

# What is Prader-Willi Syndrome (PWS)?



Prader-Willi syndrome is a rare genetic disorder characterized by chronic hunger, growth hormone deficiency, and behavior challenges. PWS is diagnosed in 1:15,000 to 1:20,000 newborns each year.

Understanding PWS is crucial for supporting those affected, enhancing their lives, and promoting inclusivity in society.



## Prader-Willi Syndrome Characteristics:

- **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 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.

### Early Life

Immediately after birth, the symptoms of Prader-Willi syndrome become noticeable. Infants often exhibit distinct physical and behavioral patterns. They typically experience **muscle weakness** (decreased muscle tone, making infants appear "floppy"), **feeding difficulties** (trouble sucking or feeding, often requiring special assistance), and **distinct facial features** (almond-shaped eyes and a narrow bifrontal diameter).

### Childhood

The toddler and childhood years see a shift in PWS symptoms. Key challenges emerge related to eating, learning, and behavior. They typically experience **insatiable hunger** (beginning around age 8, leading to weight gain if not managed), **learning challenges** (mild to moderate intellectual impairment and delayed motor skills), and **behavioral issues** (including temper tantrums, stubbornness, and compulsive behaviors).

### Teenage Years

The teenage phase is challenging, especially for individuals with PWS. They have to navigate through typical growth issues unique to PWS. They typically experience **incomplete puberty** (delayed or incomplete physical development, which can lead to short stature), **social struggles** (difficulty with peer relationships and social integration), and **ongoing hunger** (preventing obesity is important for people with PWS).

### Adulthood

As individuals with PWS transition from young adults into adulthood, they face a blend of health and social concerns. The emphasis is often on long-term health management and social integration. They typically experience **endocrine issues** (challenges like diabetes or low sex hormone levels), **orthopedic problems** (scoliosis and osteoporosis may develop), **mental health concerns** (risk of depression, anxiety, and other mood disorders). Adults living with PWS often face challenges with independence and typically reside with a family member or in a supportive group home.

