TSC RESEARCH STUDY: Do you have an infant with TSC between 0-6 months old?
(Valid through March 19, 2020)

PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TUBEROUS SCLEROSIS COMPLEX (PREVeNT TRIAL)

**Where: TSC Clinical Research Consortium sites at**
Boston Children’s Hospital, Cincinnati Children’s Hospital Medical Center, University of Alabama at Birmingham, University of California at Los Angeles, University of Texas at Houston, Minnesota Epilepsy Group, PA, Stanford University, Beaumont Children’s Hospital, Washington University in St. Louis, Children’s Hospital of Orange County, Children’s National Medical Center, The Children’s Hospital of Philadelphia, Duke University Health Center, and Mount Sinai

**Principal Investigators:**
Boston (Mustafa Sahin, MD, PhD), Cincinnati (Darcy Krueger, MD, PhD), Birmingham (Martina Bebin, MD, MPA), Los Angeles (Joyce Wu, MD), Houston (Mary Kay Koenig, MD), Minnesota (Michael Frost, MD), Palo Alto (Brenda Porter, MD, PhD), Michigan (Danielle Nolan, MD), Missouri (Michael Wong, MD, PhD), Orange County (Mary Zupanc, MD), Washington, DC (William McClintock, MD), Philadelphia (Katherine Taub, MD), North Carolina (Klaus Werner, MD, PhD), New York (Steven Wolf, MD)

**Who is eligible to participate?**

We are enrolling 0-6 month old infants with a diagnosis of tuberous sclerosis complex (TSC) and no history of seizures for a new study on prevention of epilepsy. The goal of this project is to use EEG, behavioral testing and early use of vigabatrin to help determine the developmental impact of epilepsy from birth to 36 months of age.

Infants diagnosed with TSC less than 6 months of age, no history of seizures or infantile spasms

**What will we do?**
If you agree to participate, the research team will obtain your informed consent. The study involves up to 13 visits over a three year period. The study visits will include behavioral testing, EEGs, eye exams, and physical exams, optional blood draws.

**Cost/time commitment:**

Study visits will vary in length based on your child’s age, but generally be a few hours in time.

There is no fee to participate in this study. Travel funding may be available.

 **Results**Summary scores of your child’s behavioral testing and EEG results will be provided to you. Every step of the way, if new results from the testing are concerning, we will notify you and assist you in obtaining referrals or interventions. After all study data has been analyzed, we will inform families of the overall results.

**Contacts**
If you are interested in learning more about this study, please contact Regina Ryan – PREVeNT Project Manager at prevent@uabmc.edu or 205-975-2890.