

Rescue Medications for Children with DEE




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From Parent-Reported Experience


Natural History Study


Home Page


Welcome to the Natural History Study !

- 
For the Participant
To register for a new study or continue with an ongoing study, click here.
- 
For the Medical Practitioner & Researcher
- 
Study Results

Supported by the Stanley Manne Children's Research Institute, Ann & Robert H. Lurie Children's Hospital of Chicago under the Precision Medicine Strategic Research Initiative and the Pediatric Epilepsy Research Foundation (PERF).


CLIRINX
Clinical Research IT


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PERF
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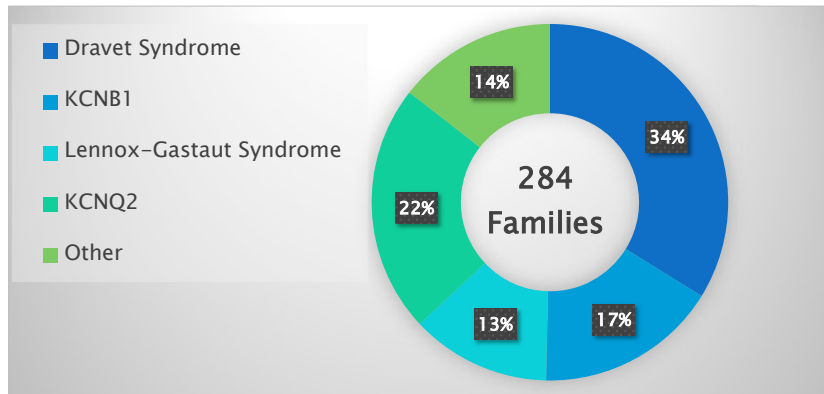
<http://earlylifeepilepsy.org>

How is this different?

- ▶ Designed with and by parents and researchers together

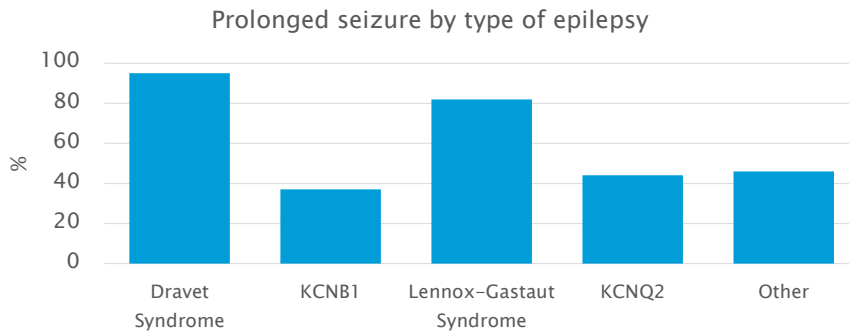
The screenshot shows the top section of the 'Natural History Study' website. At the top is a dark blue banner with the text 'Natural History Study' and a starry background. Below this is a 'Welcome to the Natural History Study!' message. The page features several logos: CLIRINX Clinical Research, 'For the Participant' (with a family icon), 'For the Medical Professionals & Researchers' (with a stethoscope icon), and 'Study Details' (with a brain icon). A large blue arrow points upwards from the bottom right towards the 'Study Details' section. At the bottom left of the screenshot is the URL <http://earlylifeepilepsy.org>.

Parent-Driven Survey: Participation

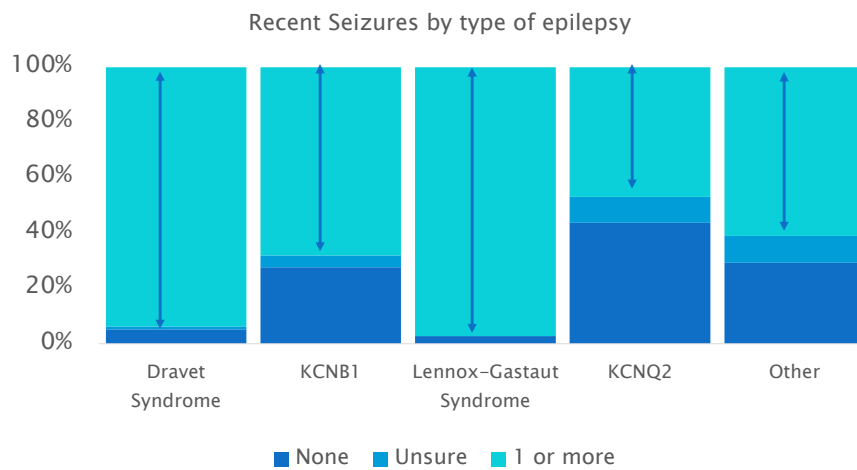


Seizure Emergencies

- ▶ 65% ever have had a seizure or seizure cluster >10 minutes



Seizures in the Past 6 months



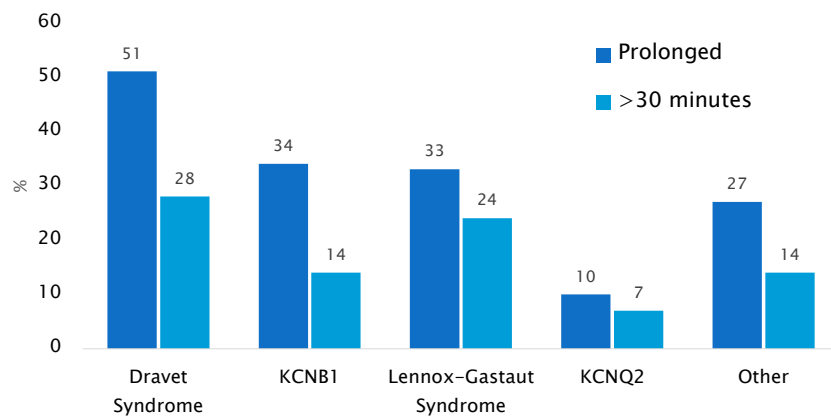
Seizure Emergencies*

- ▶ In the previous 6 months
 - 37% had prolonged seizures (>5 minutes)
 - 20% had seizures >30 minutes
- 21% Convulsive
 - 18% multiple events
- 17% Nonconvulsive
 - 13% multiple events
- 10% Myoclonic
 - 10% multiple events
- 12% Other
 - 8% multiple events

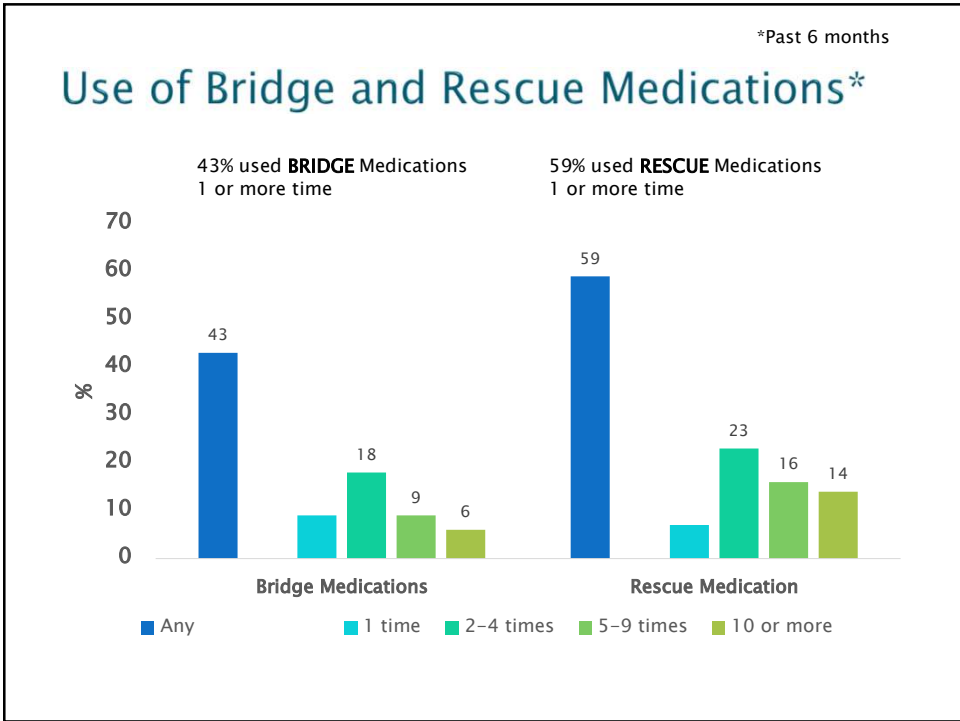
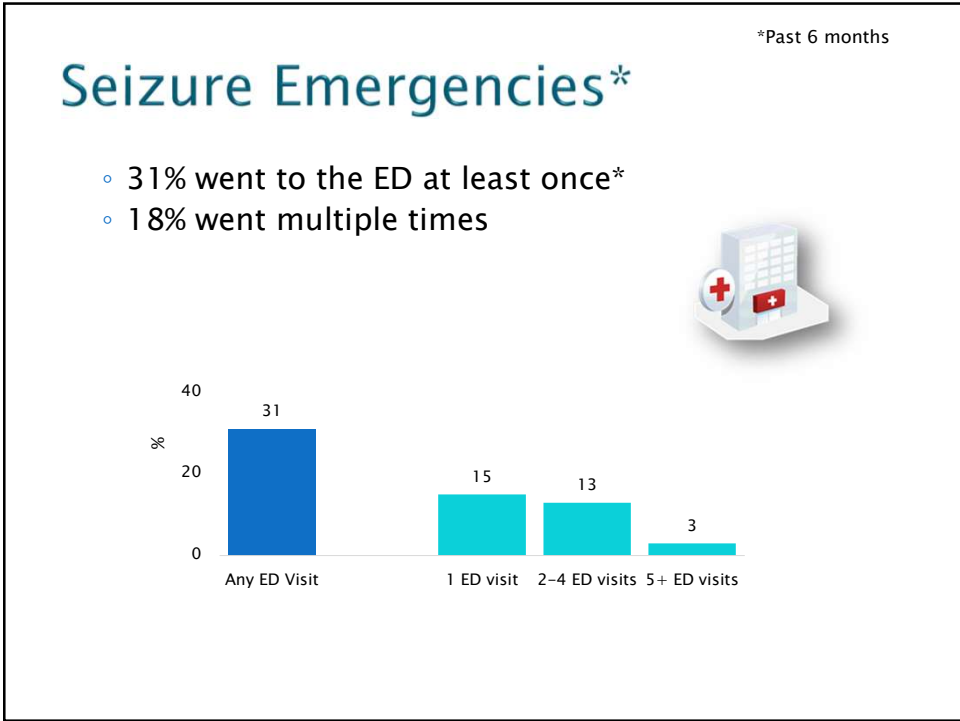


*Past 6 months

Seizure Emergencies by Epilepsy type*

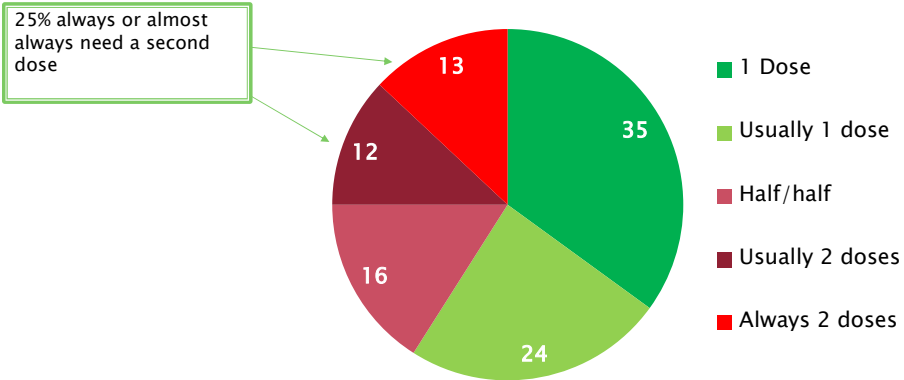


*Past 6 months



How many rescue doses needed?*

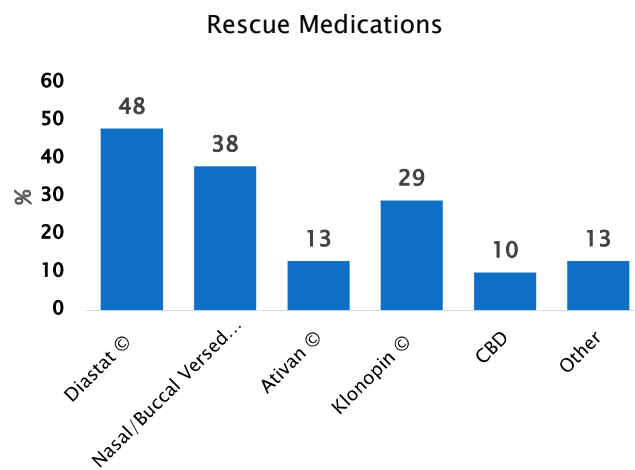
Of those reporting rescue medication use:



*Past 6 months

Rescue medications in common use*

*Past 6 months



Seizure Action Plans



- ▶ Currently, 58% have a seizure action plan
- ▶ 42% do not

Who DOES NOT have a SAP?

In previous 6 months

