



May: A Month of Awareness for Rare Vascular Disorders springs into Action at the Sturge-Weber Foundation

Sturge-Weber Syndrome and Klippel-Trenaunay Are Little Known

Media Advisory

MT FREEDOM, N.J./EWorldWire/May 12, 2008 --- For family members of 4,000 identified people worldwide who bear a purple port wine stain birthmark on the face, intolerance, accusatory questions and rude stares are commonplace, with a growing number of exceptions over the last 21 years during May as the Sturge-Weber Foundation (SWF) has brought awareness of rare vascular disorders, Sturge-Weber syndrome (SWS) and Klippel-Trenaunay syndrome (KTS) into the mainstream.

The SWF does not receive U.S. Census reports and can only rely on statistical estimates. It is estimated that 3 of every 1000 newborns have a port wine stain birthmark, and of those 3-of-1000, between 8 and 16 percent will be diagnosed with Sturge-Weber syndrome. The Month of Awareness in May underscores the SWF's year-round work to support its members and to help create awareness in communities around the globe.

While the SWS hallmark is usually visible as a purple port wine stain birthmark on the face, Sturge-Weber syndrome (SWS) often lays under the radar of the public's awareness, while Klippel-Trenaunay syndrome (KTS) is even more hidden, being a purple birthmark on an arm or leg.

According to Karen Ball, the Sturge-Weber Foundation founder, "The most benign question is usually, 'What happened to your face?'"

A small global network of physicians and scientists is engaged in research on the cause and treatment of SWS and KT. A vital focus for them is education among their colleagues. A percentage of contributions to the Foundation goes toward research grants.

A host of everyday quality of life issues challenge families and individuals coping with SWS and related conditions. Educational materials and personal stories presented to schools, businesses, churches and community groups spur polite questions, thoughtful comments and often generous financial donations.

For lack of education and information:

- . Well-meaning strangers have sometimes unnecessarily alerted child protective services.
- . School children have run the gauntlet of teasing and bullying from kindergarten through high school and college.
- . Adults have been denied retail employment or advancement for fear they would frighten customers.
- . Individuals have often been mistakenly assumed to have cognitive impairment or mental retardation.

"The reality is," said Ball, "that Sturge-Weber syndrome is a congenital neurological disorder of unknown cause and no cure. It is not contagious. It occurs in both males and females and in all racial groups. It is a random

disorder, with different characteristics in each person."

Stated Ball, "People with a PWS do not always have SWS or KT, but only medical studies can tell. A small percentage will have KTS, with some persons having SWS and PWS combined."

KTS is a vascular disorder where the birthmark appears on the body, usually an arm or leg, and can bring overgrowth, enlargement, pain and disfigurement.

The striking facial port wine stain (PWS) can be treated by laser therapy, which will diminish the mark, and sometimes eliminate it. While there is presently no cure for SWS, the Foundation funds and encourages research.

Left untreated, the PWS will, with age, grow and thicken, often with a pebbly appearance. Many older adults who were untreated as children undergo extensive surgery to attempt reduction of the overgrowth as adults.

Of greater concern is the possibility of seizures or cognitive decline. About 75 to 80 percent of persons with SWS will develop seizures. Many medications have been developed for control, and proper management by physicians has lessened the devastating effects of seizures.

Since 1987, New Jersey-based Sturge-Weber Foundation (SWF) has spent countless hours educating and driving awareness of SWS, KTS and PWS birthmarks, to dispel inaccurate and misleading information about SWS, KTS and birthmarks with the public, governmental agencies and the medical community. The best allies are the Foundation's own members, who can testify to the reality and the challenges of their lives.

As a private not-for-profit organization, the SWF depends on people who have SWS - and other port wine stain conditions like KTS - to make themselves known. The SWF registry includes nearly 4,000 identified cases worldwide. Via the Foundation's Web site ('<http://www.sturge-weber.org>'), a network of families chat, comfort and encourage each other daily. As a 501(c)3 non-profit, the SWF is dependent on private, voluntary contributions. It receives no government funding.

HTML: <http://www.eworldwire.com/pressreleases/18483>

MOBILE: <http://e4mobile.com/pressreleases/18483>

PDF: <http://www.eworldwire.com/pdf/18483.pdf>

ONLINE NEWSROOM: <http://www.eworldwire.com/newsroom/2765.htm>

LOGO: <http://www.eworldwire.com/newsroom/2765.htm>

CONTACT:

Anne Howard
The Sturge-Weber Foundation
1240 Sussex Turnpike
Randolph, NJ 07869
PHONE. 973-895-4445
FAX. 973 895-4846
EMAIL: ahoward@sturge-weber.com
<http://sturge-weber.com>

KEYWORDS: sturge-weber syndrome, port wine stain, Klippel-Trenaunay syndrome

SOURCE: Sturge-Weber Foundation