PWS AWARENESS MONTH FACT #1

PWS affects one in 15 – 20,000 births

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #2

Prader-Willi syndrome affects all races and genders equally

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #3

Doctors Prader, Willi, and Labhart discovered PWS in 1956 based on the clinical features of nine children. Since 1956, diagnosis has been confirmed through genetic testing as early as a few days after birth.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #4

There are three genetic causes of PWS:

- Uniparental Disomy
- Deletion
- Imprinting Defect

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #5

Deletion occurs when the 15q11-13 region is missing on the paternal chromosome 15

51% of individuals with PWS have deletion

There are several deletion subtypes

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #6

Imprinting defect occurs when the 15q11-13 region is inactive on the paternal chromosome 15

Less than 5% of people with PWS

The only type that can be hereditary

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #7

Uniparental Disomy occurs when the child receives two chromosome 15s from mom and none from dad

51% of individuals with PWS have deletion

There are several deletion subtypes

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

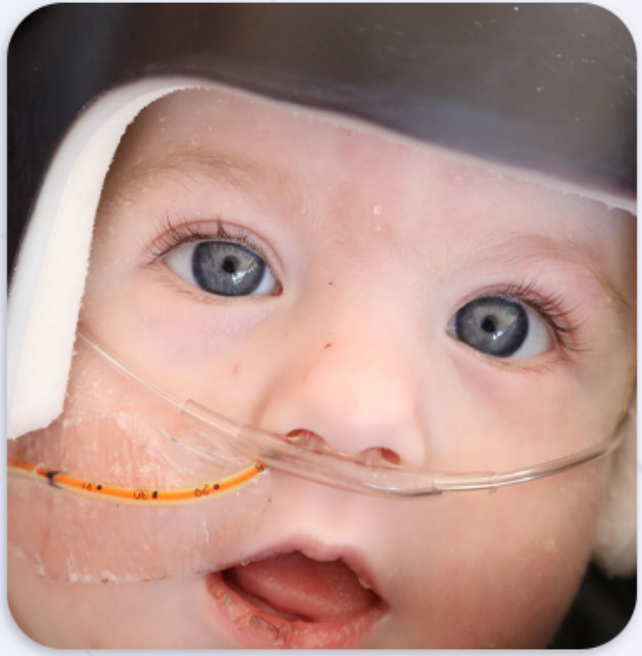
PWS AWARENESS MONTH FACT #8

Human growth hormone (GH) is the only FDA approved drug to treat PWS. GH decreases body fat, increases muscle mass, improves bone density and positively affects behavior and cognition. Many individuals with PWS start GH before their first birthday.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #9

Infants with PWS may require the use of feeding tubes to obtain adequate nutrition.



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #10

Individuals with PWS have an incidence of developing scoliosis at rates between 40-90%. Thankfully, there are several treatment options available.

- Bracing
- Casting
- Surgery

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #11

Impaired vision is a treatable symptom of PWS either with corrective lenses or surgery.

Prader-Willi SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #12

Hypogonadism and cryptorchidism are common in infants with PWS. Treatment options include medication and surgical intervention.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #13

Many individuals with PWS have sensory integration deficits in their vestibular, proprioceptive, tactile and oral-motor systems. A sensory integration program designed by an Occupational Therapist is the most common form of treatment.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #14

Many individuals with PWS have decreased pain signals, often masking injuries and illness.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #15

Excessive daytime sleepiness (EDS), cataplexy, and narcolepsy affect many individuals with PWS. Join us September 27th for PWSA | USA's Virtual Sleep Summit to learn more about disordered sleep in PWS.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #16

Individuals with PWS experience high levels of anxiety that negatively affects functioning. With the help of therapies, social stories and medication, anxiety may be better managed.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #17

Hypotonia affects individuals with PWS throughout their lives. The use of growth hormone, play, and therapies improves muscle tone.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #18

PWS caregivers incur high caregiver burden that impacts most aspects of caregiver life.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #19

Gross motor milestones are often delayed due to hypotonia. Early access to physical therapy and gross motor play aid in improving gross motor strength.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #20

There is not one best “PWS” diet, following what is sustainable for your family is best. Making healthy life-style choices, limiting processed foods and eating a diet focused on natural whole foods and healthy fats is encouraged.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #21

Temperature regulation can be a concern for individuals with PWS. They may overheat on a warm day or be at risk for hypothermia on a cold day.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #22

PWS is one of 7,000 rare diseases. This is why we need YOU to join our advocacy efforts.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #23

Similar to other spectrum disorders, individuals with PWS may have difficulty reading facial expressions and social cues. The use of social stories can be helpful in identifying emotions.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #24

At PWSA | USA, we work to integrate what we have learned about the needs of our families with research that will make a practical difference in the lives of those affected by PWS.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #25

Historically, measured IQ's range from normal to moderate intellectual disability. Many individuals with PWS are now working on post-secondary education goals.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #26

Hyperphagia symptoms commonly begin between ages 3 and 8. Currently, there are no FDA approved treatments for hyperphagia.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #27

Individuals with PWS are at increased risk for choking, subclinical dysphagia (silent choking) and aspiration and should be supervised while eating or drinking.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #28

Many families utilize cabinet and refrigerator locks to keep their loved ones safe and decrease their anxiety.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #29

Many individuals with PWS have poor impulse control placing them at risk of injury or harm. The use of social stories and therapy may improve impulse control.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #30

Many individuals with PWS present with speech and language deficits. Speech therapy is often provided through early intervention services.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS AWARENESS MONTH FACT #31

Each year, PWSA | USA's staff helps thousands of families.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES