



PHOTO AVAILABLE: The Sturge-Weber Foundation Held Successful Annual National Week Of Awareness May 1-7

Conditions affect more than 1,000,000 in U.S.

For Immediate Release

MT. FREEDOM, N.J./EWorldWire/May 11, 2005 --- Sturge Weber Syndrome, Klippel-Trenaunay Syndrome and Port Wine Stain birthmarks affect more than one million children and adults in the United States, afflicting them with an emotionally and physically disfiguring disease that can only grow worse over time.

To help find a cure and to provide care and support to those afflicted with these crippling conditions, the Sturge-Weber Foundation designated May 1 through May 7 as National Week of Awareness. The foundation's goal this year is to raise \$100,000 to help cover the rapidly rising costs of medical research and to continue its extensive outreach efforts.

The Sturge-Weber Foundation is the only international non-profit organization dedicated to finding a cure and improving treatment for port wine stains, Sturge Weber Syndrome and Klippel-Trenaunay Syndrome. It currently funds three medical research programs at major universities and medical institutions during 2004-2005, and conducts extensive outreach programs including National Awareness Week and its web site www.sturge-weber.com.

"Birth defects such as port wine stains, Sturge Weber and Klippel-Trenaunay syndromes can be devastating not only to the sufferer but to their families as well. And the conditions continue to get worse as individuals age," said Karen Ball, the Foundation's president and CEO and the parent of a Sturge-Weber child. "Many of these patients must deal with not only facial birthmarks but seizures similar to epilepsy and ophthalmic disorders such as glaucoma. Our Foundation exists to help them understand their conditions and to locate treatment in their communities."

The Sturge-Weber Foundation, along with its physician partners (including dermatologists, ophthalmologists, neurologists, and plastic surgeons), parents, and patients across the country will be hosting golf tournaments, celebrity dinners, auctions, races, bake sales and other events.

"Ninety cents of every dollar we raise goes directly to fund our web site, physician referrals, patient pamphlets, multimedia materials, special support for severely challenged patients and their families, and research grants in the areas of gene expression, angiogenesis, laser treatment, brain imaging, glaucoma and other studies," said Ball.

About The Sturge Weber Foundation

The mission of the non-profit Sturge Weber Foundation is to improve the quality of life for individuals with Port Wine Stains (PWS), Sturge-Weber Syndrome (SWS), and Klippel-Trenaunay Syndrome (KT). Since the Foundation's founding in 1987, it has experienced a 15% yearly increase in the need for information and telephone counseling services.

FACT SHEET

(Information from NINDS and U.S. National Library of Medicine, National Institutes for Health, Bethesda, MD)

What is Sturge-Weber Syndrome?

Sturge-Weber syndrome is a neurological disorder indicated at birth by seizures accompanied by a large port-wine stain birthmark on the forehead and upper eyelid of one side of the face. The birthmark can vary in color from light pink to deep purple and is caused by an overabundance of capillaries around the trigeminal nerve just beneath the surface of the face. Sturge-Weber syndrome is also accompanied by the loss of nerve cells and calcification of tissue in the cerebral cortex of the brain on the same side of the body as the birthmark. Neurological symptoms include seizures that begin in infancy and may worsen with age. Convulsions usually happen on the side of the body opposite the birthmark and vary in severity. There may be muscle weakness on the same side. Some children will have developmental delays and mental retardation; most will have glaucoma (increased pressure within the eye) at birth or developing later. The increased pressure within the eye can cause the eyeball to enlarge and bulge out of its socket (buphthalmos). Sturge-Weber syndrome rarely affects other body organs.

What is Klippel-Trenaunay Syndrome (KTS)?

Klippel-Trenaunay syndrome (KTS) is a congenital circulatory disorder characterized by hemangiomas (abnormal benign growths on the skin consisting of masses of blood vessels), arteriovenous abscesses, and varicose veins, usually on the limbs. The affected limbs may be enlarged and warmer than normal. Fused toes or fingers, or extra toes or fingers, may be present. Bleeding may occur, often as a result of a rectal or vaginal tumor. The cause of the disorder is unknown. A similar port-wine stain disorder in which individuals have vascular anomalies and limb enlargement is Sturge-Weber syndrome. These patients may experience seizures and mental deficiency.

What is a Port Wine Stain (PWS) Birthmark?

A port-wine stain is a vascular birthmark consisting of superficial and deep dilated capillaries in the skin which produce a reddish to purplish discoloration of the skin. Port-wine stains (PWS) are present at birth. Port-wine stains occur most often on the face but can appear anywhere on the body. Early stains are usually flat and pink in appearance. As the child matures, the color may deepen to a dark red or purplish color. The presence of PWS can cause emotional and social problems for the affected person because of their cosmetic appearance. Port-wine stains that involve the upper and lower lids (trigeminal distribution) may be associated with the development of glaucoma. PWS may be one of a group of symptoms and signs in which case it is considered to be part of a syndrome such as Sturge-Weber syndrome or Klippel-Trenaunay syndrome.

MEDIA: Phone interviews with Founder Karen Ball can be made by calling 973.895.4445. Photographs are also available.

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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>

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