



**FOR IMMEDIATE
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Texas Advocates Hold Important Advocacy Event for Rare Disease Day® on February 29, 2020

Sugar Land, Texas—February 29, 2020—Join rare disease patients, caregivers and other health care advocates looking to make a difference in Texas on February 29, 2020 as part of Rare Disease Day® 2020.

This will be a family friendly event to help raise awareness of rare diseases. The event will include live music by Flashback, bounce houses, photo booths and more, including exhibitor tables of patient organizations and medical and research industry organizations.

My 8 year old granddaughter was diagnosed with a rare terminal genetic, metachromatic leukodystrophy (MLD), shortly before her 2nd birthday. I have seen firsthand the issues that are faced by rare disease patients and caregivers, which is why I became a patient advocate and the Ambassador for the Texas Rare Action Network.

Many important decisions related to health care that affect the 1 in 10 Americans with rare diseases are made at the state level, including prescription drug cost-sharing, newborn screening coverage, Medicaid and Children's Health Insurance Program (CHIP) eligibility, and Medical Foods coverage. The implementation of the Affordable Care Act has highlighted the increasingly important role of states in assuring that the health care needs of Americans are addressed.

The event will be held Sugar Land, Texas. Participating organizations include Baylor College of Medicine, Texas Children's Hospital, Sickie Cell Association of Houston, Inc., COPA Syndrome Foundation and many more. Register to attend at www.rareTX.org.

The event is organized by patient advocates who have joined with the National Organization for Rare Disorders (NORD)®, the largest and leading independent, nonprofit committed to the identification, treatment, and cure of rare diseases. NORD is the national sponsor of Rare Disease Day in the U.S. and it serves 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 nearly half of these patients are children. There are more than 7,000 rare diseases, 95 percent of which have no treatment. 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 people face. 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 85 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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