STXBP1 ENGAGE:

WE ARE LOOKING FOR CAREGIVERS OR PARENTS, WHO WOULD LIKE TO GIVE FEEDBACK ON LIVING WITH STXBP1

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** STXPB1 has on the child and the family, and much more.

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

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.

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.



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

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.







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