If you are interested in participating, we ask that you to complete a 10 to 15 minute initial online questionnaire to help us establish eligibility and ensure a balance of participants. Following completion of the questionnaire, admedicum will be in touch with next steps.

Please note that we might not be able to interview everyone who fills out the initial questionnaire.

Eligibility Criteria:
- Adult (18 years or older) caregiver to a child living with STXBP1 who is 8 years of age or younger.
- Currently live in the US, UK, Australia, Canada, or Spain.
- Able to hold a conversation in either English or Spanish.
- Have access to a computer and able to join the Zoom online meetings platform.

Through 60 to 90 minute interviews with around 20 families, we hope to learn about children's experiences living with STXBP1 from the time before they got a diagnosis up until today.

Interviews will explore topics like which symptoms the child experienced and when, the types of physicians the child has seen, the different treatments the child has tried, the impact STXBP1 has on the child and the family, and much more.

An honorarium will be provided to those who participate in the interview.

About Us

This project is sponsored by Encoded Therapeutics, a biotechnology company based in California, USA, in collaboration with the STXBP1 Foundation, a patient advocacy organization based in the USA. Project support is provided by admedicum.

Questions:

Please contact the admedicum team: engagestxbp1@admedicum.com

LINK TO THE QUESTIONNAIRE: https://eu.research.net/r/STXBP1