



FOR IMMEDIATE RELEASE

Rare Disease Advocates Raise Important Awareness at Liberty Plaza Atlanta, Georgia State House Event for Rare Disease Day® on February 29, 2016

Atlanta, Georgia—February 29, 2016—Join rare disease patients, caregivers and other health care advocates in Georgia on February 29, 2016 to raise important awareness for rare diseases as part of **Rare Disease Day®**.

During the event, NORD Georgia Ambassador Beth Nguyen RN will present on the importance of recognition, collaboration, and continuity of care for patients and families facing rare disease in Georgia. Dr. Justin Kunes a practicing pediatric orthopaedic surgeon in Atlanta, GA treats pediatric patients with rare disease and will speak about the importance of having resources available when transitioning from pediatric care to adult care in Georgia. Dr. Erik Fisher, Ph.D will speak about the importance of ongoing support for the patient with rare disease in Georgia so that they do not get “lost in the cracks” and the psychological aspect of coping with a rare disease as it pertains to the patient and their families. In addition, we will hear from patient speakers who are rare disease patients in Georgia. Come out and participate, ask questions, and enjoy a refreshment. Join us to celebrate National Rare Disease Day!

Many important decisions related to rare diseases are made at the state level, including newborn screening; support services to help families cope with complex medical needs; an environment that promotes innovative medical research and product development; and insurance practices that assure patient access to medically-necessary therapies. The implementation of the Affordable Care Act has highlighted the increasingly important role of state policies and programs in assuring that the health care needs of Americans are addressed.

The event will be held at Liberty Plaza directly across from the Georgia State Capitol downtown Atlanta from 1 to 3 pm. Participating organizations include National Organization for Rare Disorders, Worldwide Syringomyelia & Chiari Task Force, Transverse Myelitis Association, Mal de Debarquement Foundation, Vestibular Disorders Association, Immune Deficiency Foundation, Your Opportunities Unlimited, NFP, Acoustic Neuroma Foundation, & Neuromyelitis Optica.

The event is organized by patient advocates who have joined with the **National Organization for Rare Disorders (NORD)®**, a leading independent, non-profit organization committed to the identification, treatment, and cure of rare diseases, and national sponsor of Rare Disease Day in the U.S., to educate and inform the public, elected officials, legislative staff and the media.

According to the National Institutes of Health (NIH), a disease is rare if it affects fewer than 200,000 Americans. One in 10 Americans live with a rare disease—affecting 30 million people—and two-thirds of these patients are children. There are more than 7,000 rare diseases and only approximately 450 FDA-approved medical treatments. Many diseases are not being studied by medical researchers. Often, research gets funded by the families and friends of patients or by patient organizations.

Rare Disease Day is an annual awareness day celebrated around the world dedicated to elevating public understanding of rare diseases and calling attention to the special challenges faced by patients. Rare Disease Day takes place every year on the last day of February (February 28 or February 29 in a leap year)—the rarest date on the calendar—to underscore the nature of rare diseases and what patients face. It was established in Europe in 2008 by EURORDIS, the organization representing rare disease patients in Europe, and is now observed in more than 80 nations.

For more information about Rare Disease Day in the U.S., go to www.rarediseaseday.us. For information about global activities, visit www.rarediseaseday.org. To search for information about rare diseases, visit NORD's website, www.rarediseases.org.

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