



Progress Studying The Burden Of Disease In Sturge-Weber Syndrome

For Immediate Release

MT. FREEDOM, N.J./EWorldWire/March 21, 2005 --- In 2004, the Sturge-Weber Foundation of Mt. Freedom, N.J. awarded Dr. Suephy Chen and her colleagues at the Emory University School of Medicine's Department of Dermatology, Atlanta, a two-year, \$20,000 research grant to study the "Burden of Disease in Sturge-Weber Patients and Families." Phase One of this study has been completed and work has begun on the second phase.

Sturge-Weber syndrome (SWS) is a rare neurological disorder affecting the brain, the eye and the skin. It is congenital and progressive. Affected individuals who may not have seizures at birth may still develop them at a later age. The characteristic facial, port wine stain birthmark can darken and thicken with age. Glaucoma, which can be diagnosed at birth, can progress with age and require significant treatment.

The researchers are exploring how the patients and families deal with the manifestations and complications of the disease on a daily basis. They will measure the significant burden that is felt by the impact of SWS on the quality of life, family relationships, financial status and health care utilization.

For the past year, the team at Emory has been interviewing individuals and families affected by Sturge-Weber syndrome. In Phase One they designed a battery of tests and questionnaires to address the issues specific to SWS. This was done with the collaboration of a sample of SWS patients and families. This phase has been completed.

Phase Two has now been launched and will apply these testing instruments to a selected population of SWS patients. These data will be compared to published data for other diseases in order to place the burden of SWS in perspective.

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KEYWORDS: burden, disease, quality, life, Emory, University, Medical, School

SOURCE: The Sturge-Weber Foundation