



<sup>1</sup>Dravet Italia Onlus, Affi (VR) Italy; <sup>2</sup>Dravet Syndrome European Federation, Brest, France; <sup>3</sup>Associazione Famiglie Lennox-Gastaut Italia Onlus, Bologna, Italy, <sup>4</sup>Federazione Italiana Epilessie, Milano, Italy; <sup>5</sup>Centro Ricerca Epilessie in età Pediatrica, Verona, Italy

## INTRODUCTION

The European Federation of Dravet Syndrome with Dravet Italia Onlus, Associazione Famiglie Lennox-Gastaut Italia Onlus, Federazione Italiana Epilessie and Centro Ricerca Epilessie in età Pediatrica, has promoted a short and simple questionnaire in order to evaluate the impact of falls arising from seizures associated with the different forms of epilepsy.

## GOALS

- Generate a new evidence base to aid our understanding of the incidence of falls in patients with epilepsy.
- Enhance the data comprehension in order to start ventures aimed at the research of protection systems focused on improving quality of life for patients with drug resistant epilepsy.

## METHODS

An online survey collecting anonymous data, open from 12<sup>th</sup> May to 31<sup>st</sup> October 2017, composed of 21 questions relating to:

- epilepsy type
- age of person affected by epilepsy
- type of fall during seizure
- helmet use
- interest in having a head protection system in case of an epileptic fall

The survey was completed both by patients affected by epilepsy that fall during or after a seizure, and by those who do not, but only those who reported falls were taken into consideration.

The attendees were recruited by mail, through Facebook and Twitter, and, in Italy, via posters displayed in the various expertise centres.

The survey was translated into English, Spanish, Portuguese, French, German, Italian, Croatian, Romanian and Dutch. All the translations were verified by local operators before the launch of the survey itself.

## THANKS TO:

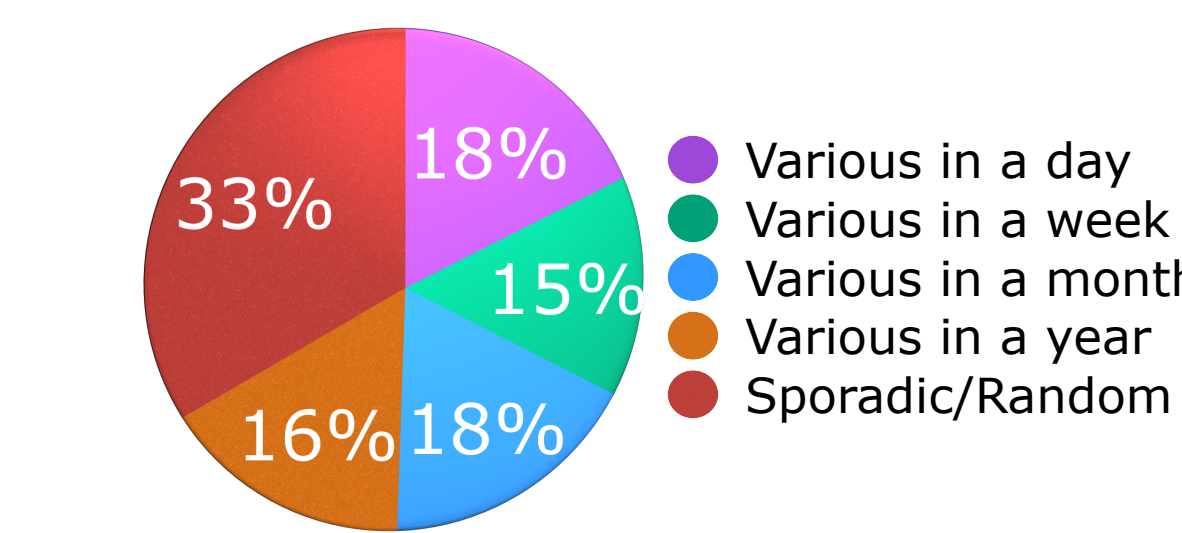
The authors would like to thank all those who responded to the survey. The authors would also like to thank the European Federation of Dravet Syndrome members, the Associazione Famiglie Sindrome Lennox-Gastaut Italia Onlus members, the Federazione Italiana Epilessie members, and the Dravet Italia Onlus members for the preparation, correction and translation during the preparation of the survey material and for the dissemination of the campaign.

## RESULTS FROM PRELIMINARY DATA

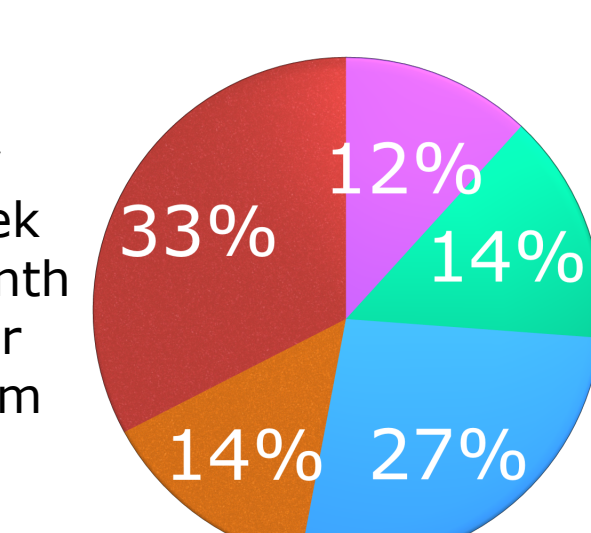
### Iteration

- The daily and weekly rate of violent falls in respondents who answered the question was 33% (154), while the daily and weekly rate of falls during a convulsion was 26% (128).

**"SUDDEN AND VIOLENT" falls**  
Tot. Pt = 465



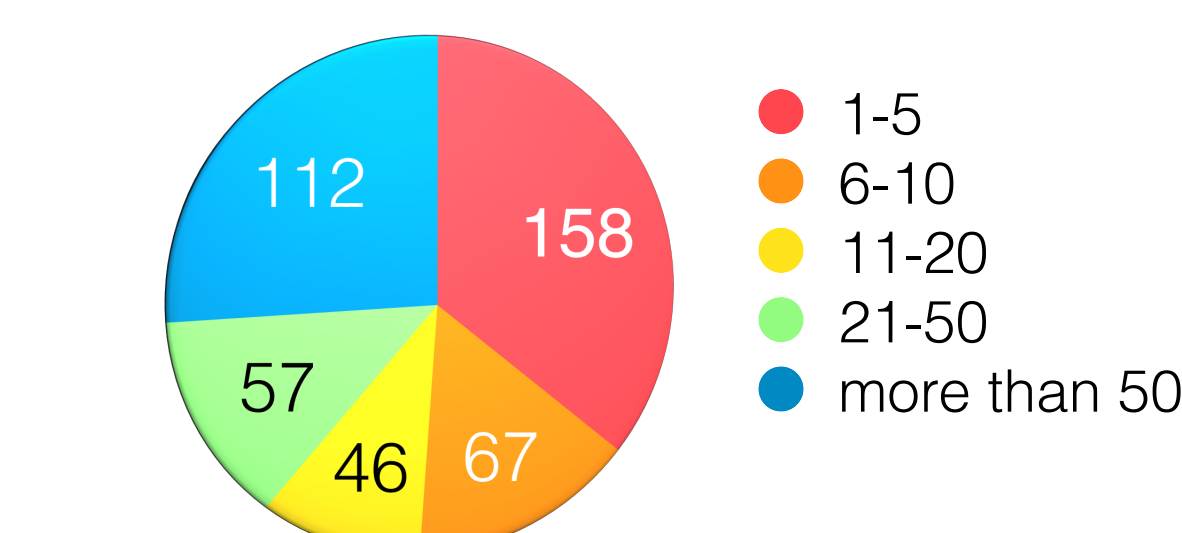
**"CONVULSIVE SEIZURES" with falls**  
Tot. Pt = 493



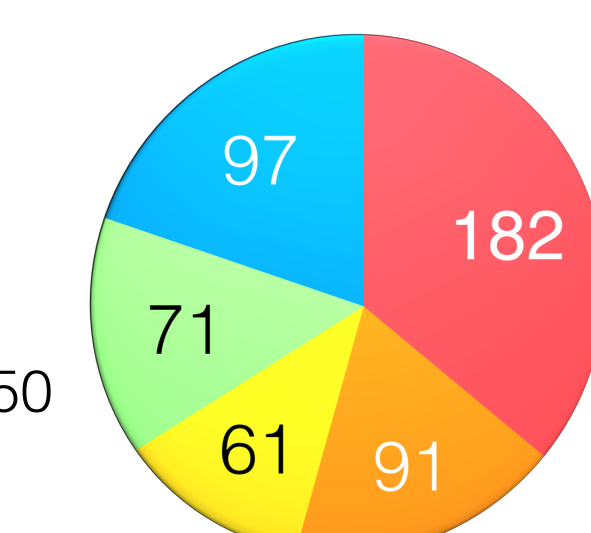
### No. of seizures during a year

- 25% (112) have more than 50 violent falls in a year.
- 38% (170) have from 6 to 50 drops in a year.
- 35% (158) dropped from 1 to 5 times in a year.

**"SUDDEN AND VIOLENT" falls**  
Tot. Pt = 440



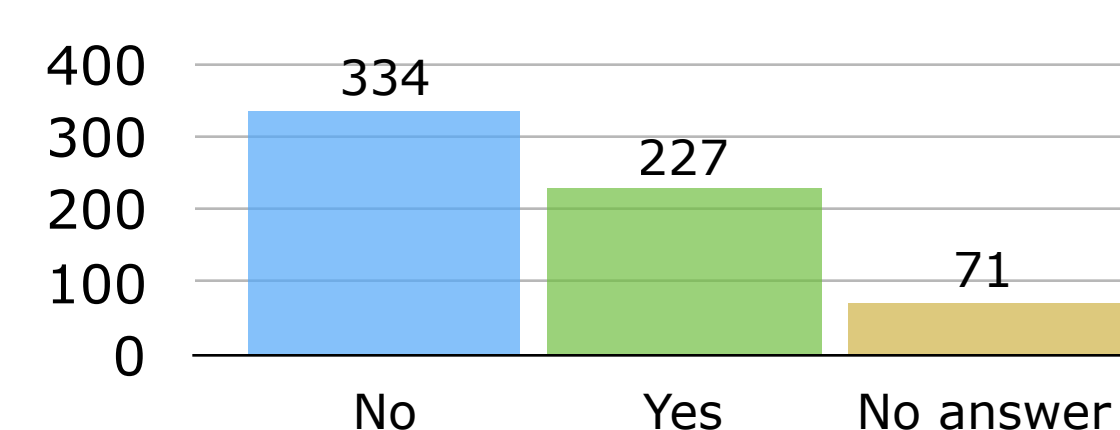
**"CONVULSIVE SEIZURES" with falls**  
Tot. Pt = 502



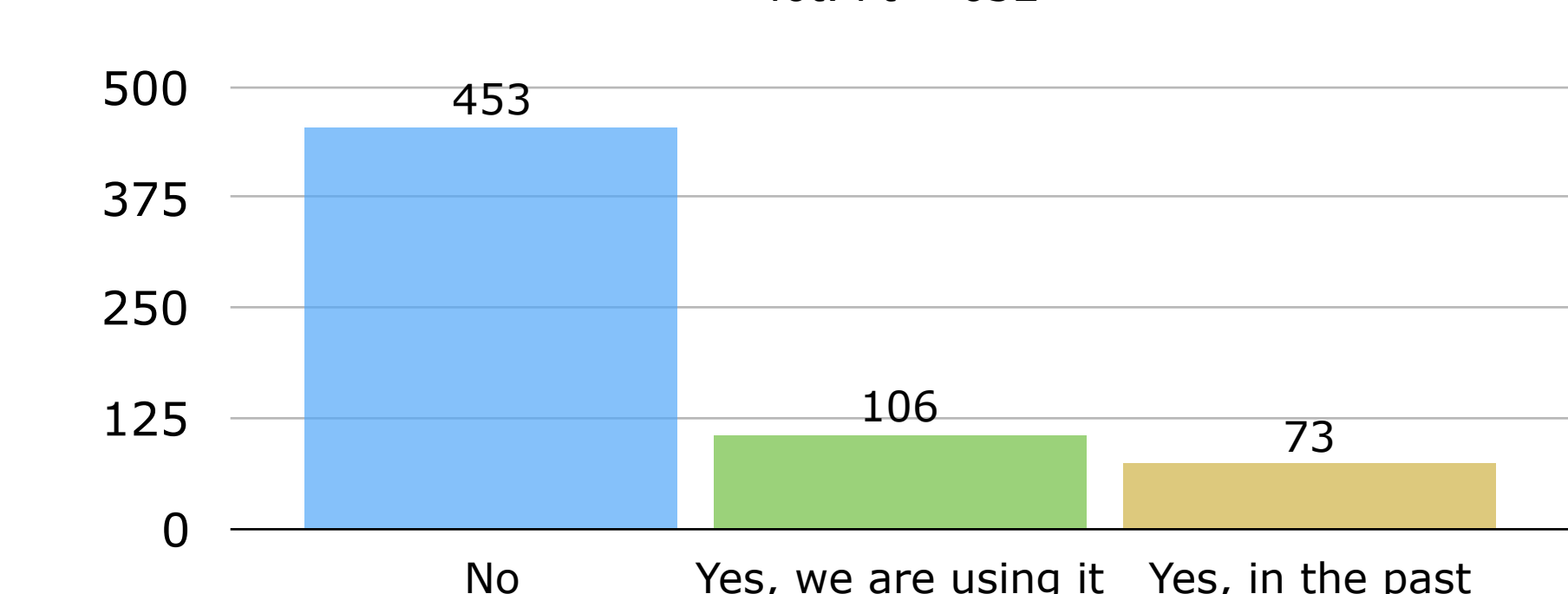
### Helmet

- Only 36% considered the use of the helmet
- The helmet is only used by 17% of patients.

**CONSIDERATION OF HELMET USE**  
Tot. Pt = 632

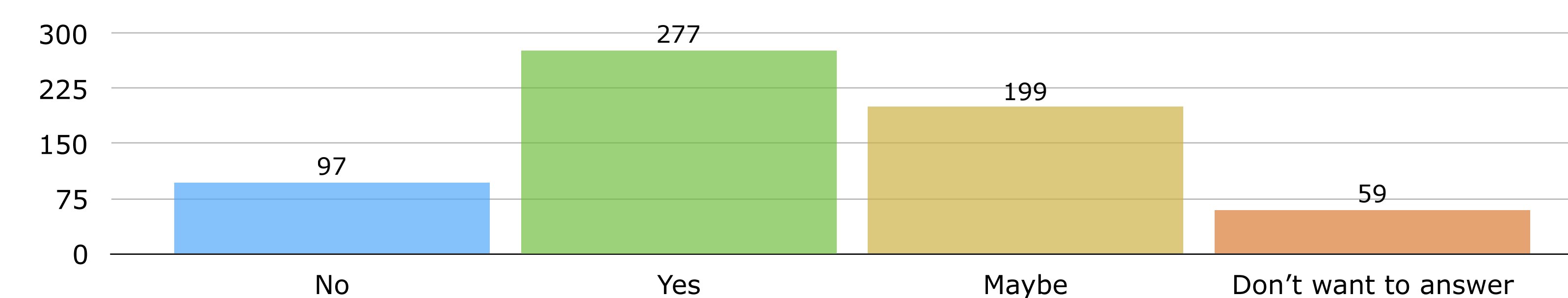


**HELMET USE**  
Tot. Pt = 632



### Interest in a system such as an AIR-BAG or other system in order to PROTECT the head in case of epileptic fall

- 75% of patients expressed interest in a fall protection system.



## CONCLUSION

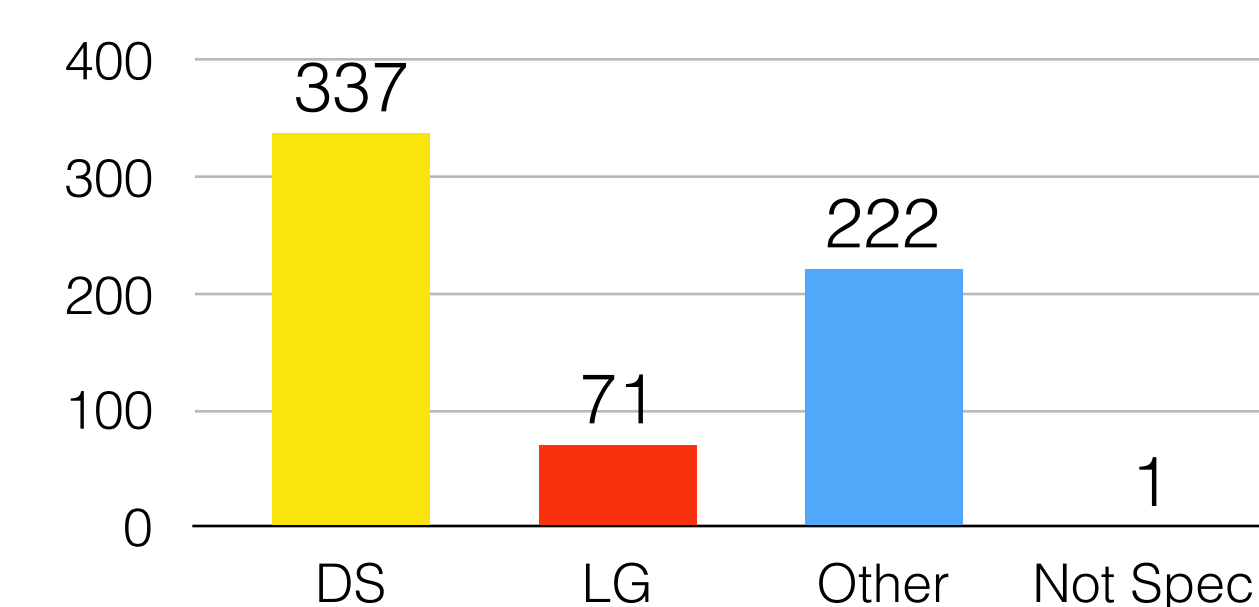
- Expected closure of European Survey: 31<sup>st</sup> October 2017
- Start of data analysis: 1<sup>st</sup> November 2017

### Demographics

- 632 fully completed surveys were submitted (50% from Italy, 12% from France, 6% from Germany, 5% from Romania, 4% each from the Netherlands, the UK and Brazil, 3% each from Portugal and Croatia, 2% from Belgium and 1% from all other countries).

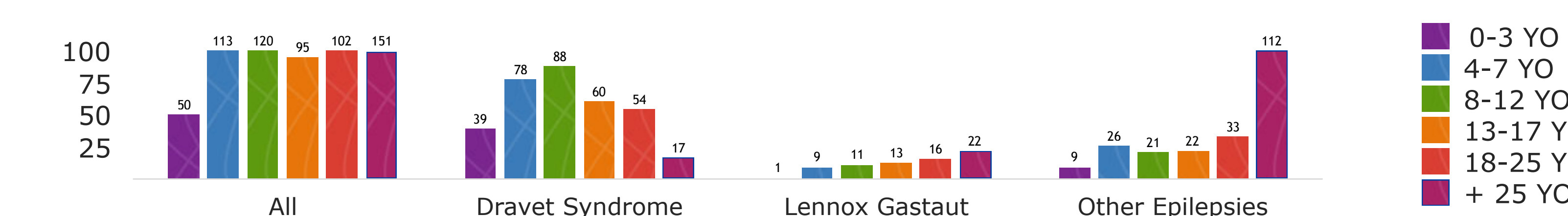
### Epilepsy type

- 337 patients were affected by Dravet Syndrome, 71 by Lennox Gastaut Syndrome, 222 by other Epilepsy and 1 was not specified.



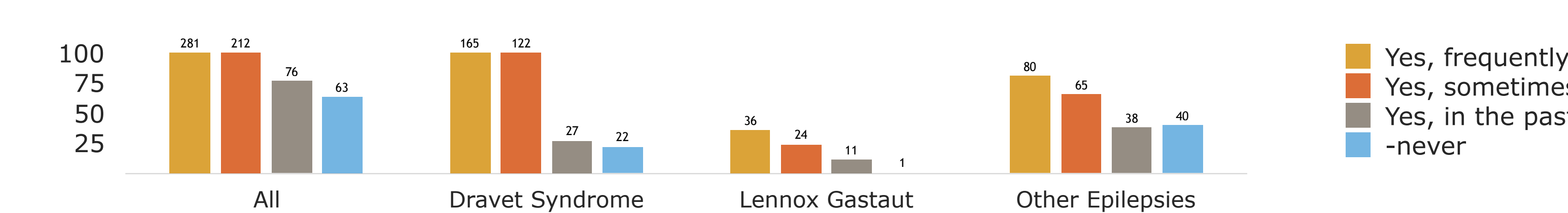
### Age of person affected by epilepsy

- The population is quite heterogeneous except in the case of "other epilepsy" where there is a high proportion of adults (50%).



### Falls during a seizure

- Falls were reported in 281 out of 632 responses (44%) and fallbacks in 212 responses (33%).



### Fall type

- 289 (36%) subjects had violent falls, and 453 (56%) subjects fell during a seizure. Analysing violent falls, 315 patients (46%) dropped from a tone increase, 121 (18%) tone drops, and 247 (36%) did not specify the type of reaction.

