JOHNS HOPKINS MEDICINE

Approved September 17, 2026

Epidiolex Pilot Trial for Presymptomatic Treatment of Sturge-Weber Syndrome (IRB00326943)

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This trial will evaluate whether Cannabidiol (Epidiolex) in presymptomatic Sturge-Weber syndrome (SWS) patients can safely delay or prevent the onset of seizures and improve neurological outcome. Six subjects will join the study.

Epidiolex is a purified derivative of cannabis (i.e., marijuana). It does not have psychoactive properties of its original plant formulation. It is a pharmaceutical grade drug. It does not produce a high. It is not addictive. Epidiolex is FDA approved for treatment of seizures in Lennox-Gastaut and Dravet syndromes and has been clinically used in infants with seizures.

The most common adverse reactions are somnolence (abnormal sleepiness), decreased appetite, diarrhea, fever, and fatigue. Dr. Comi has published two prior drug trials on Epidiolex use in SWS patients. Epidiolex was generally well tolerated, reduced the number of seizures in most subjects with medically refractory seizures, and was associated with improvements in cognitive function and mood.

To enroll in this study your child must:

1) Have a clinical diagnosis of Sturge-Weber syndrome brain involvement.
2) Be between the ages of 1 and 18 months, inclusive.
3) Have neuroimaging demonstrating brain involvement of 3 or more lobes, or bilateral brain involvement.
4) No history of seizures.
5) Have a parent or legal guardian provide written informed consent prior to treatment initiation.

This study is funded by Jazz Pharmaceuticals. If you are interested, please contact Dr. Comi at 443-923-9172 or comi@kennedykrieger.org.