Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

FOR IMMEDIATE RELEASE:

National PWS Awareness Day Press Release Announcement

A Historic Milestone for the PWS Community: Prader-Willi Syndrome Association | USA Receives Joint Congressional Support to Declare May 15th as National PWS Awareness Day

NEWS PROVIDED BY
PWSA | USA
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The Prader-Willi Syndrome Association | USA (PWSA | USA), a non-profit organization dedicated to enhancing the quality of life and empowering those affected by Prader-Willi syndrome, announced today that United States Congressman Paul D. Tonko (D-NY) and Congresswoman Maria Elvira Salazar (R-FL) have filed a joint resolution declaring May 15, 2023, and every May 15th thereafter, **Prader-Willi Syndrome (PWS) Awareness Day** in the United States of America.

"Securing May 15th as PWS Awareness Day in the United States has been a priority for PWSA | USA, and we are thrilled to see it come to fruition. Thank you to Congressman Tonko and Congresswoman Salazar for supporting this resolution and, in turn, the many families and individuals affected by PWS. When we are united, our hard work, dedication, and HOPE can become a reality. I am proud to say we are witnessing that today," said PWSA | USA CEO Paige Rivard, MBA.

"Rare and ultra-rare diseases pose numerous challenges for the millions of Americans living with a disease, from a lack of available treatments to less public awareness and medical expertise. This leaves patients and their loved ones with few places to turn. I authored the HEART Act to help amplify the voices of patients and families living with rare diseases and provide hope and possible treatments to those affected. My work to uplift the needs of those living with these rare conditions is far from over. I'm proud to introduce this resolution on Prader-Willi Syndrome alongside Rep. Salazar and am thankful to all those who have added their voice to raise awareness on this disorder," said Congressman Tonko.

"Prader-Willi syndrome is a rare genetic disorder, which has a lifelong impact on individuals living with PWS, their families, and caregivers. There is nothing more important than the health and well-being of our most vulnerable communities," said Congresswoman Salazar. *"I remain committed to ensuring families impacted by rare diseases like PWS get the help and resources they need, which is why I am happy to support this resolution declaring May 15th as PWS Awareness Day."*

Watch PWSA | USA's PWS Awareness Day announcement video, which features Congressman Tonko and CEO Paige Rivard, by clicking here.

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About Prader-Willi Syndrome:
Prader-Willi syndrome (PWS) is a variable, complex rare genetic neurobehavioral spectrum disorder with symptoms resulting from the loss of function of a critical region in the paternally derived 15th chromosome.

Its symptoms vary widely in severity between individuals. Infants have failure to thrive due to feeding problems and hypotonia. Toddlers have increased weight gain. Most of the medical problems in Prader-Willi syndrome are related to obesity, hypotonia, and hypothalamic dysfunction. Other medical complications include high pain tolerance, gastrointestinal and respiratory issues, and difficulty with temperature regulation. Adrenal insufficiency occurs in a small percentage of the population. The most common and challenging symptom among those diagnosed is hyperphagia, insatiable hunger, which can lead to life-threatening obesity which is not responsive to bariatric surgery (PMID: 35416416). The worldwide average lifespan of a person with PWS is 29 years old. Currently, the only FDA-approved treatment for PWS is human growth hormone which was approved over 20 years ago. PWS has no cure.

About Prader-Willi Syndrome Association | USA:
Prader-Willi Syndrome Association | USA was formed in 1975 to unite parents, professionals, and other interested citizens to enhance the quality of life of those affected by Prader-Willi syndrome. PWSA | USA empowers the PWS community through shared experiences, research, education, advocacy, and support. We can’t do it alone. We invite you to help us continue to assist our loved ones affected by PWS by making a donation or learning more about how you can be involved.

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