SPRING 2016 NEWSLETTER

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Meet Vivienne Reyna

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Current studies at the clinic
Upon our first visit to the neurologist in Fort Worth, he told us about a study being conducted by the UT-TSC Clinic at Children’s Memorial Hermann Hospital (CMHH) in Houston. The simple mention of the study and clinic would change Vivienne’s and our lives forever! While a little apprehensive because we did not want our daughter poked and prodded, we enrolled Vivienne for the study as she was the ideal target. Our hope was that Vivienne could help other children with TSC. What we did not expect was the overwhelming display of affection and care we have received from Dr. Hope Northrup and her team. The amount of knowledge that the team at UT/CMHH on TSC is beyond compare. The study has allowed us to gain a better understanding of TSC and the opportunity to enroll Vivienne in an evaluation process that tracks her development. The clinic also helped us get Vivienne involved with Early Childhood Intervention (ECI). Most importantly, the TSC Study introduced us to a world class team of doctors headed by Dr. Mary Kay Koenig and Dr. Northrup. Oh...and as far as the worry about being poked and prodded...there are only hugs and kisses from Mrs. Elida Salazar, which are no concern at all!

Shortly after being introduced to the TSC Clinic, we moved all of Vivienne’s care to CMHH. Over the past year we have experienced many of the typical symptoms of TSC including seizures. While the seizures are unwelcome, both the TSC Clinic team and the medical staff at CMHH have been wonderful in helping to navigate getting the seizures under control. Whether it’s from where to park our car to looking at getting an EEG, the TSC team has been there for us each step of the way. We are also happy to say that Vivienne is everything you would expect from a 1 year old...engaging, funny, a bit stubborn and simply a joy! We are 100% confident that Vivienne is receiving the very best care that the world has to offer. More so, we know we have a family at the TSC Clinic and we know the advances being made by the TSC Clinic cannot be measured. Vivienne will always have TSC, but it is so comforting to know that Dr. Northrup and her team are dedicated to doing everything they can to make Vivienne’s life and so many other lives out there as fulfilling as possible.

PATIENT SPOTLIGHT—VIVIENNE REYNA

By Chris Reyna

Vivienne Faye Reyna was welcomed into the world at 5:46 pm February 2, 2015 weighing a robust 7 lbs 1 oz and measuring 21 inches. Like all parents, Connie and I were ecstatic to welcome our baby girl into the world. For us, our enthusiasm was tempered as we learned only 4 days prior in utero that Vivienne would be born with a condition called Tuberous Sclerosis Complex (TSC). The fact that Vivienne was being born with a condition was scary enough, but to then learn this was a rare disease many doctors had very little experience only amplified our concerns. After Vivienne’s birth, which proceeded without incident, we were referred to a team of doctors in Fort Worth.

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In February, Dr. Hope Northrup was a guest speaker at the Region 15 LAM Educational meeting where she presented on how lymphangiomyomatosis (LAM) can affect individuals with Tuberous Sclerosis Complex. Also present was Alejandro Carrillo, TSC Clinic Nurse Coordinator, to help represent the UT-TSC in support of the LAM Foundation. This was a wonderful opportunity for the TSC clinic to work with The LAM Foundation and provide education to the community.

As part of the TS Alliance 2015 Town Hall Educational Series, Dr. Mary Kay Koenig participated as a guest speaker at the University of Texas at Houston Medical School and at Texas Scottish Rite Hospital in Dallas, Texas. These events provided a space for individuals with TSC and their families to speak one-on-one with a physician who specializes in TSC. It also allowed individuals and families who have been affected by TSC to meet and share their personal stories with others.

Dr. Hope Northrup will be traveling to Sydney Australia for a site close-out as part of the TREATMENT Trial, a study to determine the efficiency of using Topical Rapamycin Cream daily to treat angiofibromas. She will be joined by Patti Tate Research Coordinator to see Dr. David Mowat at Sydney Children’s Hospital who has

UPCOMING EVENTS
worked with the Australian TS Alliance to gather valuable information for the research study. The data collected is currently being analyzed and will be published as soon as it is completed.

While in Sydney Dr. Northrup has been invited to be a speaker for a meeting of the Australian Genetics Society to discuss TSC. She will also be travelling to Brisbane to speak at a TSC family conference conducted by the Australian TS Alliance. The partnership that the UT-TSC Center of Excellence, the Sydney Children’s Hospital, and the Australian TS Alliance share is just one of many treasured relationships that helps connect the UT-TSC center to other Centers of Excellence across the world. The partnership enhances knowledge and strengthens relationships among the TSC community.

CARING FOR THE CAREGIVERS

A recent article by Rentz et al (2015) addressed the effects of caring for a patient with Tuberous Sclerosis Complex on the caregiver. The research found those caregivers who were responsible for driving their patients to the doctor, researching specialists and TSC, and worrying about their child’s quality of life had both lower physical and mental health. In fact, the more time the caregivers spent on these activities, the lower their quality of life status became.

Since TSC patients can require multiple specialties in order to address a varying array of symptoms, TSC Centers of Excellence in fact benefit not only the patient but also the caregiver. These clinics are able to provide access to many specialists in the same area and answer any stressful questions about the disease. This helps alleviate any stress complicating their mental health and allows for time to relax and not only take care of their child, but also their own self. UT-TSC is proud to be able to help out in this way!
Our Mission is to provide the highest level of cutting edge medical care to individuals affected by Tuberous Sclerosis Complex (TSC), to perform both clinical and basic research on TSC, and to educate medical professionals and the public about TSC.

This past summer the team participated in many events to help raise awareness and funds for those affected by Tuberous Sclerosis Complex.

Physician’s Spotlight: Adelaide A. Hebert, MD

Dr. Hebert is a Professor of Dermatology and Pediatrics at the University of Texas Health Science Center at Houston. She is also a Professor in the Section of Dermatology at the University of Texas M.D. Anderson Cancer Center. After earning a BS in microbiology at Louisiana State University and her MD degree from Tulane University, she completed an internship in internal medicine and a residency in dermatology at the University of Texas Medical Branch in Galveston, followed by a pediatric dermatology fellowship at Northwestern University in Chicago.

Clinical research has been one of Dr. Hebert’s interests during her tenure at the University of Texas. She has been involved in a wide array of research areas with special focus on atopic dermatitis, psoriasis, tuberous sclerosis complex and neurofibromatosis. Other areas of research interests have included skin and soft tissue infections, acne, diaper dermatitis and many more.
1. ACE - The purpose of this research study is to look for early signs of autism in children with Tuberous Sclerosis Complex (TSC). The ages of eligibility for this study are 3 to 12 months, and may or may not have seizures. If interested, contact Elida Salazar at 713-500-5766.

2. Exist 3 - The purpose of this research study is to determine the efficacy of the use of Everolimus as a therapy in patients with TSC who have refractory partial-onset seizures. The ages eligible for this study are 2 to 65 years. If interested in this study, contact Patti Tate, RCP, CCRP at 713-500-5659.

3. QOL - The purpose of this research study is to check the quality of life of those patients who have been on the Topical Rapamycin cream. This is a database study with no age requirement. If interested contact Patti Tate, RCP, CCRP, at 713-500-5659.

4. RDCRN - The purpose of this research study is to learn more about TSC patients with suspected or confirmed Autism Spectrum Disorder, intellectual disability, or both. We want to see if we can find earlier signs of ASD/ID and gain a better understanding of this in individuals with TSC so that effective treatments and interventions can be found. If interested in this study, contact Elida Salazar at 713-500-5766.