

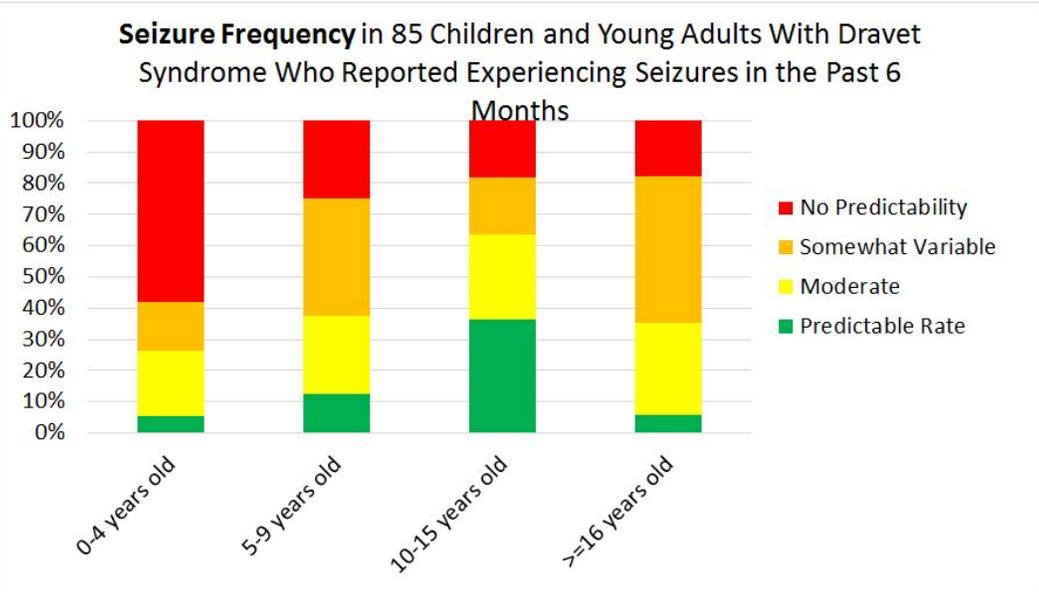
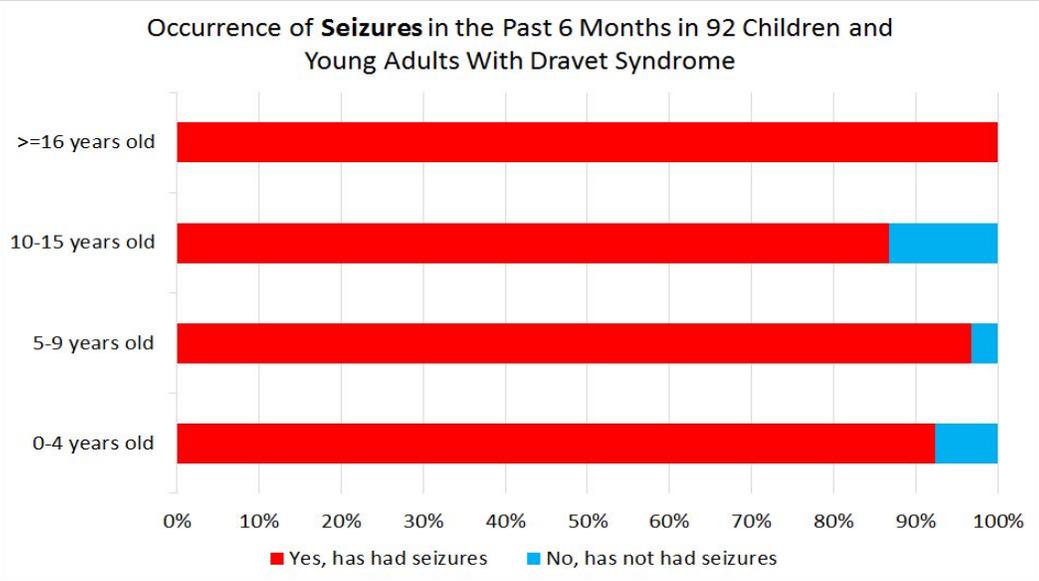
Dravet Syndrome Natural History Results

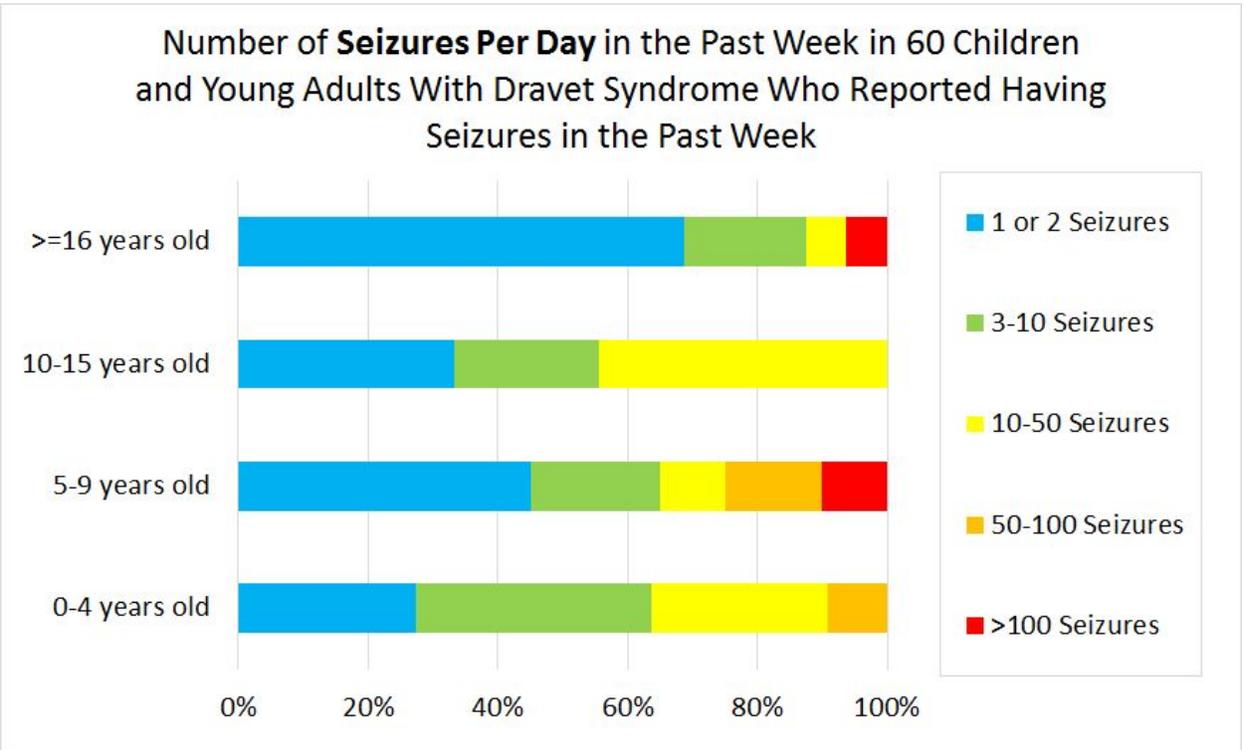
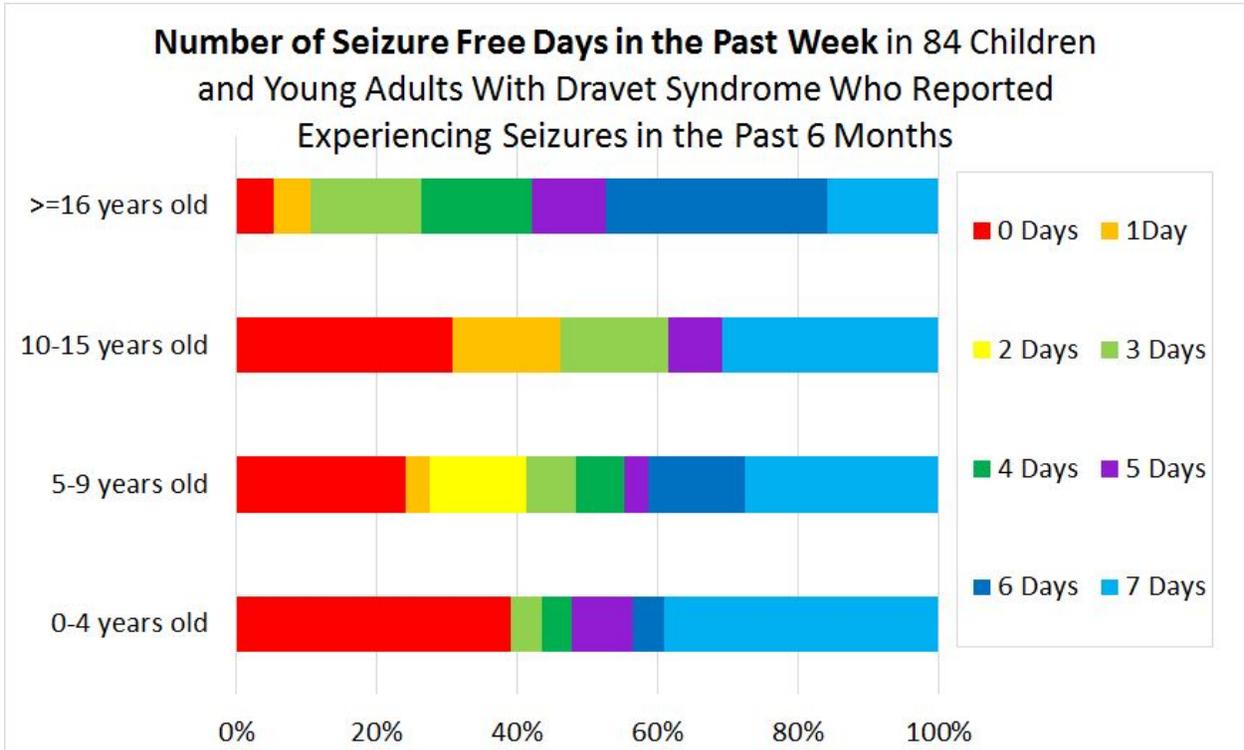
Seizure History by Age Group

Thank you to everyone who participated in the Early Life Epilepsy Natural History Study. Below are some preliminary results that we have collected so far. So far, about **100** Dravet parents have registered in the study. **27** have a child age 0-4, **32** have a child age 5-9, **15** have a child aged 10-15, and **23** have a child aged ≥ 16 . **We will release more information as more information continues to come in!**

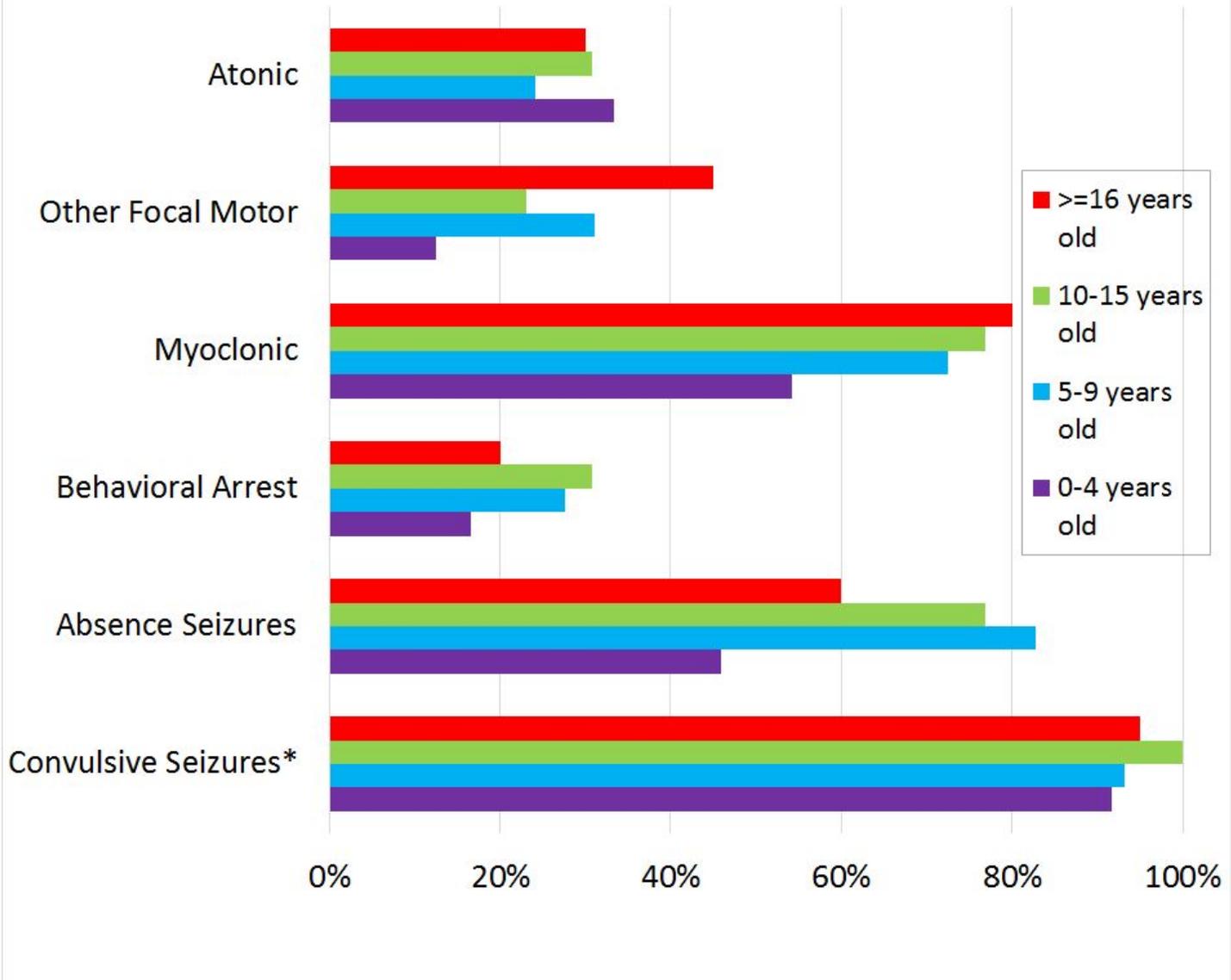
Seizure History

[A large majority of children with Dravet syndrome reported having seizures recently, regardless of age]





Occurrence of **Seizure Types** in the Past 6 Months in 86 Children and Young Adults With Dravet Syndrome



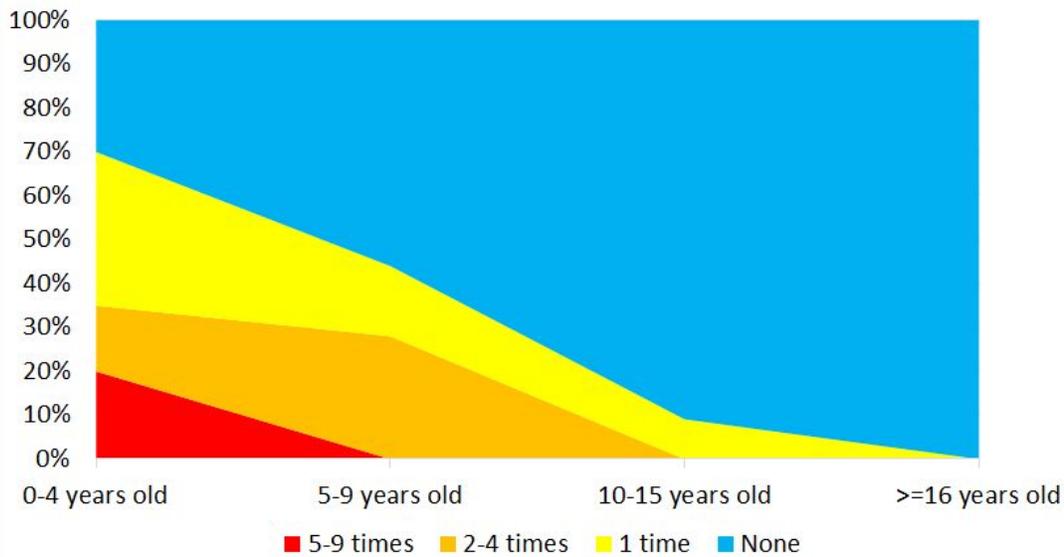
* Convulsive seizures represent anyone who reported that their child had hemiconvulsions (63%), bilateral tonic seizures (37%), bilateral clonic seizures (28%), or bilateral tonic-clonic seizures (88%).

[At least 95% of respondents reported that their child had at least one convulsive seizure in the past six months, regardless of age.]

[There is no evidence to suggest that any seizure types varied by age.]

Rescue Medications and ER Visits

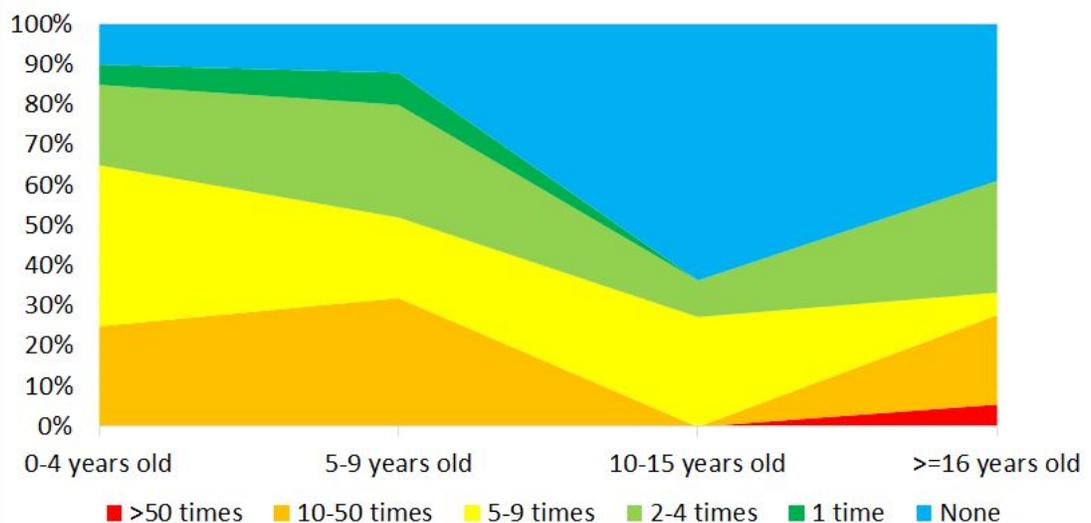
Occurrence of **Visits to the ED for Prolonged Seizures** in the past 6 Months in 74 Children and Young Adults with Dravet Syndrome who Reported Having Seizure in the Past 6 Months



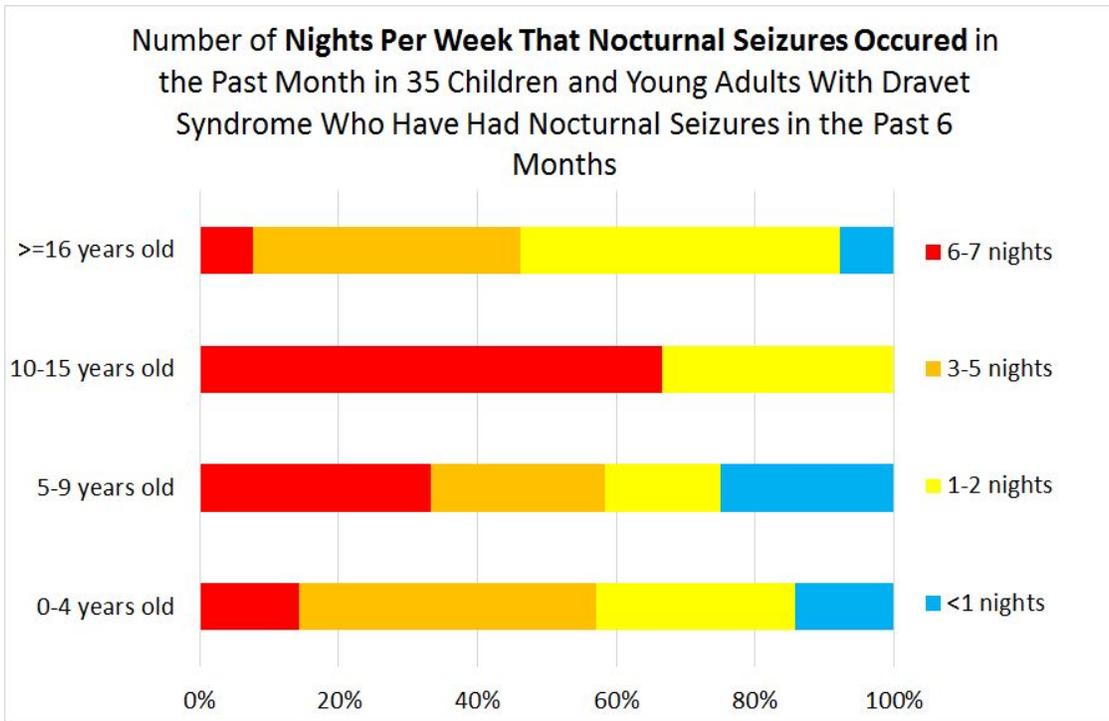
[Younger children appear to be going to the emergency room more often for prolonged seizures and older children appear to be using more rescue medications.]

[There were fewer respondents in the 10-15 year old category, therefore those results are less reliable. We would like to capture more participants in this age range in the next phase of the study.]

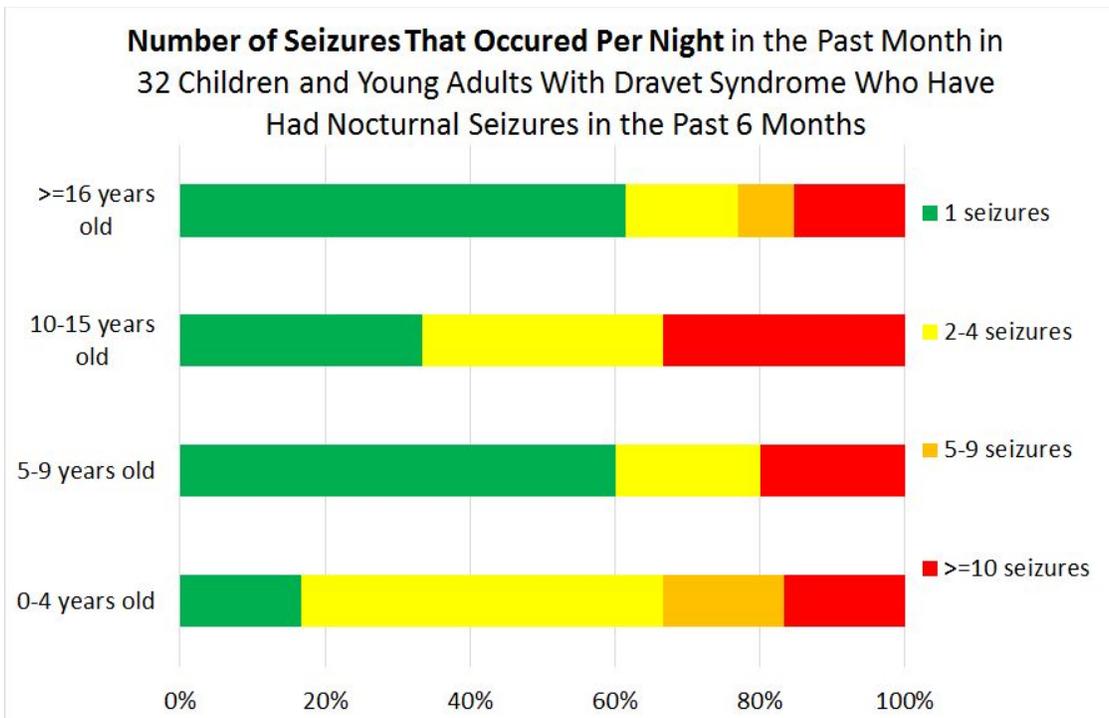
Occurrence of the **Use of Rescue Medications** in the past 6 Months in 74 Children and Young Adults with Dravet Syndrome who Reported Having Seizure in the Past 6 Months



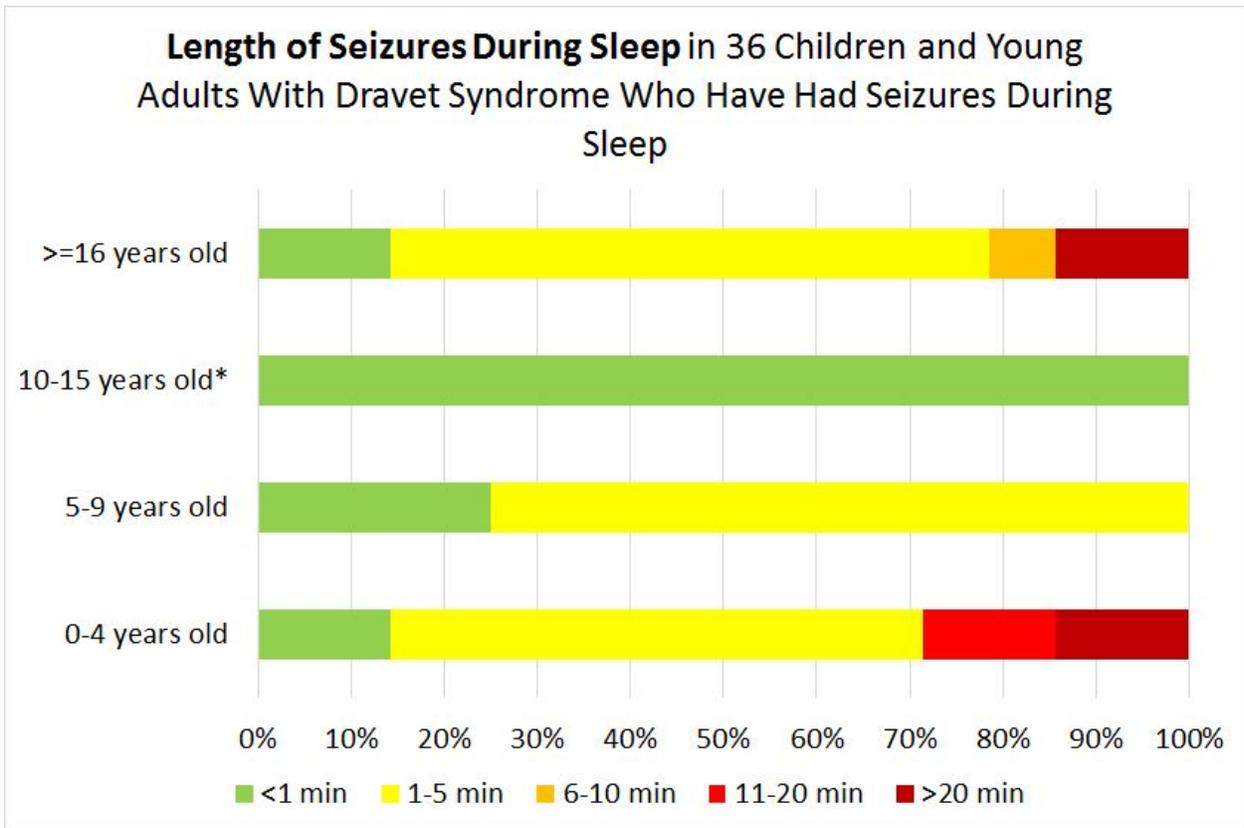
Seizures During Sleep



[Children with Dravet Syndrome, regardless of age, are experiencing seizures during sleep.]



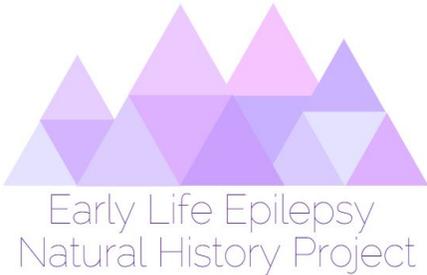
[When children with Dravet have seizures during sleep, most have between 1 and 4, however 19% have more than 10 seizures per night.]



*There were fewer respondents in the 10-15 year old category, therefore those results are less reliable.

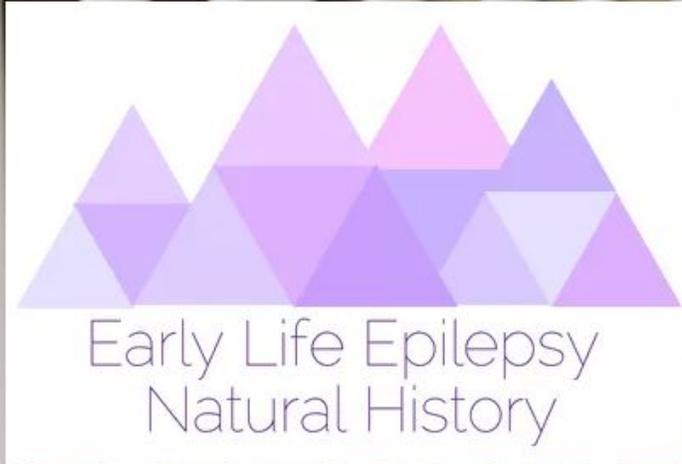
We look forward to learning more!

If you have any questions, please email WhatIsEpilepsy@luriechildrens.org



Early Life Epilepsy Natural History

Please consider participating in this online survey study if you have a child with epilepsy



What is the study about?

The Early Life Epilepsy Natural History Project has been designed with parents and providers to identify the nature and range of the many challenges affecting children and young people with early life epilepsies. These areas, identified by parents like you, include the seizures but also, sleep, behavior, communication, gross and fine motor and more.

How will the study help?

The information that comes from this project will be used to inform parents and educate providers about what to expect in a child with different forms of early life epilepsy. It will help us understand the relationships between seizures, sleep, communication, cognition, behavior motor function, and other important areas for children and families. Such information can also help support the design of clinical trials of new therapies and can be used for advocacy with policy makers.

How do I participate?

If you chose to participate, you will complete an online consent process and then fill out a questionnaire through a secure, online portal. The questionnaire covers many different areas in addition to seizure such as sleep, behavior, communication, gross and fine motor, eating and other areas. It may take up to 2 hours to finish. The questionnaire does not need to be completed all at once. You will be able to login to the survey multiple times, and it will remain available until you have completed it.

In order to learn more about the study and to begin your registration and consent process, please go to the following link: www.EarlyLifeEpilepsy.org

If you have questions about the study, please email WhatIsEpilepsy@luriechildrens.org