<Date>

Mailing Address For Senators:

The Honorable <Full Name>

<Room #> <Name of> Senate Office Building

United States Senate

Washington, DC 20510

Mailing Address For Representatives:

The Honorable <Full Name>

<Room #> <Name of> House Office Building

United States House of Representatives

Washington, DC 20515

Re: Prader-Willi syndrome awareness

Dear Senator or Representative <Last Name>,

As a <relationship to PWS> and your constituent, I am writing to you to educate you about Prader-Willi syndrome (PWS), a rare disease that results from an abnormality on the 15th chromosome, and Rare Disease Day, the official international awareness-raising campaign for rare diseases which takes place on the last day of February each year.

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.

PWS was first described by Drs. Prader, Labhart, and Willi in 1956 based on the clinical characteristics of the children they examined. The common characteristics defined in the report included small hands and feet, abnormal growth and body composition (small stature, very low lean body mass, and early-onset childhood obesity), hypotonia, insatiable hunger, extreme obesity, and intellectual disability. Definitive diagnosis is now based on genetic testing.

The symptoms of Prader-Willi syndrome are likely due to dysfunction of a portion of the brain called the hypothalamus. The hypothalamus plays a crucial role in many bodily functions, including regulating hunger and satiety, body temperature, pain, sleep-wake balance, fluid balance, emotions, and fertility.

An unregulated appetite and easy weight gain characterize the later stages of PWS. These features most commonly begin between ages 3 and 8 years old, but are variable in onset and intensity. Individuals with PWS lack normal hunger and satiety cues. Food seeking behaviors are very common. In addition, the metabolic rate of persons with PWS is lower than normal. Left untreated, this combination of problems leads to morbid obesity and its many complications.

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.

<Insert your personal story. Adding your personal story is invaluable and it doesn’t have to be heart-wrenching. Your story will simply help personalize the issue for a Member of Congress who may have no direct experience with PWS.>

My hope is that by educating you about PWS, you will support policies that make a lasting and sustainable impact for those affected by PWS. I hope you will help the PWS community by ensuring:

* The “pre-existing condition” insurance status is maintained, and that health care remains affordable
* Individuals with PWS have access to appropriate residential and day programs to learn job skills
* Education and training is available for those affected by PWS
* Communities and schools are aware of and are equipped to work with individuals with PWS and their families
* New medicines and treatments are readily available

For more information about PWS, visit Prader-Willi Syndrome Association | USA's website at www.pwsausa.org

Sincerely,

<Your Name>

<Mailing address>

<City, State Zip Code>