

## The BUTTERFLY Study

### An observational research study for children and adolescents with Dravet Syndrome

Dravet Syndrome is one of the most drug-resistant forms of epilepsy. The main goal of anti-epileptic medications is to reduce how often seizures occur and how severe they are. However, most young people with Dravet Syndrome have additional symptoms besides the seizures that strongly affect their general well-being. We need to learn more about the mental, physical, and social development of children and adolescents with Dravet Syndrome, and how their symptoms and development change over time.



The information that is collected from this study may help doctors to investigate potential new treatment options for young people with Dravet Syndrome in the future.

The BUTTERFLY Study, conducted by Stoke Therapeutics, is collecting information about the mental development, behavior, movement, communication skills, seizure frequency, and sleep pattern of young people with Dravet Syndrome. The BUTTERFLY Study is an observational study, which means that no investigational medications or other treatments will be provided. Participants will continue to receive their usual care, and they will be observed by a team of doctors and nurses over time.

About 36 children and adolescents who are 2–18 years of age will take part in this study in the United States. Participants will be in the study for about 2 years and will have 6 study visits, which may be combined with the participant's usual care appointments.

During the BUTTERFLY Study, the participant and their parents or caregivers will attend the participant's usual care appointments. The participant will continue to take the anti-epileptic medication that their treating physician prescribes as part of their usual care.

If you would like more information about the BUTTERFLY Study, please email [BUTTERFLYStudy@iqvia.com](mailto:BUTTERFLYStudy@iqvia.com).