



VIDEO AND PHOTO AVAILABLE: Week Of Awareness For Sturge-Weber Syndrome Slated For May 1-7, 2005

For Immediate Release

MT FREEDOM, N.J./EWorldWire/April 27, 2005 --- The Sturge-Weber Foundation, an international organization with headquarters in Randolph, N.J., is celebrating its annual Week of Awareness May 1- 7, 2005.

This observance gives the Foundation's members throughout the world the opportunity to raise awareness about Sturge-Weber syndrome, a rare disorder, and to raise funds for research into the cause and treatment.

Sturge-Weber syndrome is a neurological disorder, characterized by a facial port wine stain birthmark, and can include glaucoma and seizure disorder. In the U.S., there are fewer than 200,000 documented cases, making it a rare disorder or "orphan disease."

The distinctive port wine stain is caused by an overgrowth of blood vessels under the skin, which may infiltrate into the brain and other organs.

The Sturge-Weber Foundation has about 4,000 registered Partners, including adult individuals and families of children with the syndrome. The Week of Awareness gives these Partners the chance to call positive attention to the disorder, emphasizing education and the need for research.

In Chicago, a teenager and her younger brothers sell lemonade at a stand in their driveway, display posters and distribute educational brochures.

In Arizona, the family of a four year old girl with Sturge-Weber, holds a Casino Night with a cocktail party for 150 people.

Partners who do not have an event often secure local newspaper features, distribute coloring books to Sunday Schools and organize letter writing campaigns to friends and family.

The Sturge-Weber Foundation was founded in 1987 in Aurora, Colorado, by Karen and Kirk Ball, who received a diagnosis of Sturge-Weber syndrome for their infant daughter but could find no answers to the harder questions. In 1990, the Balls were the recipients, along with Sarah and James Brady, of the first Betty Ford Award for perseverance in the face of adversity.

Today, the Foundation provides networking for parents and individuals affected by Sturge-Weber syndrome, Klippel-Trenaunay syndrome, a related disorder, and Port Wine Stain conditions. It currently funds several research projects that seek to discover the cause and better avenues of treatment.

More extensive information can be obtained from the Foundation's Web site, www.sturge-weber.com where interested individuals can register to participate.

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

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AVAILABLE MEDIA: Photo: The Sturge-Weber Foundation (size: 2,500.0 k)

Teens coping with rare syndrome find friendship

http://eworldwire.com//mediauploads/cc2163_02 (3 Girls) Denver.jpg

Video Clip: The Sturge-Weber Foundation (size: 3,500.0 k)

Press Release Highlights

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