

FOR IMMEDIATE RELEASE

The LGS Foundation to Observe Rare Disease Day

(New York, NY – February 1st, 2012) ----- The LGS Foundation will join the National Organization for Rare Disorders (NORD) and others around the world in observing Rare Disease Day on February 29. The purpose is to focus attention on the needs of patients and families affected by rare diseases.

“This is a global observance,” said Peter L. Saltonstall, president and CEO of NORD. “Individuals and organizations around the world will all be sharing stories of how rare diseases affect their lives.”

The challenges of living with a rare disease, he said, include:

- Difficulty getting a timely, accurate diagnosis
- Too little research
- Too few treatments
- Reimbursement or other issues affecting access to treatments
- A sense of isolation
- Difficulty finding medical experts

In the U.S., any disease affecting fewer than 200,000 Americans is considered rare. According to the National Institutes of Health (NIH), there are nearly 7,000 such diseases affecting nearly 30 million Americans.

Studies have shown that it often takes five years or longer to get an accurate diagnosis of a rare disease. In addition, only about 200 of the diseases classified as rare have approved treatments.

Rare Disease Day started in Europe in 2008. It was launched by EURORDIS (Rare Diseases Europe). Last year, it was observed in more than 60 countries, with a national sponsor in each country. NORD is the sponsor in the U.S.

More than 500 patient organizations, government entities, research institutions, and companies developing treatments have signed up as Rare Disease Day Partners on the national website hosted by NORD (www.rarediseaseday.us). The LGS Foundation is one of those partners.

Each year, a global planning team selects a theme for Rare Disease Day. The theme for 2012 is “Rare but strong together.”

Rare Disease Day activities in the U.S. will include a “Handprints Across America” campaign to create a gallery of photos on the Rare Disease Day website; educational materials for classroom teachers; and a nationwide blitz of patient photos, stories and videos to increase awareness of specific rare diseases and the challenges of living with a rare disease.

Several special events are planned, including a scientific symposium at the National Institutes of Health (NIH) and a Rare Disease Patient Advocacy Day at the Food and Drug Administration (FDA).

“Since many of these diseases are genetic, more than half of the people who have rare diseases are children” Saltonstall said. “The problems encountered by families are enormous. It’s important for these families to know they are not alone.”

NORD was established in 1983. It provides advocacy, education, research and patient services on behalf of rare disease patients, families, and patient organizations.

The LGS Foundation is the leading organization in the United States – and across the world – dedicated to providing information about Lennox-Gastaut Syndrome (LGS), a rare and severe form of childhood-onset epilepsy. LGS is characterized by frequent seizures and multiple seizure types, a resistance to medications and/or therapies, cognitive dysfunction, regression, and an abnormal EEG with generalized slow spike-and-wave discharges. LGS constitutes between 1-4% of pediatric epilepsies and typically appears between the second and sixth year of life.