

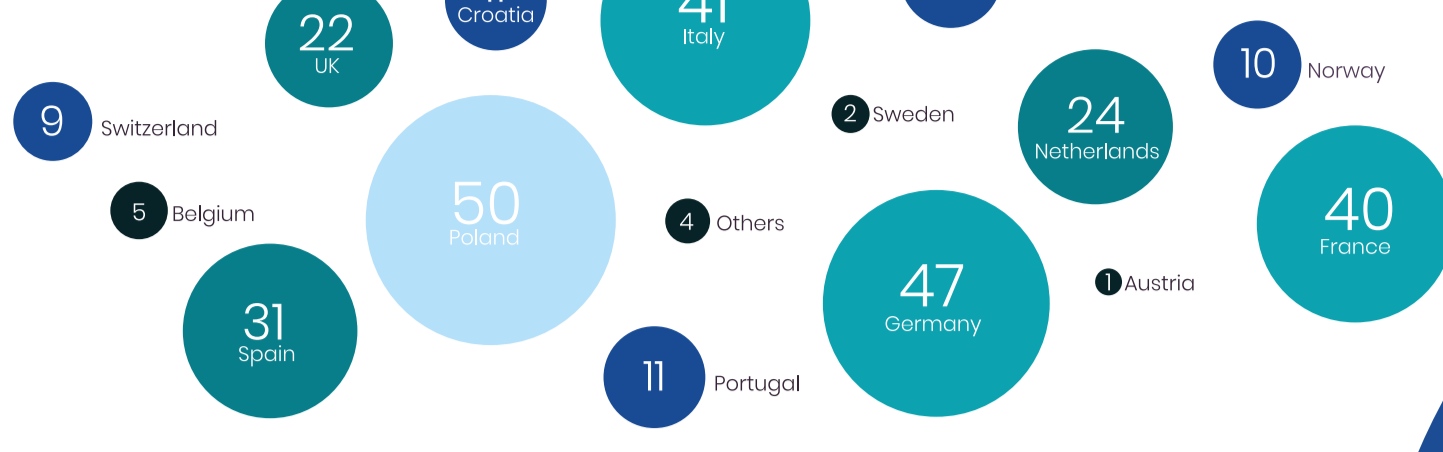
VACCINATION IN DRAVET SYNDROME

an European Survey

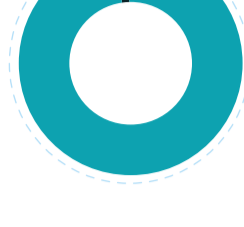
319
RESPONSES
for the
vaccination
survey



1. Analysis of the responses



2. Clinic and genetic diagnosis of responders



98% (314 people)
Diagnosis of Dravet Syndrome

2% (5 people)
Not sure yet

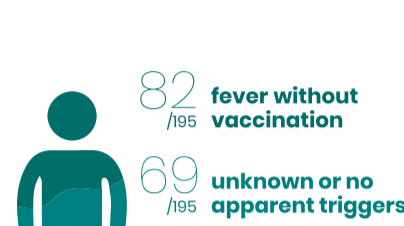
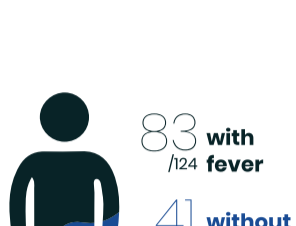
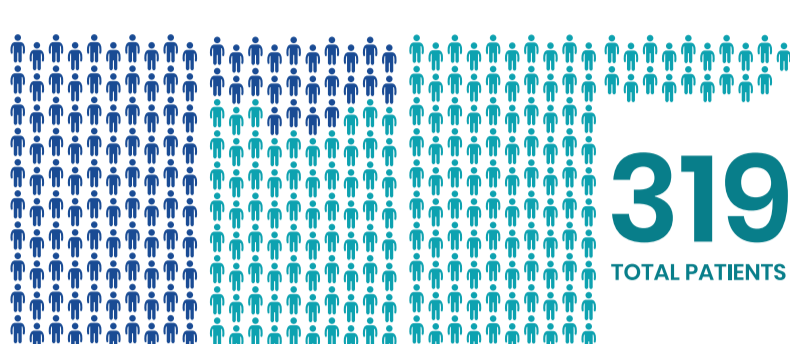


93% (297 people)
SCNA1 mutation

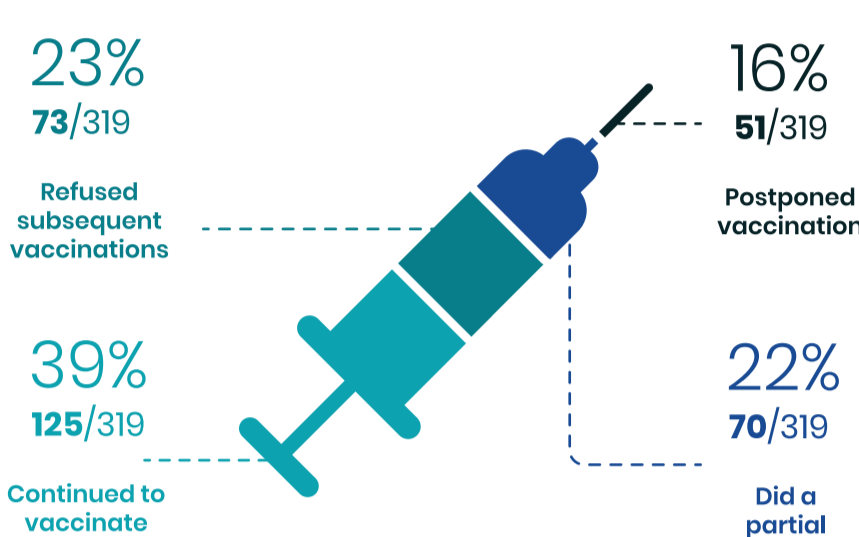
4% (13 people)
No mutations found

3% (9 people)
Other mutations

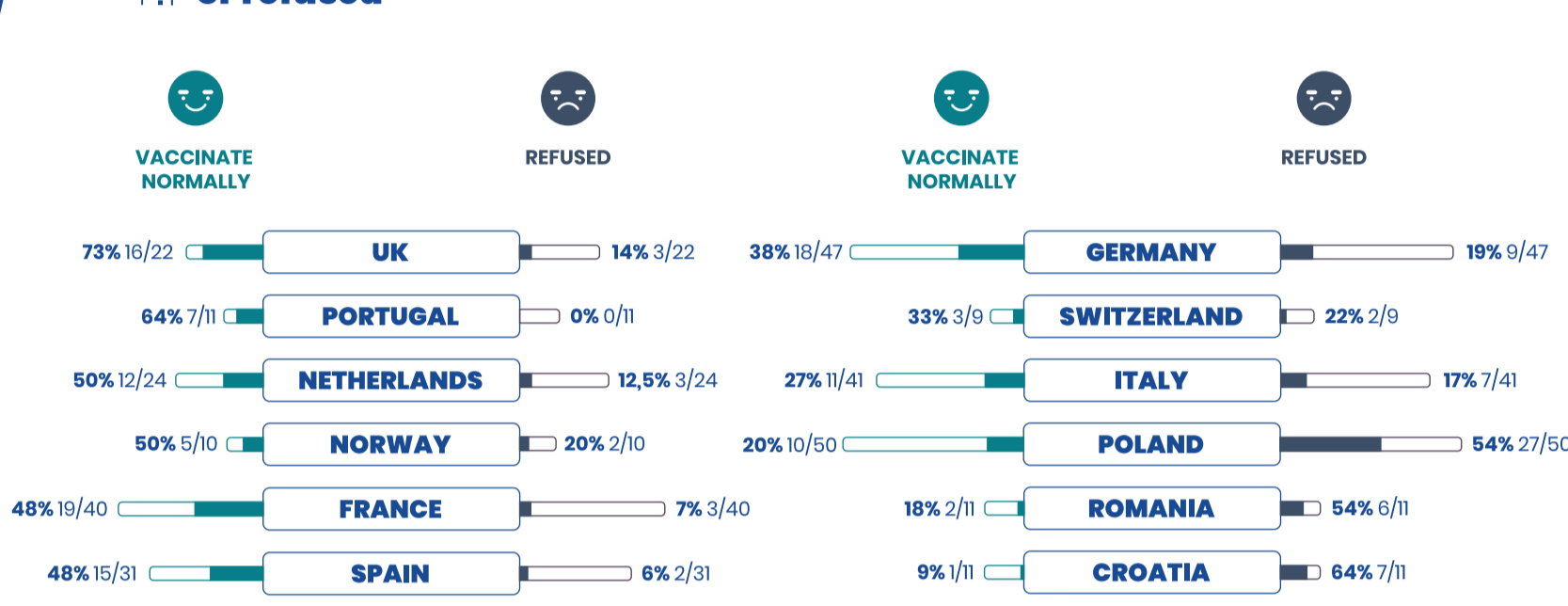
3. Occurrence of first seizure event



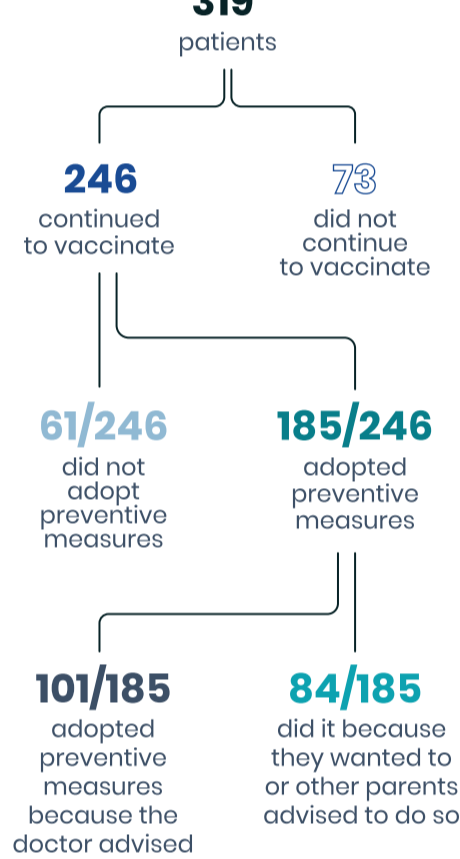
4. Behaviour after 1st vaccination



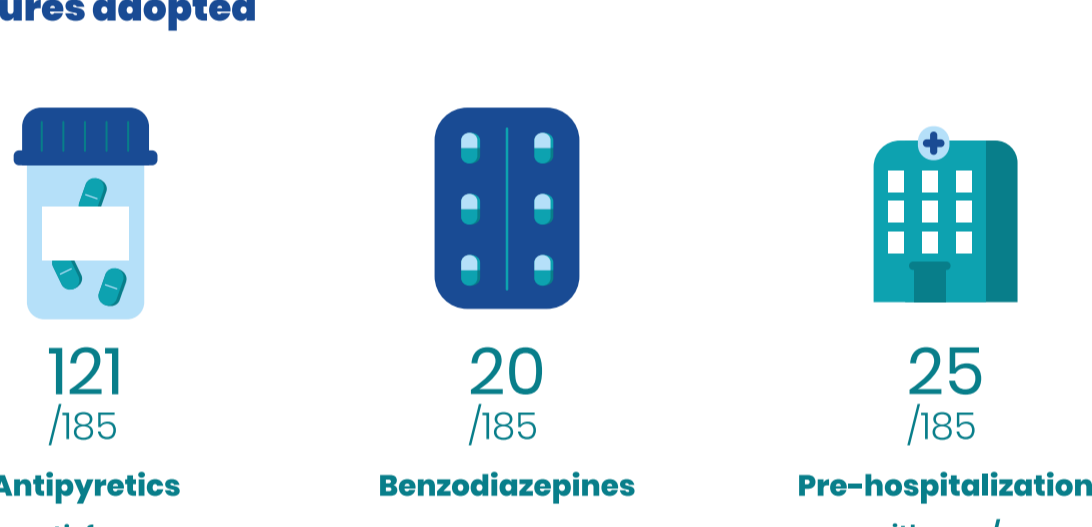
4.1. Vaccinate normally or refused



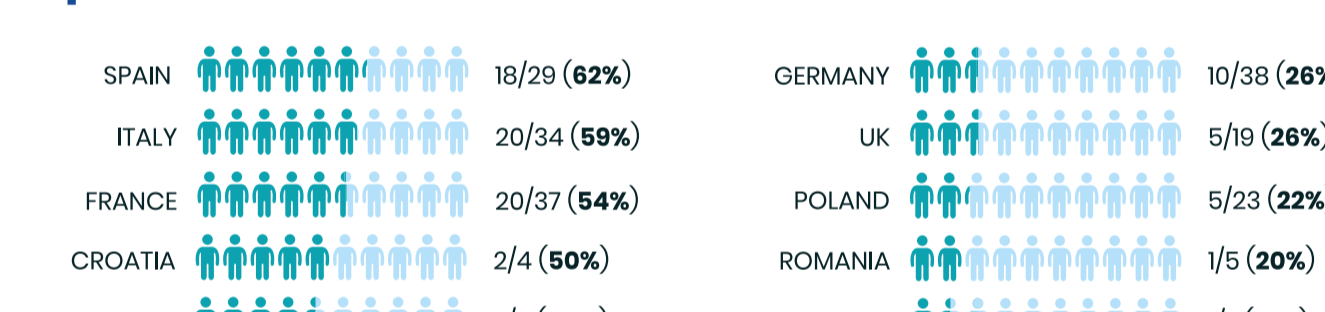
5. Preventive measures



5.1. Major preventive measures adopted



5.2. Advised by doctor to adopt preventive measures



Final remarks

1. Triggers of first seizure onset

Responders to the survey associated the onset of the first seizure with several triggers. In 39% of cases (124 patients out of 319), responders reported a correlation between vaccination and the first seizure. Among those cases (first seizure correlated to vaccination), 83 patients out of 124 also reported fever. However, the correlation between vaccination and the first seizure may be overestimated by parents because, in about 10% of cases they occurred 8-28 days after vaccination revealing a weak casual relationship as the only vaccines for which 15 days of delay could be reasonable is MMR, which is not used in the age group when the first seizure occurs. Even considering this overestimation, it results that seizure onset in subjects with DS is triggered by vaccination in about 29% of the cases, in agreement with the literature data (20 to 30%).

2. First seizure onset should lead to the interruption of the schedule?

Because many parents either refused to complete or made a partial vaccination schedule for their kids, only 55% of responders is really protected by vaccination, including 16% of persons who postponed the vaccination. Having had a seizure at the time of the first vaccination should in no case lead to the interruption of subsequent immunizations. Vaccines protect children from infections that may themselves cause fever (and thus seizures). It is important to know that, according to related scientific studies, vaccination-related seizures do not modify the outcome of the disease (McIntosh et al. 2010, Zamponi et al. 2014).

3. Which are the most commonly precautions adopted?

The most commonly used precaution to avoid febrile episodes after vaccination, by parents, is preventive treatment with antipyretics (to be taken in conjunction with vaccination).

4. Which precautions can be adopted?

In children with suspected and/or confirmed Dravet Syndrome diagnosis, if live inactivate and some attenuated and recombinant vaccines are administered, which can give reactions within 24-48 hours after the shot, it would be a good practice to administer the vaccine during a hospital admission. In all cases, parents have to be ready to control fever and to manage emergency treatment for prolonged seizures (to be prepared to stop seizures).

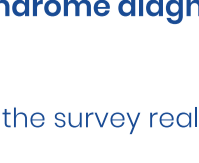
5. Should doctors advise parents about precautions to take?

Doctors may give more guidance on using preventive measures to reduce febrile events. Especially in some countries this may not be done enough (see point 5.2).

Emerging requests to scientific community

1. Prospective studies of vaccination related seizures in DS and other early onset encephalopathies
2. Establish a time frame for preventive measures for each vaccination type in patient with Dravet Syndrome diagnosis
3. Determine best preventive options in patient with Dravet Syndrome diagnosis

Data from the survey realized in 2018.



www.dravet.eu