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**PWSA | USA’s D.C. Fly-In Op-Ed Template**

[CAPITAVING TITLE]

**Example: My Son Has a Rare Disease with No New Treatment. We Need Congress’ Help.**

[PLACE YOUR HOOK AT THE BEGINNING OF YOUR OP-ED – WHAT IS YOUR SPECIFIC MOTIVATION / WHAT ARE YOUR ADVOCATING FOR IN THIS PIECE]

**Example:** One in 10 people live with a rare disease. While each individual rare disease may be statistically rare, when one in 10 people has a rare disease, then it isn’t really rare at all.

In state capitals, Congress, and the Food and Drug Administration, our public officials were quick to step in when COVID-19 struck the country. But that speed and efficiency aren’t granted to those with rare diseases, who live with limited, if any, treatments. Congress must advance legislation that would promote research for those still waiting in line for the next big innovation, like my son.

[SHARE YOUR PERSONAL STORY / CONNECTION TO PWS]

**Example:** Hunter is my beautiful, four-and-a-half-year-old son who is diagnosed with Prader-Willi Syndrome (PWS). I remember what he looked like the first time I saw him in the NICU. At 8 pounds and 20 inches, he was by far the largest baby in the NICU, but completely unable to even wrap his little hand around my fingers.

On day 16 of being in the NICU, two doctors came into the room. They couldn’t even look me in the eye. *“*Your baby has a condition called Prader-Willi Syndrome, also known as PWS,” they said*.* I had no idea what Prader-Willi Syndrome was, but I knew our lives would never be the same. The very next day, with no support, no paperwork, no person or organization to turn to, we were discharged into the world.

As I’ve come to learn, PWS is a genetic disorder that affects growth, leads to mental and behavioral problems, contributes to life-threatening obesity in children, and can result in a genetic neurobehavioral disorder due to an abnormality on the 15th chromosome.

At our doctors’ recommendation, Hunter started on the *only* FDA-approved treatment, a growth hormone, to help “some” of the symptoms associated with PWS. We also learned that there was a handful of promising orphan drug trials taking place, that would likely provide additional treatment options by the time Hunter turns 5.

Hunter will be five on July 25th. We have no additional FDA-approved treatments to alleviate the symptoms associated with PWS.

[GIVE BRIEF DESCRIPTION ABOUT WHAT PWS IS]

**Example:** PWS was discovered in 1956, yet it took over half a century for the FDA to approve *one* treatment. And this is a treatment that can help alleviate “some” of the physical symptoms associated with PWS, but *not* the extreme hunger, or hyperphagia; *not* the emotional outbursts; *not* the lack of cognitive development. Growth hormones will do nothing to improve the likelihood that my son could have a chance to live a more typical life, without constant support and supervision 24 hours a day, 7 days a week, 365 days a year.

[REITERATE ASK / WHAT YOU HOPE TO GAIN FROM WRITING THIS OP-ED PIECE]

**Example:** We need therapies, and we need them STAT. The STAT Act is a bipartisan, bicameral, community-led bill aimed at improving the development of and access to therapies for the entire rare disease community. One of the things the STAT Act does is create a Center of Excellence at the FDA. This would give rare disease communities like ours a direct connection to a center that does nothing but advocate, investigate and work to help meet the unmet needs of the rare disease community. If the FDA is serious about giving rare disease patients a voice, then a center of excellence representing our interests will be essential.

For almost the entire rare disease community, orphan drug designation and funding have been a godsend, and as inflation makes drug development even more expensive, it will only become more important. Orphan drugs are for extremely rare conditions, and therefore won’t be profitable for a company to produce.

Over the past several years, we have seen repeated attempts by our government to limit the incentives pharmaceutical companies have to continue funding the research and development of these drugs. The rare disease community cannot afford to sit back and allow people who have no conception of what it means to live with a rare disease to take away our hope that our loved ones could one day live a typical life and be productive members of society.

That’s why I’m heading to D.C. next week as part of the Patients Rising Now We the Patients Fly-In, with my husband and son, to speak with lawmakers first-hand about our experiences and needs, and encourage legislation like the STAT Act that helps those battling rare diseases.

[GIVE YOUR PERSONAL INFORMATION AND HOW YOU CAN BE CONTACTED]

**Example:** *Dorothea Lantz lives in Miami with her husband and 4-and-a-half-year-old son, Hunter, who lives with Prader-Willi Syndrome (PWS). She is a community engagement specialist at the Prader-Willi Syndrome Association USA. If you’re interested in interviewing Dorothea, please contact her at* [*dlantz@pwsausa.org*](mailto:dlantz@pwsausa.org)*.*

[INCLUDE A PICTURE IF YOU CHOOSE]