

## May is National Prader-Willi Syndrome (PWS) Awareness Month



## What is Prader-Willi Syndrome (PWS)?

Prader-Willi syndrome (PWS) 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 1:20,000 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.



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