



THE BOS EEG SIGNATURE STUDY



Do individuals with Bohring-Opitz Syndrome have a distinct brainwave pattern?

What is an EEG?

EEG stands for electroencephalogram, and it is a non-invasive way to measure activity in the brain. Sticky sensors are attached to the head to detect brainwaves. When we receive the EEG data, we can do something called “power analysis.” This allows us to learn about the different types of brainwaves and look for patterns.

What is the goal of this research?

We want to know whether individuals with BOS have a unique EEG pattern—this is called an EEG signature. If an EEG signature is found, this would allow EEGs to be used as a biomarker for BOS research. A biomarker is a tool or measure that tells us something about a person’s health, like blood pressure and temperature.

As an example, here is a simplified graphic of how EEGs could be used in future clinical trials if a medication or other treatment was developed.

BOS EEG Signature



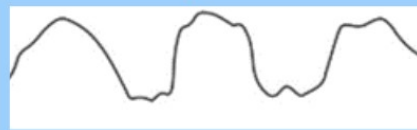
EEG in person without BOS



BOS EEG Signature with effective treatment



BOS EEG Signature with ineffective treatment



We will also be conducting an interview about your child’s development to see if there is a relationship between cognition and EEG patterns.

Has this been done successfully with other diseases?

Yes! In studies on Angelman Syndrome, a different genetic neurodevelopmental disorder, they found a strong EEG signature. This EEG signature is now being used as a biomarker to evaluate the effectiveness of treatments in medication clinical trials.

My child has never had a seizure, can they still participate?

Yes! This study is not about seizures. We want the conclusions drawn from this study to be generalizable to ALL individuals with BOS. This means including participants both with and without seizures.

Want to participate or have questions?

Contact ASXL-CHROMATIN-REGISTRY@mednet.ucla.edu