# What is Prader-Willi Syndrome (PWS)?





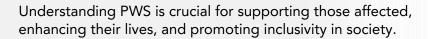








Prader-Willi syndrome is a rare genetic disorder characterized by chronic hunger, growth hormone deficiency, and behavior challenges. PWS is diagnosed in 1:15,000 to 1:20,000 newborns each year.





## **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.

