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Rare Disease Advocates Will Unite in Washington, D.C., to Celebrate National Prader-Willi Syndrome (PWS) Awareness Month and National PWS Awareness Day

May 8, 2024 (Washington, D.C.) -- Prepare for a powerful convergence in the heart of Washington, D.C., on May 15th as advocates for individuals living with Prader-Willi syndrome (PWS) gather for PWSA | USA's important advocacy event, the D.C. Fly-In. This year marks the 2nd National PWS Awareness Day, a significant milestone achieved through the dedication of U.S. Congressman Paul D. Tonko (D-NY) and Congresswoman Maria Elvira Salazar (R-FL). They introduced a joint resolution officially declaring the day of recognition last year on May 15, 2023.

Organized by PWSA | USA, the 2nd D.C. Fly-In event has seen remarkable growth since its inception in September 2022, with attendance growing from 50 individuals to nearly 150. Among those participating are parents, caregivers, siblings, extended family members, and individuals living with Prader-Willi syndrome.

This two-day event kicks off May 14th with a rare disease policy dive, which will extend through May 15th when our advocates will begin the celebration of PWS Awareness Day on the floor of the U.S. House of Representatives. Throughout the day, advocates will engage in more than 100 meetings with elected officials and their staff to raise awareness for PWS and advocate for support on three critical initiatives.

These initiatives include the Promising Pathway Act 2.0, aimed at advancing research and treatments for rare diseases like PWS; the Peer Reviewed Medical Research Program (PRMRP), which provides funding for innovative medical research; and a congressional letter of support to the FDA, urging continued attention to PWS-related issues.

"This is an extremely important time for our rare disease community," said PWSA | USA CEO Stacy Ward, MS, BCBA. "By coming together in Washington, D.C., we are amplifying our voices and advocating for policies and initiatives that can profoundly impact the lives of those affected by Prader-Willi syndrome."

“I have been an advocate for my daughter since she was born 12 years ago - every time we walk into a doctor's office, therapy appointment, or IEP meeting, when she starts a new sport or we meet a new family, every phone call with an insurance agent or pharmacy, and beyond. I have always been the only PWS parent in the room, with the exception of my husband. Now I get to travel to our nation's capital and share our story in the halls of legislature alongside people who can relate. Attending this fly-in is an incredible opportunity to not only advocate for my daughter, but an entire community,” said Anne Fricke, mom to Freya (12), living with PWS.

For more information about PWS Awareness Month and how you can get involved, please visit PWSA | USA's dedicated webpage: https://www.pwsausa.org/pwsawarenessmonth/

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About PWSA | USA

Prader-Willi Syndrome Association | USA (PWSA | 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. With chapters in most states, ours is the only national PWS support organization whose sole purpose is to assist individuals with the syndrome, and their families, every step of the way.

About Prader-Willi syndrome (PWS)

Prader-Willi syndrome is a variable and complex genetic disorder resulting from an abnormality on the 15th chromosome. It occurs in males and females equally and in all races. PWS is diagnosed in 1:15,000 to 1:25,000 newborns each year.

Key features include:

- Insatiable Hunger: A distinctive trait of PWS is an unending appetite. This, paired with a slowed metabolism, often leads to significant weight challenges.
- Muscle & Growth: Individuals with Prader-Willi syndrome typically have weak muscle tone and less muscle mass. They also often grow to be shorter than average if they don't receive the right treatment.
- Cognitive Aspects: People with PWS can face learning disabilities, making everyday tasks a little bit tougher.
- Behavioral Challenges: People with Prader-Willi syndrome often face various behavioral challenges. These can include frequent temper tantrums, compulsive skin-picking, stubbornness, and obsessive-compulsive behaviors. Managing these behaviors requires patience and understanding.
- Sleep-Related Issues: Individuals living with PWS often experience sleep-related issues including Excessive Daytime Sleepiness (EDS) and Narcolepsy

PWS is rare and many have not heard of it. There are very few medical specialists familiar with PWS. However, Prader-Willi Syndrome Association | USA is here to offer support and hope to families who are newly diagnosed and throughout your journey with PWS! Our website is full of resources on PWS, and we have a dedicated staff standing by ready to assist you 24 hours a day, 365 days a year.