under France's welfare system.

Another challenge is **the lack of adapted infrastructure** for adults with Dravet syndrome. This is a struggle for parents who must find the right structure years in advance. Knowing that **their child will want to experience autonomy** - and that they will not always be around to care for them, parents may decide to invest in local projects to create those structures.

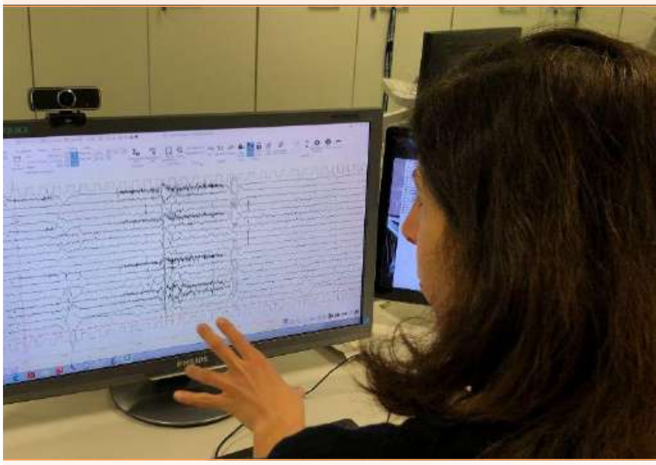
---

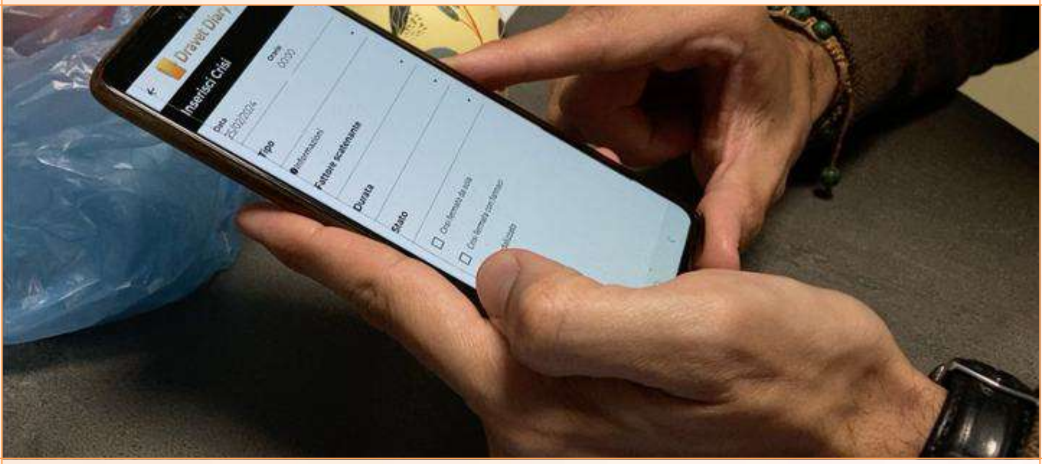
[1] Para la cita exacta: «adolescence is a powder keg», trad. lit. «la adolescencia es un polvorín»

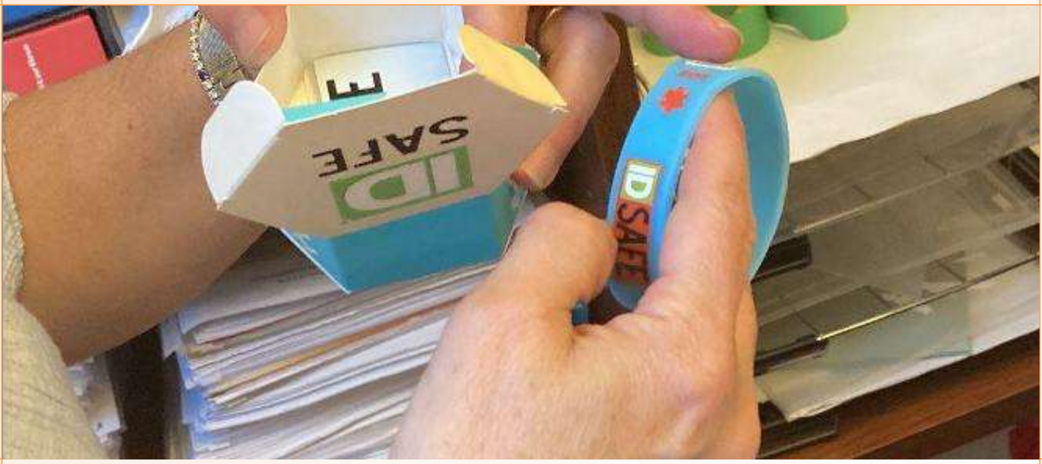
Parents’ Relationship to Dravet Syndrome and Importance of Ecosystem

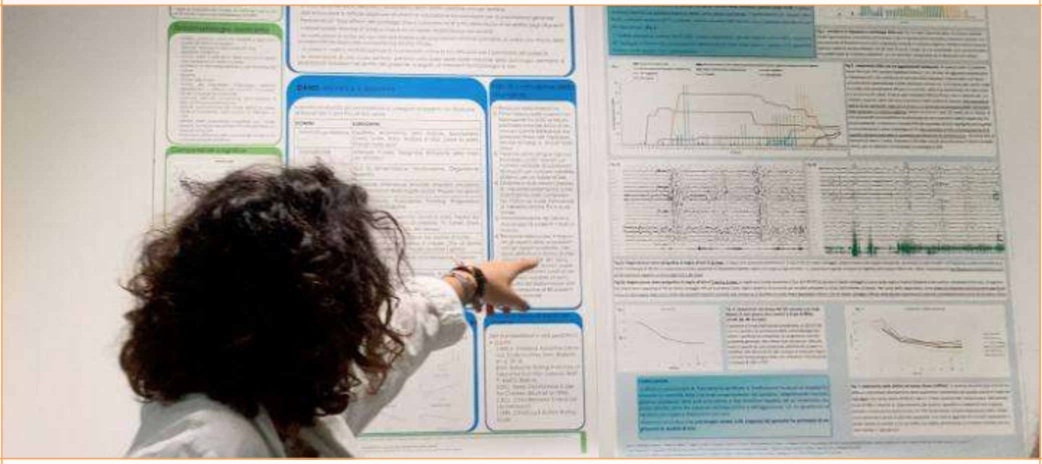
We found that parents relate to Dravet Syndrome in a variety of ways and that this positionality directly impacts the unique ecosystem of support parents must create and facilitate for their child’s specific needs. There are parents who seek out as much medical and other information as possible on Dravet Syndrome, sometimes in an attempt to gain control over the situation. On the other extreme are parents who feel lost at sea in an overabundance of information and prefer to cede as much control as possible to experts. How parents relate to their child’s diagnosis impacts the size of their ecosystem, with the ecosystem increasing in size the more parents become experts on the way the condition manifests in their particular child.

The core actors in all families’ ecosystems are Dravet Syndrome specialists, i.e., **the child’s medical team:** the neuropediatrician, neuropsychiatrist for some, specialized nurses, and emergency medical team; and above all the **family itself.** The internet—often a first sources of information for parents is a key part of the ecosystem for many, as are local institutions. Larger ecosystems include numerous actors outside the core medical team, including physical therapists, speech therapists, alternative therapeutic specialists, as well as patient associations. Of course, parents’ positionality towards Dravet Syndrome and their ecosystems are not fixed and can, and often do, change overtime.




Dravet Diary
Inserisci Crisi
Data
Ora
Tipo
Fattore scatenante
Durata
Stato


ID SAFE
ID SAFE



There are various motivations and constraints that parents face in joining and staying involved with associations

In our conversations with parents and patient associations we learned that there are many motivating factors that lead parents to join Dravet Syndrome associations, as well as factors that can prevent families from approaching associations:

Motivations for joining associations include:

A desire to not feel alone

01

"You realize, hey, you're not so alone with all your problems, all your questions, all your fears, worries" *– Participant from the study*

A desire to feel understood by people who are having similar experiences

02

"They're trustworthy, reliable people, and they're people who make your day-to-day life easier, because you don't have to explain. Nobody around me understood, not enough anyway, in my opinion." – Participant from the study

Socialisation

Having a child with Dravet Syndrome can be isolating. Joining an association is a way to meet new people who already understand.

03

"I'm too sociable to stay in my corner and so I... Yes, I needed to meet people who were going through the same thing as me."
– Participant from the study

Access to support, equipment and information

An association can provide access to people, events, and scientific studies.

04

"Often, parents are already aware of the latest developments and treatments... Information flows well among families, especially through associations, which allows them to be well informed." *– Participant from the study*

Factors that prevent families from joining associations:

01

Comparison

Some parents resist joining an association because they don’t want to compare their child and their experiences with others.

"It took a long time to sign up because I didn't really feel like meeting other parents [...] I was worried that I would meet parents there who would simply show me everything about how bad my child could be in the future." – Participant from the study

02

A desire to avoid life revolving around Dravet Syndrome

Some caregivers worry that joining an association will prevent their families from spending time on or focusing on things other than Dravet Syndrome.

"I think that being in it all the time, making friends, being surrounded by Dravet, I couldn't. It would always be the same topics. (...) Now we enjoy the moments, you see, this summer there was no seizure, so we didn't want to hear about Dravet anymore.” *– Participant from the study*

03

A lack of legitimacy

Some parents feel a lack of legitimacy, either before the diagnosis is made, or over the course of the illness if they feel they are experiencing a different reality from others, for example fewer seizures or different comorbidities than others.

“And at the same time, I find that when you talk to other parents with older children who don't talk, who don't go to school, who have crises every day, who don't have a social life, I don't want to talk too much about my daughter and say, well yes, she goes to school.” *– Participant from the study*

04

Not ready to accept the diagnosis

Joining an association involves being ready to accept the condition of your child, which can take time for some people.

“I don't think everyone can accept this illness. (...) Well, I see the father of my children. He doesn't accept the disease, he didn't join the association. As a result, he has no information about anything, really.”

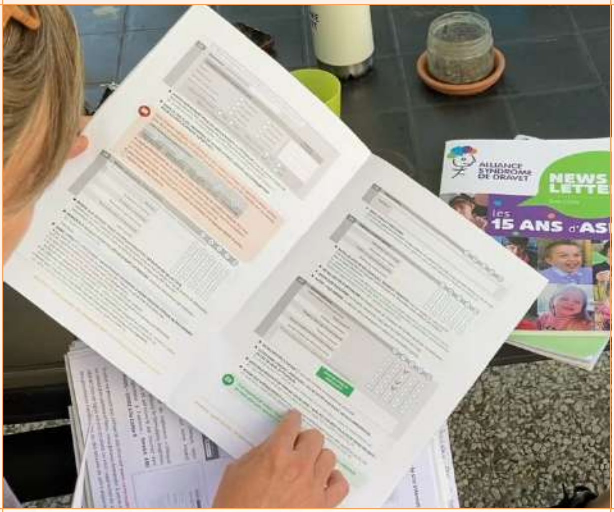
Similarities and differences among associations

All the associations interviewed are dedicated to providing practical and emotional support to caregivers as well as being a place where caregivers can find reliable information about Dravet Syndrome.

Some associations also provide financial support for low-income families like Dravet Syndrome UK and Alliance Syndrome de Dravet.

Some associations have a specific focus on raising public awareness of Dravet Syndrome. DRAVET-Syndrome.V., for example provides trainings for neurologists and pediatric neurologists, while others are deeply engaged in generating scientific research on the illness like Gruppo Famiglie Dravet, Dravet Syndrome UK and Apoyo Dravet. Most associations, with the exception of Gruppo Famiglie Dravet do not have physical offices.

We also learned that across Europe, associations generally have little contact with each other despite the fact that there is a desire for increased communication and connection among the associations.



CONCLUSION

04

Thanks to your participation in this ethnographic study, information about the experiences of families of children with Dravet Syndrome was collected. This research will be invaluable for developing strategies to assist families impacted by Dravet Syndrome and supporting healthcare professionals.

To that end, we have identified **four key themes that we would like to address based on our research findings:**

Once again, we wish to extend our gratitude to you for speaking with us, inviting us into your homes, and sharing your family experiences with us. We are deeply grateful. As mentioned, a scientific article with additional data is under preparation and we are looking forward to being in touch with you for the official publication!

01 ***The needs of families at the moment of diagnosis.***

02 ***The accessibility of scientific information about Dravet Syndrome.***

03 ***The education of the general public about epilepsy and seizure so that kids and families experience less stigmatisation.***

04 ***Preparation for the future and adulthood with Dravet Syndrome.***

Steering committee

1. Department of Pediatric Neurology, Hôpital Necker-Enfants malades, APHP, Paris, France ;
2. The Paediatric Neurosciences Research Group, Royal Hospital for Children, Glasgow, UK ;
3. School of Health and Wellbeing, University of Glasgow, Glasgow, UK ;
4. Department of Pediatric Neurology, CHU Hôpital, Robert-Debré, APHP, Paris, France; Expert Center for Rare Epilepsies, CHU Hôpital Robert Debré, APHP, Paris, France ;
5. Association Dravet-Syndrom e.V, Frankfurt, Germany ;
6. Clinical and Experimental Neurology, Full Member of European Reference Network EpiCARE, Bambino Gesù Children's Hospital, IRCCS, Rome, Italy ;
7. Chairman of SC, and Dravet syndrome European Federation, Paris, France

D'Unseen
Ethnographic insights
into Dravet Syndrome

BIOCODEX
healthcare with passion and conviction