



## Sturge-Weber Foundation Joins With NORD To Celebrate 25th Anniversary of the Orphan Drug Act

For Immediate Release

MT. FREEDOM, N.J./EWorldWire/Jan. 14, 2008 --- In a statement released today, Karen Ball, president and CEO of the Sturge-Weber Foundation, released the following:

On the 25th anniversary of the signing of the Orphan Drug Act, we join with the National Organization for Rare Disorders (NORD) and its members in continuing our commitment to, and support for, patients around the world with rare diseases. We also celebrate the success of this legislation in bringing improvement in healthcare to millions of Americans.

Through a diverse range of drugs, the ODA has offered new opportunities for patients that might never otherwise have existed.

NORD was founded in 1983 to help people with rare orphan diseases and to assist the organizations that serve them. The founders of NORD were a driving force behind the passage of the ODA. This is an appropriate time to congratulate them on their vision and recognize them for their persistence and their success.

We also recognize that the achievements of companies like Genentech, Amgen, Genzyme, Allergan, Cephalon, Celgene and others have been profoundly influenced by the existence of the ODA, which has brought jobs for thousands in the biotech and pharmaceutical industries, financial rewards for many of the early investors in such companies, and diverted the focus of scientific inquiry to chronic and life-threatening diseases that were previously untreated, leaving patients hopeless, until the ODA was enacted.

With the current advances in such areas as genomics, proteomics, targeted therapeutics, personalized medicine, and stem cell biology, we can expect to see a vast array of new breakthrough products developed for rare disorders in the next 25 years, and we need to make sure that such products will be available and accessible for the patients with these disorders who so badly need them."

### About the Orphan Drug Act

On January 4, 1983, President Ronald Reagan signed groundbreaking legislation that brought real hope for more than 25 million Americans living with one of the 7,000 rare disorders recognized today. The Orphan Drug Act of 1983 (ODA) spurred breakthrough drug research and development for little-known diseases, while providing a potent catalyst to the growth of the pharmaceutical and biotechnology industries in the U.S.

An orphan disease is defined by the U.S. Food and Drug Administration (FDA) as a disease or condition that affects fewer than 200,000 Americans. In the past, because of very low prevalence, orphan diseases were overlooked by drug and medical device developers. In the 10 years prior to passage of the ODA, only 10 new drugs for rare diseases were developed by the pharmaceutical industry. In the 25 years since the approval of the ODA, more than 300 new orphan drugs have been approved in the U.S., an average of about 22 new drugs every year.

### About the Sturge-Weber Foundation

The Sturge-Weber Foundation is just one organization that acts on behalf of patients and their healthcare professionals to promote improvements in diagnosis and treatment for the rare diseases, Sturge-Weber

syndrome (SWS), Klippel-Trenaunay syndrome (KT) and Port Wine Stain related conditions (PWS). These disorders affect an estimated 3 in 1000 newborns, but the number of new patients is extremely variable because of the difficulty in determining the number of untreated conditions in the general population.

Sturge-Weber syndrome is a neurological disorder affecting the brain, skin, eye and sometimes internal organs which is usually characterized by the presence of a port wine stain facial birthmark. KT is a vascular and neurological disorder where the PWS is on an extremity or on the body. Learn more online at '<http://sturge-weber.com>'.

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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](mailto:ahoward@sturge-weber.com)  
<http://sturge-weber.com>

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