Dear XXX,

I am writing today to ask for your help raising awareness for the over 25 million Americans affected by
a rare disease.Rare Disease Day is **Monday, February 28** – the rarest day of the year – and it is an annual celebration of and awareness campaign for the rare disease community. On the day,landmarks and buildings all over the country will be illuminated in support of all those affected by rare diseases and their families. We call this incredible network to shine a light on rare disease, **Light Up for Rare**. The Light Up for Rare concept began in 2019 when the Empire State Building in New York City was striped in pink, green, blue, and purple, the colors of Rare Disease Day. Now, we Light Up for Rare every year to put a spotlight on the over 7,000 known rare diseases and advocate for health equity for those affected by rare diseases.

Prader-Willi syndrome (PWS) is a rare disease that results from an abnormality on the 15th chromosome. Building awareness of rare diseases is so important because 1 in 20 people will live with a rare disease at some point in their life. Despite this, there is no cure for most rare diseases, and many go undiagnosed. PWS is a rare disease that occurs in approximately one out of every 15,000 live births. PWS affects all sexes, races and ethnicities. PWS is recognized as the most common genetic cause of life-threatening childhood obesity. In addition to obesity, a variety of other symptoms can be associated with Prader-Willi syndrome. Individuals usually exhibit cognitive challenges, with measured IQs ranging from low normal to moderate intellectual disability. Those with normal IQs usually exhibit learning disabilities. Other issues may include growth hormone deficiency/short stature, small hands and feet, scoliosis, sleep disturbances with excessive daytime sleepiness, high pain threshold, speech apraxia/dyspraxia, and infertility. Behavioral difficulties may include obsessive-compulsive symptoms, skin picking, and difficulty controlling emotions. Adults with PWS are at increased risk for mental illness. PWS is a spectrum disorder and symptoms vary in severity and occurrence among individuals. Individuals diagnosed with PWS require life-long supports and services.

Could you join us by lighting up (building/landmark) in Rare Disease Day colors this year? We would love
to see as many buildings, monuments, and landmarks as possible lit up on **Monday, February 28!** I am happy to work with you further on how to light up (building/landmark) and join the global chain of lights.

For more information about Rare Disease Day and the #LightUpForRare campaign, visit the [website of the National Organization for Rare Disorders (NORD)](https://rarediseases.org/rare-disease-day/), the official US sponsor of Rare Disease Day. For more information on Prader-Willi Syndrome, visit the official website for PWSA | USA at [Home Page - Prader-Willi Syndrome Association | USA (pwsausa.org)](https://www.pwsausa.org/).

Let me know if you have any questions, and I look forward to hearing from you.

Kind regards,

Your contact details