THEO'S STORY

"We are thrilled that our experience walking through Theo's hemispherectomy surgery may have benefits that are far-reaching to the Sturge-Weber community. We were able to donate the removed affected tissue, the entire left hemisphere of his brain, to aid in research and serve to better inform others in the future. It is amazing how our lives have changed since his surgery. He is a new little boy, engaged and full of life!"

Brandi and Peter Shamberger

Questions About Donating to a Registry

What Tissues Are Needed? Many types of tissue from individuals are needed: skin, blood, oral swabs, even brain tissue. Donations from patients and sometimes unaffected family members are extremely beneficial.

How much Tissue is Needed? Very small to large amounts of tissue can be used. Donating normally has little risk, and can only be performed with consent.

Why Donate to a Tissue Bank and not a Specific Researcher? Tissue banks are funded to help coordinate storage and distribution of tissue samples specifically for research on rare and developmental disorders.

CAN WE COUNT ON YOU?

Register | Update | Donate Today!

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE

The Sturge-Weber International Registry
SWF Registry Coordinator
coordinator@sturge-weber.org
(Subject line: SWIR)

UNIVERSITY OF MARYLAND BRAIN & TISSUE BANK
A Brain and Tissue Repository of the NIH NeuroBioBank

Maryland Brain and Tissue Bank
1-800-847-1539
http://www.medschool.umaryland.edu/btbank/family/

The Sturge-Weber Foundation
The stronger the wind, the tougher the tree.

12345 Jones Road, Suite 125
Houston, TX 77070
973.895.4445
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swf@sturge-weber.org

REGISTRY

CLINCIAL DATA AND TISSUE

The Sturge-Weber Foundation

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE

Working together we can improve the quality of life and care for our loved ones.

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE

The Sturge-Weber International Registry (SWIR)

The SWF funded and launched the online Sturge-Weber Internation Registry in order to accelerate basic laboratory research to meaningful health outcomes, such as therapies and treatments, related to Sturge-Weber syndrome (SWS) and Port Wine birthmarks (PWB). The registry contains consented clinical data collected in some cases since 1987. This data has been instrumental in engaging clinicians and scientists to study the syndrome and has been acknowledged in highly respected medical journals. The data was also a key factor in many researchers obtaining National Institutes in Health (NIH) grant awards.

The SWIR is important for characterizing and understanding the syndrome better and the impact of birthmarks. The registry provides valuable information for families and doctors to make the best possible care decisions. It will help researchers decide what the most significant challenges are to address in SWS. The Registry will also help scientists find out if there are any SWS affected individuals who might be a good match for research studies.

Protecting the privacy of these individuals who donate is of highest priority to SWF. In order to protect privacy, Invitae, formerly Patient Crossroads, the company that designed the registry, has safeguards in place and stores the information on a HIPAA compliant server. The patient's and family's information will be "deidentified" so no one looking at the data will be able to identify the individual. If any contact needs to be made, an SWF coordinator will make contact. A scientist will only be able to contact a patient and family with explicit consent specified to that researcher.

UNIVERSITY OF MARYLAND BRAIN & TISSUE BANK
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About the University of Maryland Brain & Tissue Bank (UMBTB)

The Maryland Brain and Tissue Bank (MBTB) is an organization whose primary purpose is to obtain, preserve and distribute human cells, tissue and organs to researchers and scientists. They are directly affiliated with the NIH. The NIH strongly supports MBTB, a project that provides the materials needed to understand and treat rare disease.

The UMBTB has been a leading organization in the initiative to collect and bank vital specimens from individuals living with a rare disease. Their friendly and knowledgeable staff are on hand 24 hours a day in the event of a surgery or sudden death where time is of the essence to recover critical specimens.

The SWF is proud to be working with the MBTB and NIH toward a cure for SWS and also for the increased clinical trials need for capillary malformation and PWB.

Why Invitae and UMBTB?

These two highly respected organizations are focused on advancing the cause and cure of rare diseases. They have registries of similar vascular malformation related diseases which give interested researchers a wider pool to investigate. The SWF believes this will increase the pace of discovery.

These partnerships are advantageous to individual living with SWS and to the SWF because they understand rare diseases and the burdens that can impact daily life. They make enrollment and securing tissue samples easy and understandable. More importantly, they both work closely with the NIH, and they care which is why signing up now is so important.

ACCEPT
RESPECT
CONNECT
HOPE