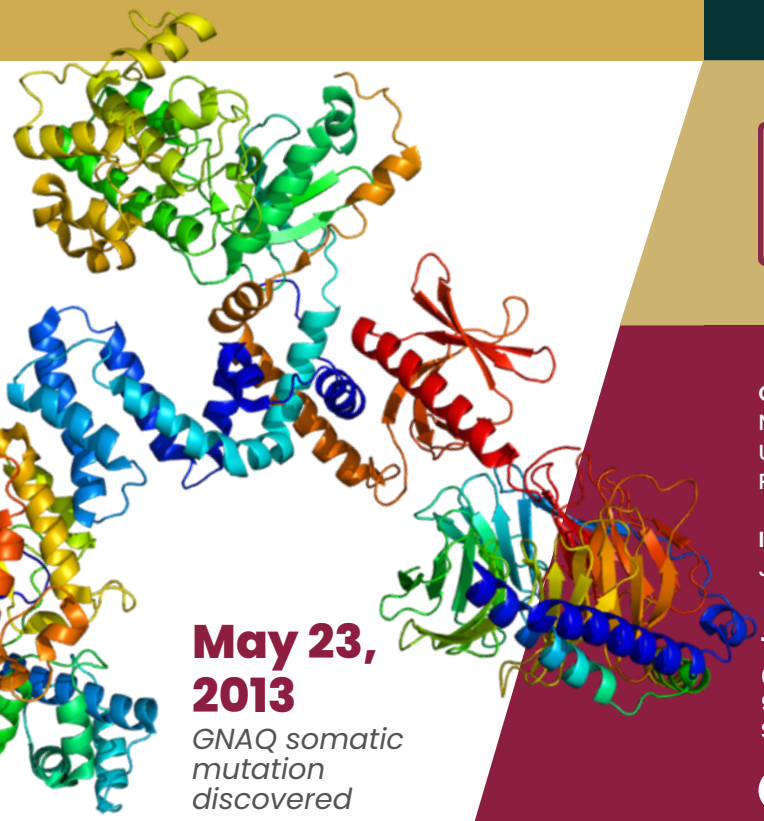
25+ CLINICAL CARE CLINICS

Our Network has over 25+ centers that provide the comprehensive care necessary for treating adults and children who have a port wine (PW) birthmark, Sturge-Weber syndrome (SWS) or Klippel-Trenaunay (KT).

Each center is staffed by a team of specialists who collaborate in the evaluation and management of each patient. This team approach ensures the individual's treatment plan is carefully developed and coordinated.



May 23, 2013

GNAQ somatic mutation discovered

Karen L. Ball
Founder and CEO

"The SWF recognizes the collaborative care received at the clinical care centers and researchers play a key role in improving the quality of life for individuals living with port wine birthmark conditions. Together patients, dedicated physicians and the SWF will increase the pace of discovery."

STRONGER BECAUSE WE ARE
UNITED

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE

ON THE FRONT COVER:
Nathan D. Lawson, PhD
UMass Chan Medical School
Professor, Researcher

INSIDE:
Joyce Biscoff, PhD and Anna Pinto, MD, PhD

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The Sturge-Weber Foundation is a 501 (c) (3) non-profit organization.

ROOTS TO A CURE

35+ YEARS UNITED

About Our Foundation

The SWF was founded by Kirk and Karen Ball. They began searching for answers after their daughter, Kaelin, was diagnosed with Sturge-Weber syndrome at birth in 1987.

In 1992, the mission was expanded to also support and serve individuals with capillary vascular birthmarks, Klippel-Trenaunay (KT), and Port-Wine Birthmarks. Today, The SWF is leading the way in awareness and research.

How we Advance Research Forward

When The Sturge-Weber Foundation was founded, not much was known about Sturge-Weber syndrome (SWS), Port Wine birthmarks, and Klippel-Trenaunay syndrome. Today, we know the cause of SWS is the somatic mutation in GNAQ somatic mutation on chromosome 9q21.

In 2013, the GNAQ gene mutation responsible for Sturge-Weber syndrome was researched and discovered by our CSO, Matthew Shirley, PhD working in Jonathan Pevsner's, PhD lab along with Dr. Anne Comi. The SWF supports their work to understand how these mutations cause both SWS and Port Wine birthmarks in order to identify potential treatments.

The SWF is committed to driving and accelerating SWS research. The SWF funds research through grants and fellowships each year, as well as facilitates collaborations between established researchers and clinicians.

Research Grants

The research accomplishments and increasing the understanding of SWS biology and pathology of glaucoma, seizures, calcification, growth hormone, migraines and more have been facilitated and in many cases funded by seed grants ($5000 range) and full basic and clinical research grants and fellowships ($10,000–$50,000). ***Yes,*** it does take money and we support is needed and appreciated! This research is vital to understanding SWS before we can find a cure.

Translational Research

The SWF is engaging in translational research with the SWS Project of the Brain Vascular Malformation Consortium (BVMC) by doing genetic studies and looking into potential biomarkers.

New Research

Currently, research on zebrafish and mouse models are working to understand SWS biology and discover new treatments.

SWS Patient Registry

With our patient's help, researchers and physicians have access to accurate clinical data to understand how SWS affects patients allowing for improved quality of care.

Clinical Trials

The SWF works in collaboration to facilitate clinical trials and drive patient participation.

STRONGER BECAUSE WE ARE

UNITED

We are UNITED to achieve greater results.

For Our Professionals

The SWF International Research Network (SWFIRN) and Clinical Care Network (CCN) are designed to bring basic and clinical researchers and physicians together to increase the pace of discovery and cures.