

TACERN

Tuberous Sclerosis Complex
Autism Center of Excellence Research Network

Early Biomarkers of Autism in Infants with TSC

ACE STUDY NEWSLETTER

Winter 2013



The ACE Study has
a New Website!

www.tscstudy.com

Contact Us at Our
Email Address:

info@tscstudy.com

Volume 1, Issue 1

Off to a Successful Start!

Since receiving our grant from the National Institutes of Health in September 2012, the entire TACERN research team, in close collaboration with the Tuberous Sclerosis Alliance and The National Institute for Neurological Disorders and Stroke, has worked tirelessly to launch the Early Biomarkers of Autism in Infants with Tuberous Sclerosis (TSC) Study.

After launching in March of 2013, we are now well into our first year of the study. We are excited to report that already over 25 babies have enrolled with many more families showing interest in joining! The TACERN team is extremely impressed with the enthusiasm of the TSC community, both with the families that are directly involved in the study and the families that continue to show tremendous support in dedicating their time and effort to TSC Research. Your eagerness to help us learn more about identifying early signs of autism in children with TSC is inspiring and represents an important step forward in the early detection and treatment of autism.

The ACE Study has a New Website!

We created a TACERN family website as a resource for you to stay connected to the study and to be informed of new and exciting research opportunities! Check out the website at: www.tscstudy.com

Where are we?



The Early Biomarkers of Autism in Infants with TSC study is currently enrolling infants *ages 3-9 months who meet genetic or clinical criteria for TSC* at five premier children's hospitals throughout the United States, including Boston Children's Hospital, Cincinnati Children's Hospital Medical Center, University of Alabama at Birmingham, University of Texas at Houston, and University of California at Los Angeles.

To contact a study coordinator, send us an email at info@tscstudy.com or contact our site study coordinators:

Boston: Molly.Valle@childrens.harvard.edu

Cincinnati: molly.griffith@cchmc.org

Birmingham: jessicakrefting@uab.edu

Los Angeles: aperez@mednet.ucla.edu

Houston: Elida.L.Salazar@uth.tmc.edu

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Meet your Investigators!

The Early Biomarkers of Autism in Infants with TSC studies' five Principal Investigators (PIs) are part of the newly formed TSC Autism Center of Excellence Research Network (TACERN).

Boston Children's Hospital



Mustafa Sahin, MD, PhD

Cincinnati Children's



Darcy Krueger, MD, PhD

University of Alabama at Birmingham



Martina Bebin, MD

University of California at Los Angeles



Joyce Wu, MD

University of Texas at Houston



Hope Northrup, MD

What is TACERN?

TACERN is a program that fosters collaboration between teams of specialists to address the causes of autism and to find new treatments. Our PIs not only have years of research experience, but they also have years of clinical experience leading the top TSC Clinics throughout the United States!

Frequent EEG Tests Capture Early Seizure Activity: A Participant's Story

An important component of the ACE study is the EEG test, which is done at each study visit. The EEG test monitors the brain's electrical activity and helps to see if seizures are occurring and what kind they are. Our researchers believe that there is a relationship between increased seizure activity in infants and autism.

Baby J* enrolled in the study seizure free at four months of age and had an EEG at his first study visit, which did not show any seizures. At his second study visit, just two months later, when he was six months old, his EEG test showed that Baby J had started having a type of seizure called infantile spasms. Because of the frequency of the EEG tests done in the study, we were able to treat Baby J for his seizures sooner than he may have been treated if he had not been part of the study.

The parents of Baby J share their feelings: "We feel like the study is really win-win for everyone. Baby J gets extra medical attention and care and it's allowed us to build a strong relationship with Neurology. At the same time, Dr. Sahin is getting valuable data for research."

*name changed, story shared with permission of the family.

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Let's Stay in Touch!

Please let us know the best way to stay in touch with you. If you like e-mail, phone calls, text message or Facebook, let us know which you prefer! We will publish this newsletter two times per year. If you have any suggestions that you would like to see in future issues, please contact us. We would love to hear from you!

Don't forget to check out the ACE Family Website! The web address is www.tscstudy.com.

The website provides information about our study, as well as information about other TSC studies, current publications, site contact information, among other things.

If you have any questions or comments, please do not hesitate to contact us at info@tscstudy.com.

TSC Clinical Research Consortium

TACERN is part of the TSC Clinical Research Consortium (TSC-CRC). The TSC-CRC was established in July 2011 as a large, multicenter collaborative research network with the objective of accelerating human clinical trials focused on novel therapies and optimal treatment in TSC. The TSC-CRC is currently comprised of the five TACERN sites, a preclinical studies site led by Dr. Michael Wong at Washington University in Missouri, and the TS Alliance.

As of December 2013, the TSC-CRC has three ongoing research projects: TACERN, TSC Epilepsy Biomarker Study (TRC-EBS), and EXIST3-DTI sub-study. TRC-EBS is led by Dr. Bebin and is aimed at identifying early predictors of infantile spasms and epilepsy. EXIST3-DTI sub-study is led by Dr. Krueger and is aimed to understand how everolimus effects brain networks in TSC patients with epilepsy.

Stay tuned—Additional research projects are already in development for 2014. These include plans to add additional participating clinical sites and researchers to the TSC-CRC.



TSC-CRC

Tuberous Sclerosis Complex Clinical Research Consortium