Sturge-Weber Studies for Which You/Your Child May be Eligible

An open patient registry and two open studies are available at Cincinnati Children’s for patients with Sturge-Weber syndrome.

**Patient Registry:** New Methods to Measure Progression of Sturge-Weber Syndrome  
*Goal:* To better understand the range of symptoms and long-term outcomes

**Biomarker Study:** Urine Markers of Disease  
*Goal:* To find if a link exists between degree of symptoms and markers found in urine

**Treatment Study:** Safety of Sirolimus for the Treatment of Cognitive Impairments in Sturge Weber Syndrome Brain Involvement.  
*Main Goal:* To determine if a drug improves neuropsych testing scores (such as behavior and school performance)  
*Other goals:* To determine if a drug changes seizure frequency  
To determine if a drug changes the color of birthmark

Contact [HVMCResearch@cchmc.org](mailto:HVMCResearch@cchmc.org) or 513-803-HVMC (4862) if you have interest in joining or would like more information.