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PRISMS, Inc. Supports Rare Disease Day® and Joins Global Movement to Raise Important Awareness for Rare Diseases

Sterling, VA - February 19, 2020 - Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) has joined forces with 30 million Americans and health care advocates around the world for **Rare Disease Day**® on February 29th. Rare Disease Day is an annual awareness day dedicated to elevating public understanding of rare diseases and calling attention to the special challenges that "rare" persons encounter in their daily lives.

PRISMS is a 501c3 organization dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS. Smith-Magenis Syndrome is a chromosomal disorder characterized by a recognizable pattern of physical, behavioral, and developmental features caused by a missing piece of genetic material from chromosome 17.

As a patient organization supporting a rare population, PRISMS understands and values the importance of raising our voice alongside the thousands of other rare disease communities to ensure that awareness and progress is advanced for all of the rare diseases. We all succeed when any rare disease or syndrome is illuminated, thus progressing the awareness of all.

According to the National Institutes of Health (NIH), a disease is rare if it affects fewer than 200,000 people. Nearly 1 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 and only approximately 450 FDA-approved medical treatments.

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. Rare Disease Day is sponsored in the U.S. by the National Organization for Rare Disorders (NORD)[®], the largest and leading independent, nonprofit organization committed to the identification, treatment, and cure of rare diseases.

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

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