

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES



PWS Awareness Month Fact Toolkit



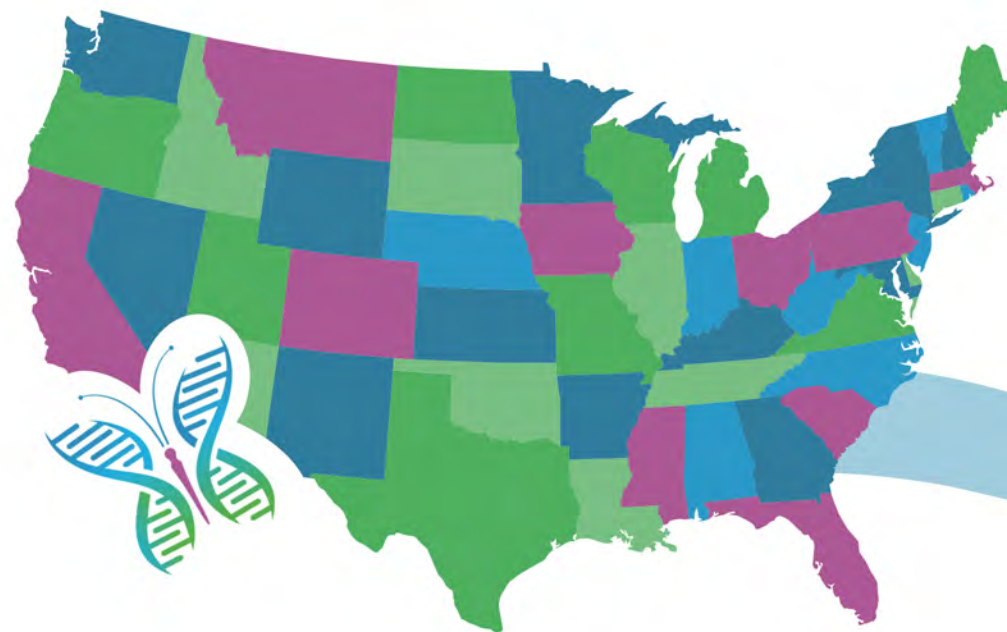
FACT #1



**PWS affects one in
15,000-20,000 births.**

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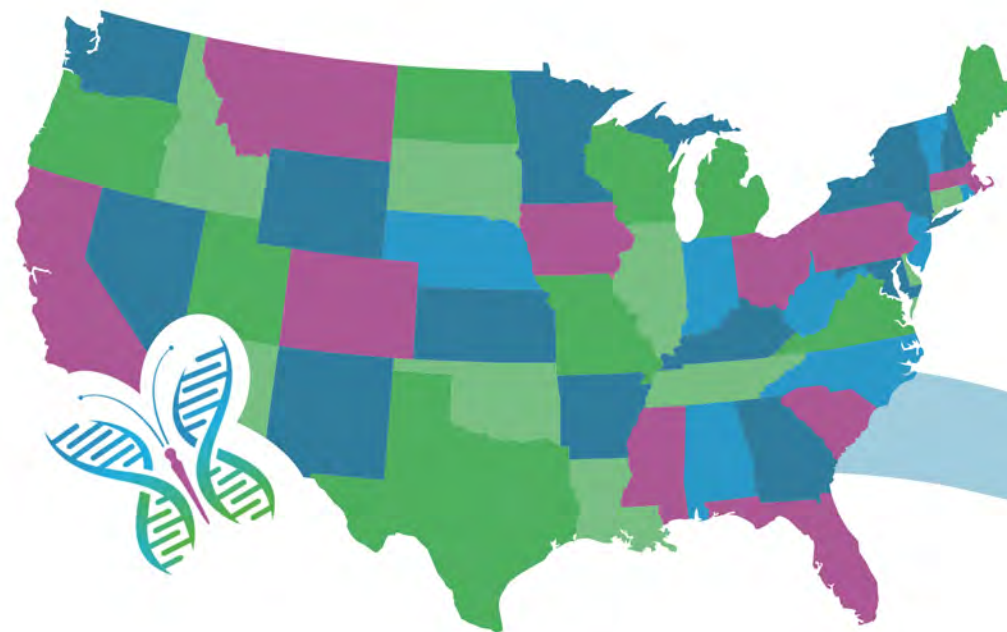
FACT #2



**PWS affects all races
and genders equally.**

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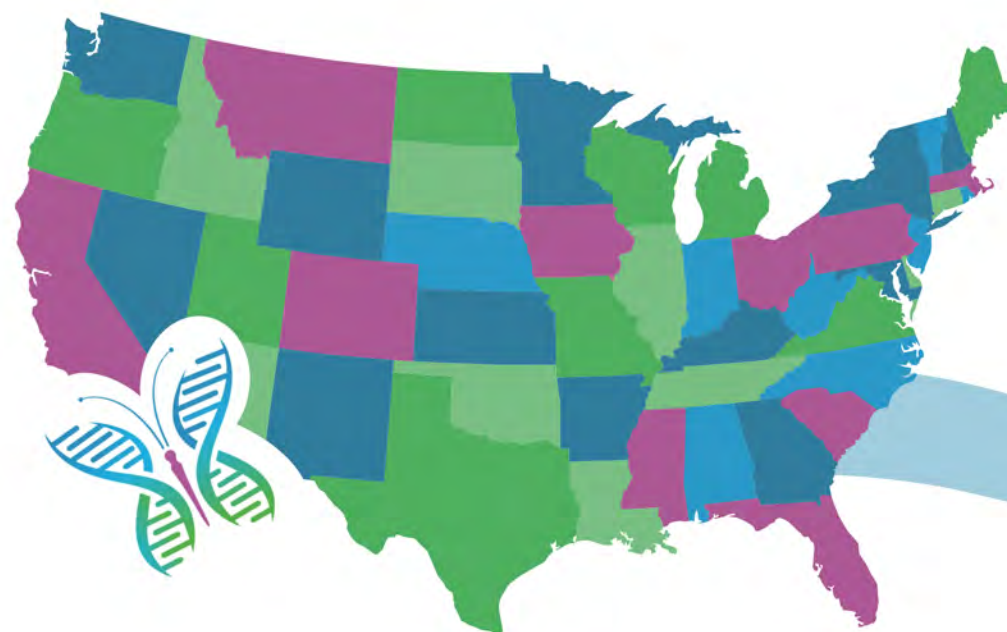
FACT #3



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 male testing as early as a few days after birth.

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FACT #4



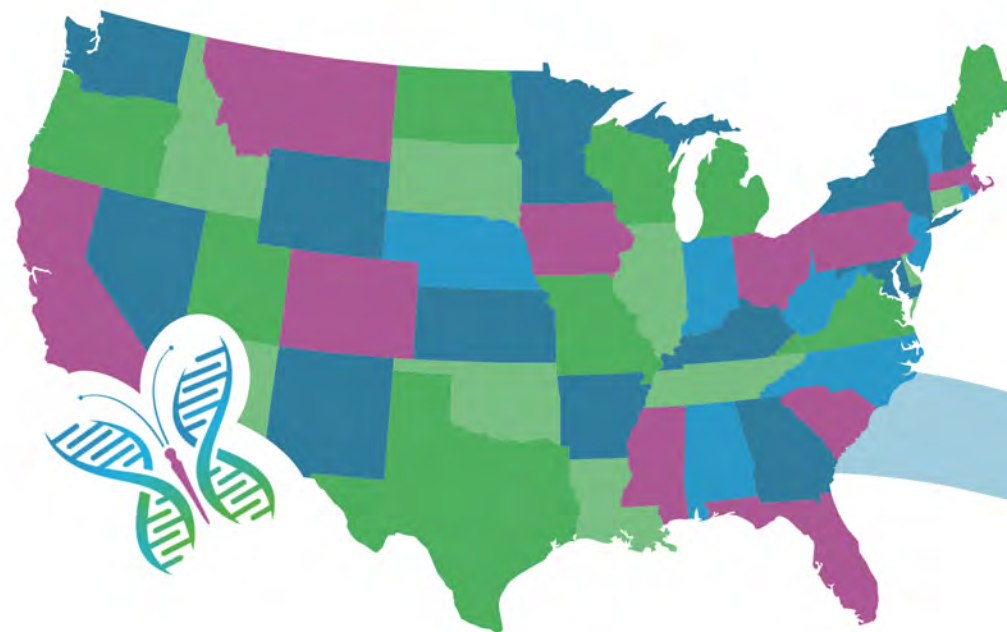
There are 3 genetic causes of PWS:

- Uniparental Disomy
- Deletion
- Imprinting Defect



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FACT #5

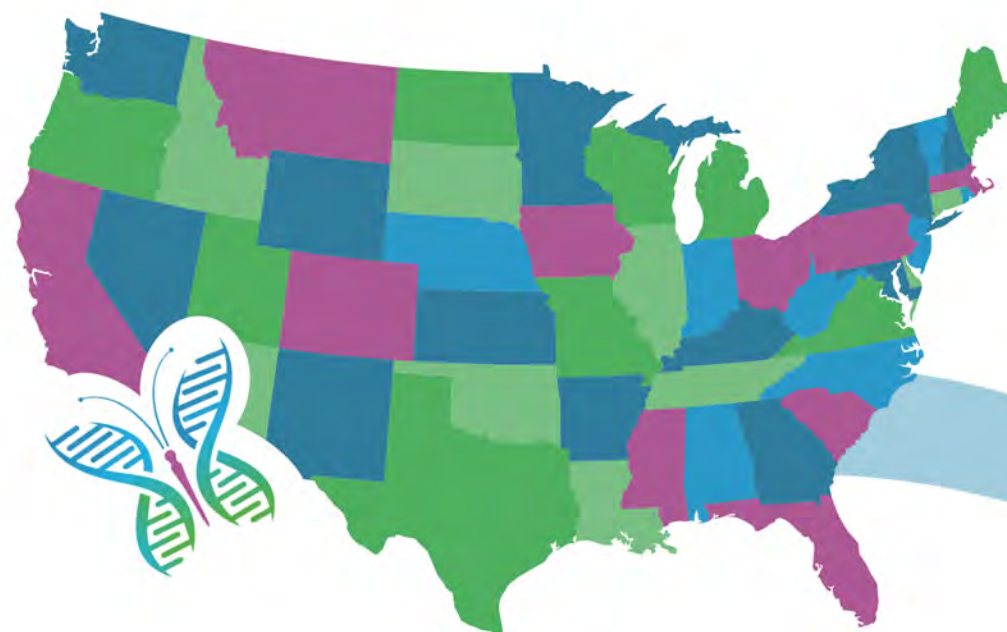


Deletion occurs when the 15q11-13 region is missing on the paternal chromosome 15.

- 51% of individuals with PWS have deletion
- There are several deletion subtypes

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FACT #6



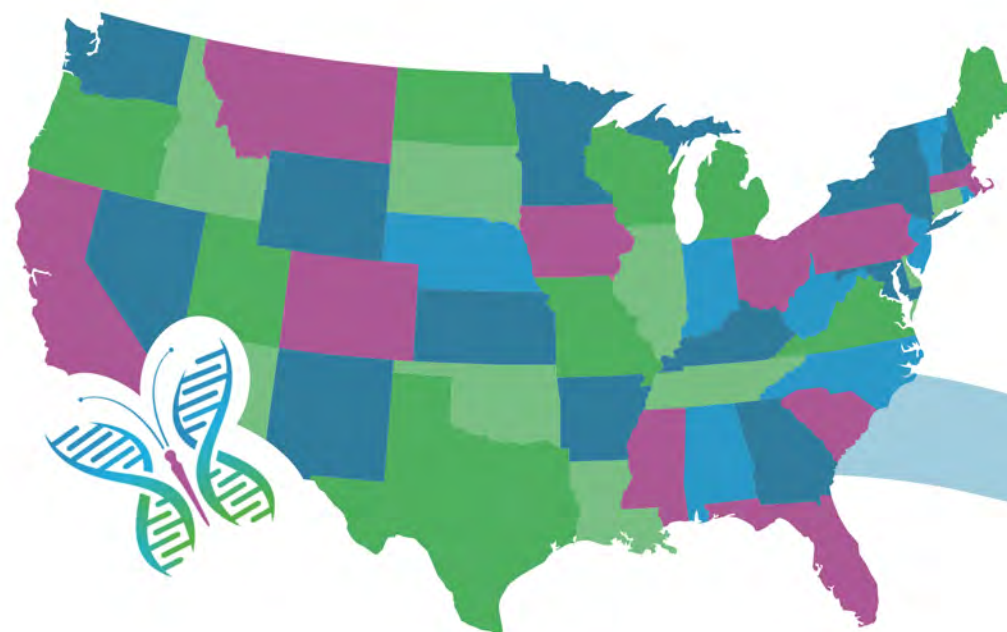
The imprinting defect occurs when the 15q11-13 region is inactive on the paternal chromosome 15.

- Found in less than 5% of people with PWS
- The only type that can be hereditary



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FACT #7

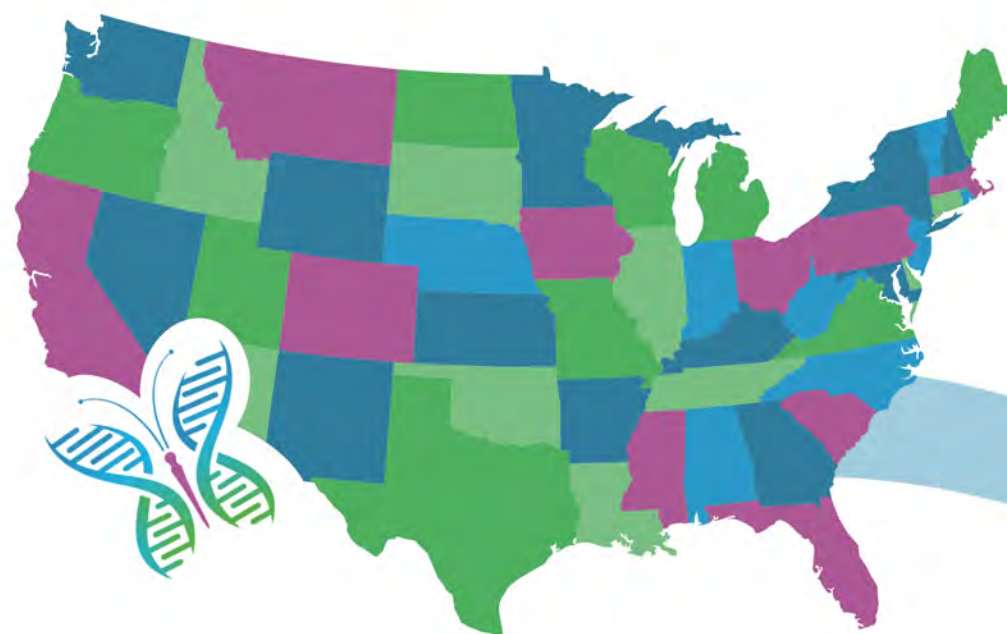


Uniparental Disomy occurs when the child receives two chromosomes 15s from Mom and none from Dad.

- 51% deletion, 38% UPD less than 5%
- There are several deletion subtypes

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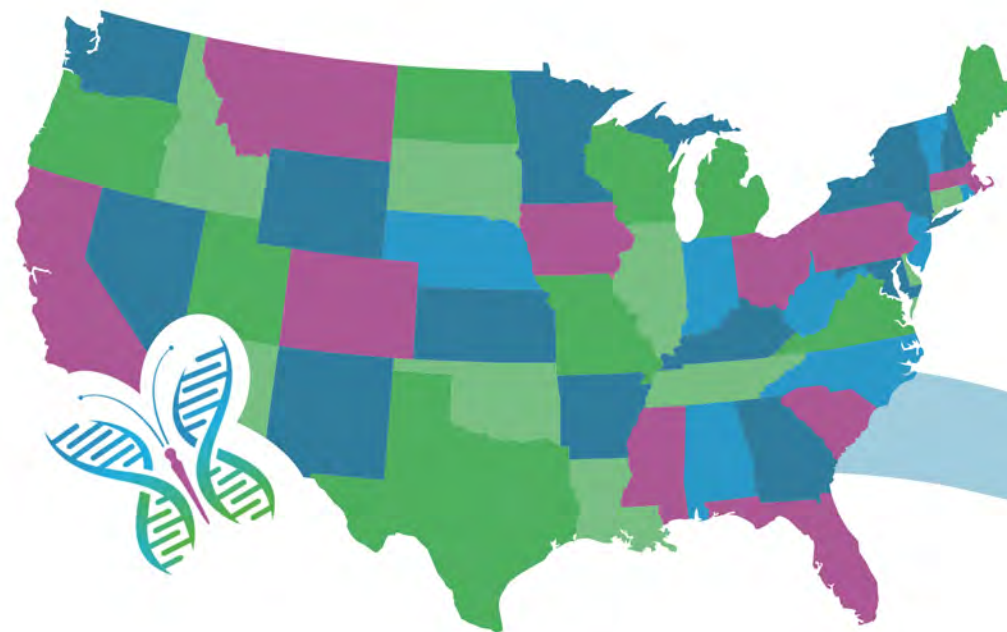
FACT #8



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.

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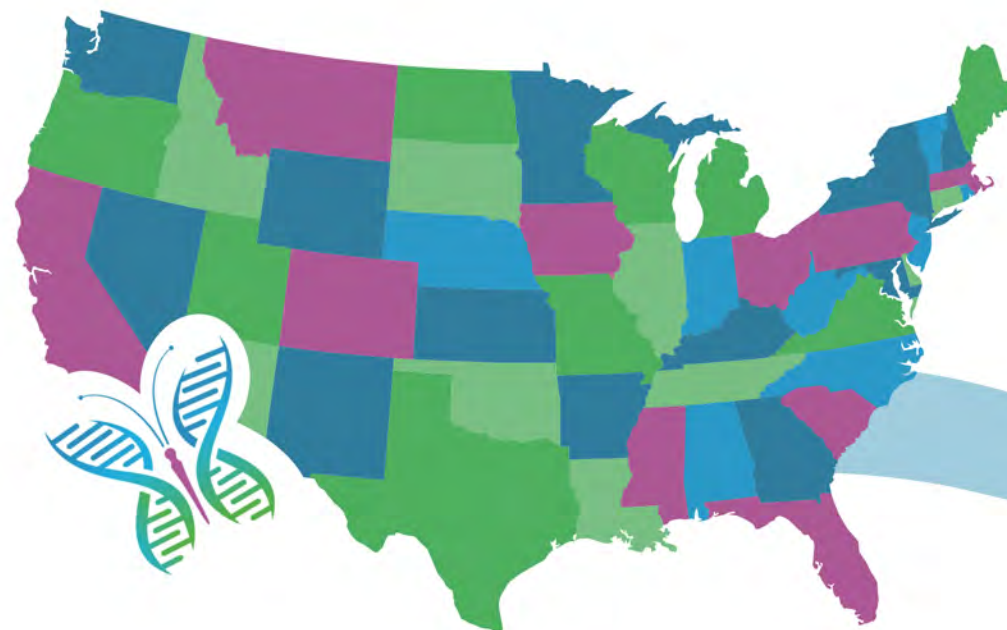
FACT #9



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

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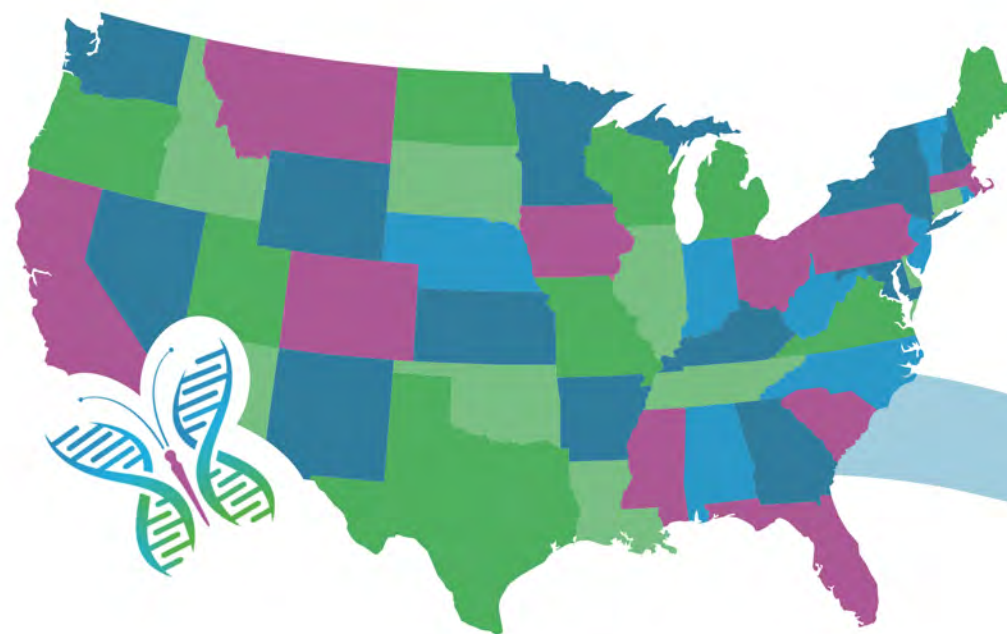
FACT #10



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

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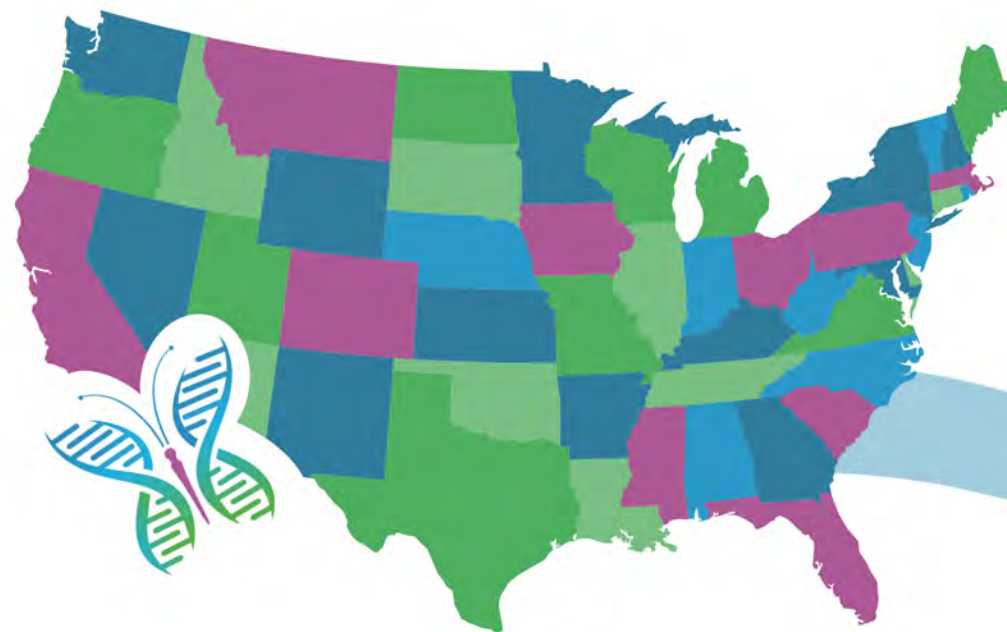
FACT #11



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

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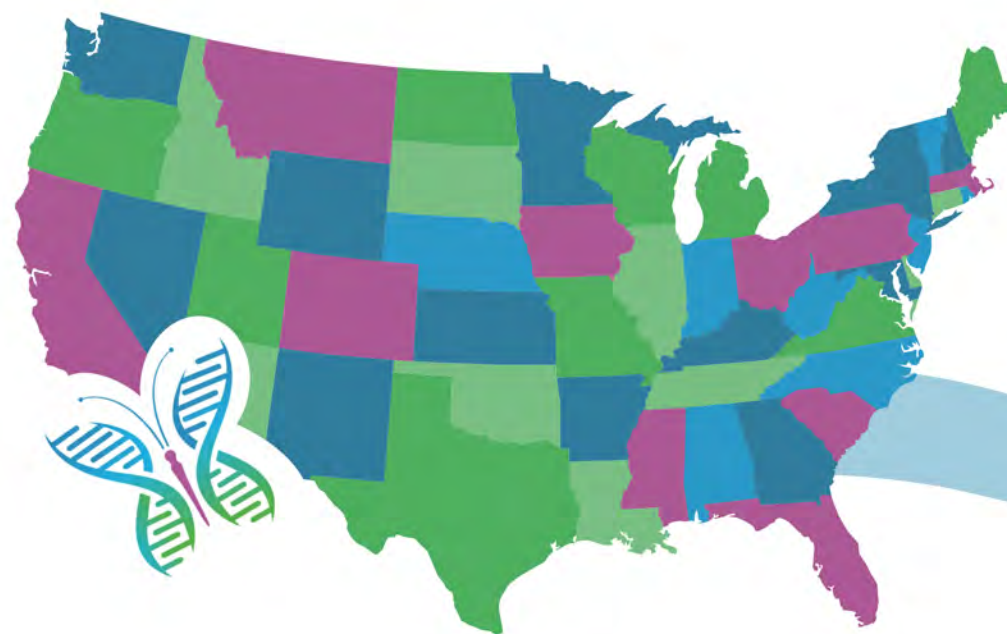
FACT #12



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

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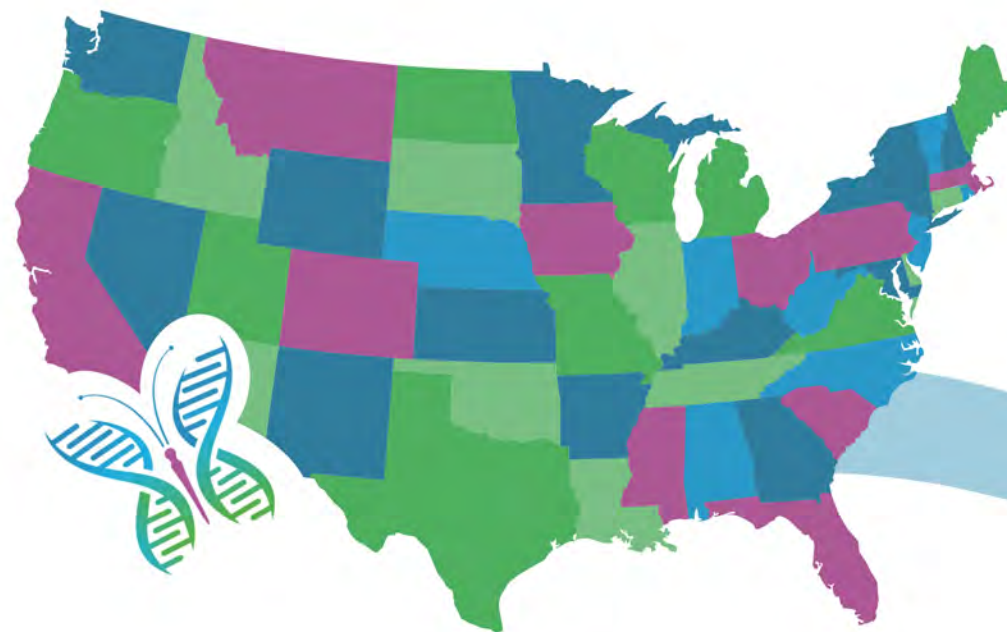
FACT #13



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

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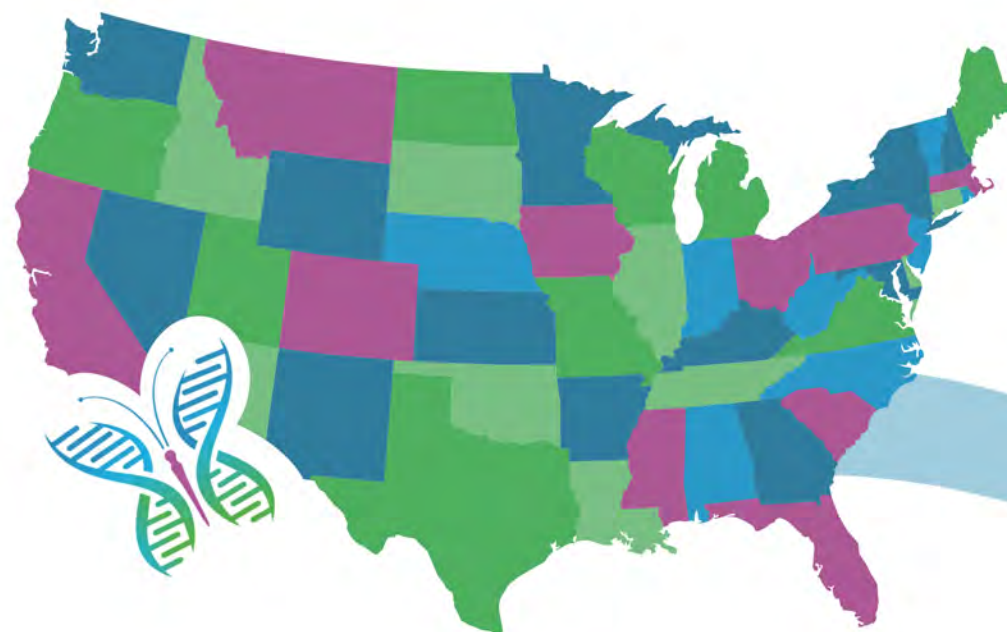
FACT #14



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

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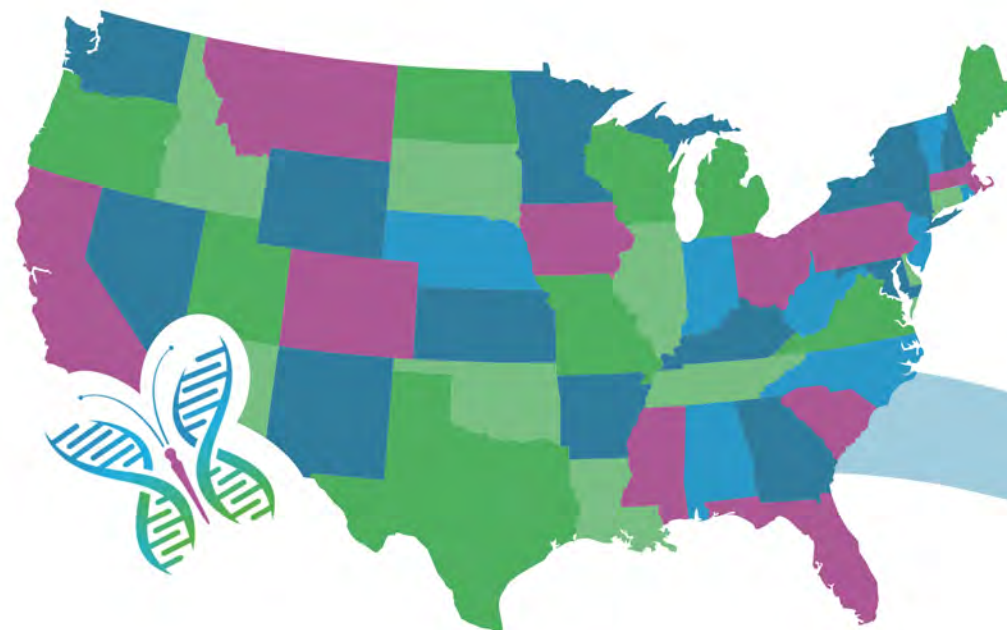
FACT #15



Excessive Daytime Sleepiness (EDS), cataplexy, and narcolepsy affect many individuals with PWS. There is at least one pharmaceutical trial drug showing promising results in the management of EDS. PWSA has gathered important information from our Sleep Summit and will be unveiling a Sleep Resource Section on their website this year.

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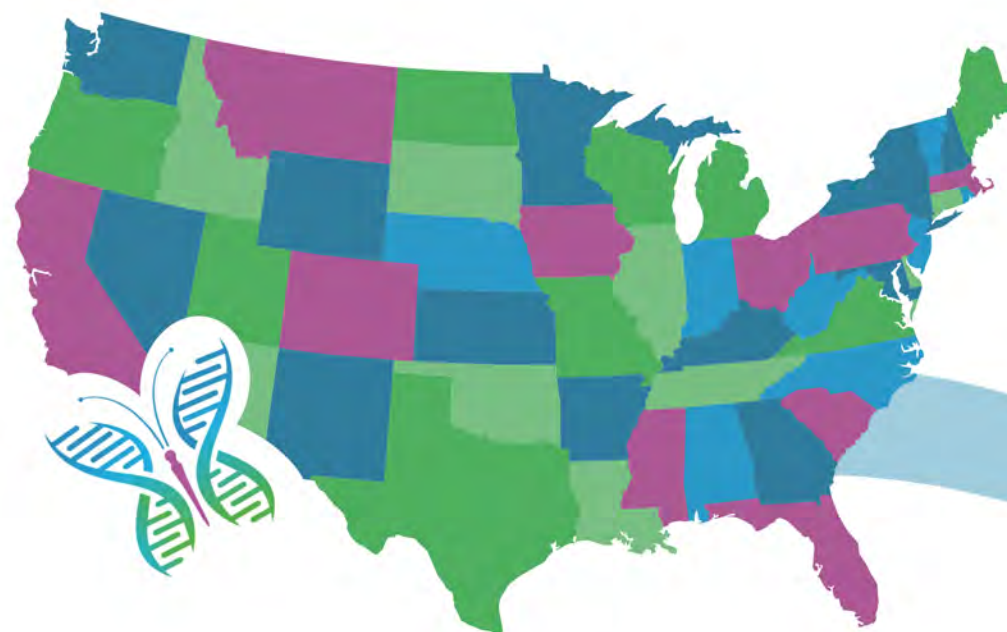
FACT #16



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.

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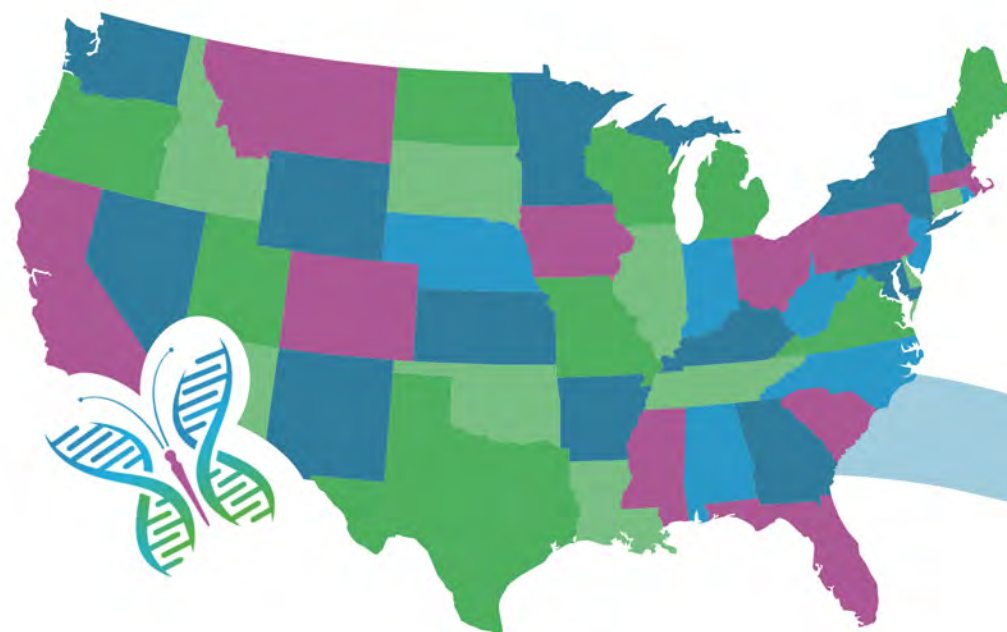
FACT #17



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

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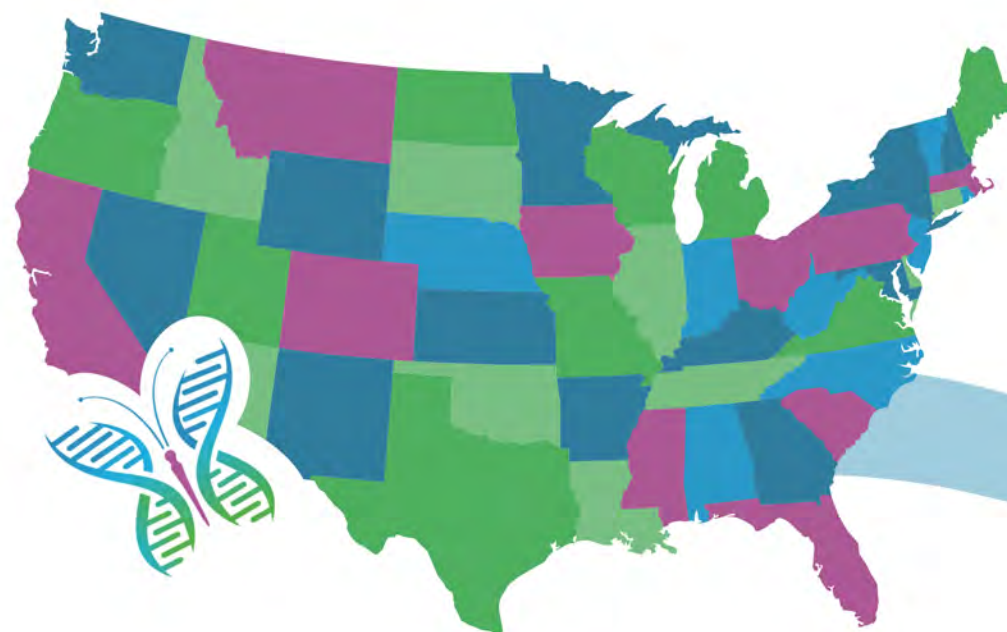
FACT #18



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

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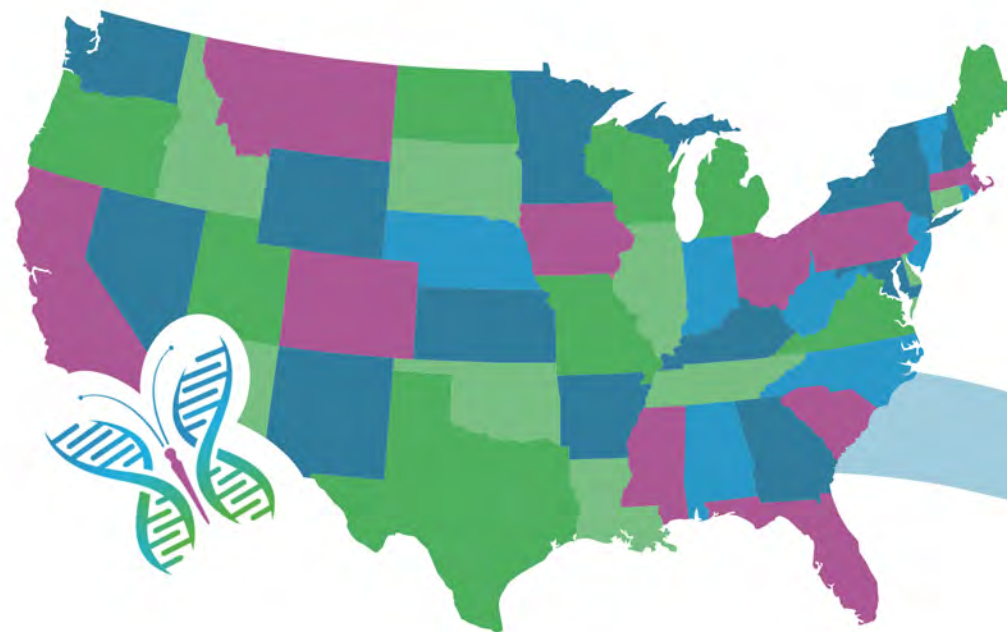
FACT #19



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

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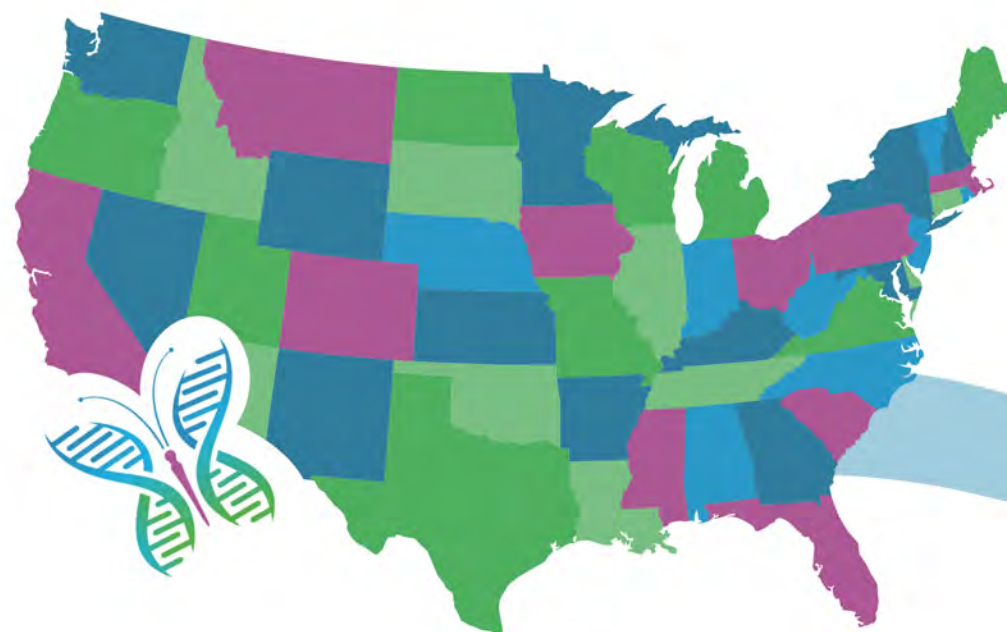
FACT #20



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.

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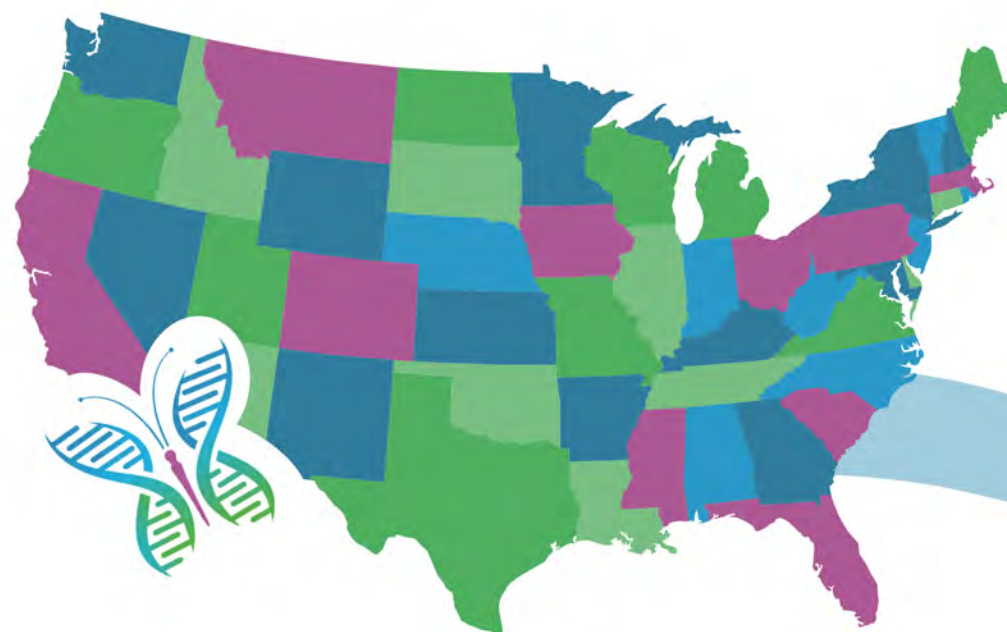
FACT #21



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.

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FACT #22



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

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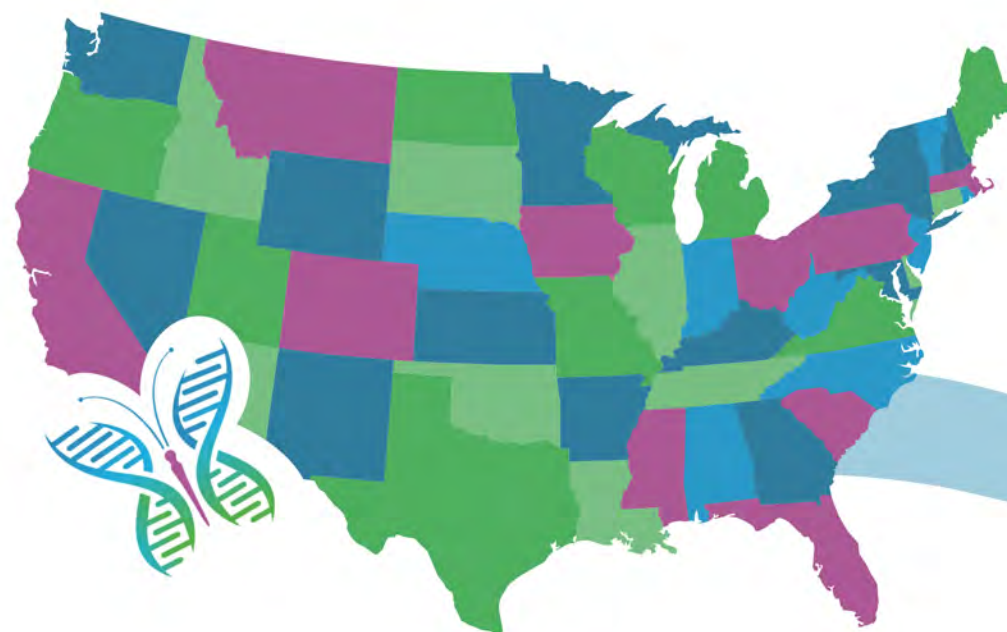
FACT #23



Like 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.

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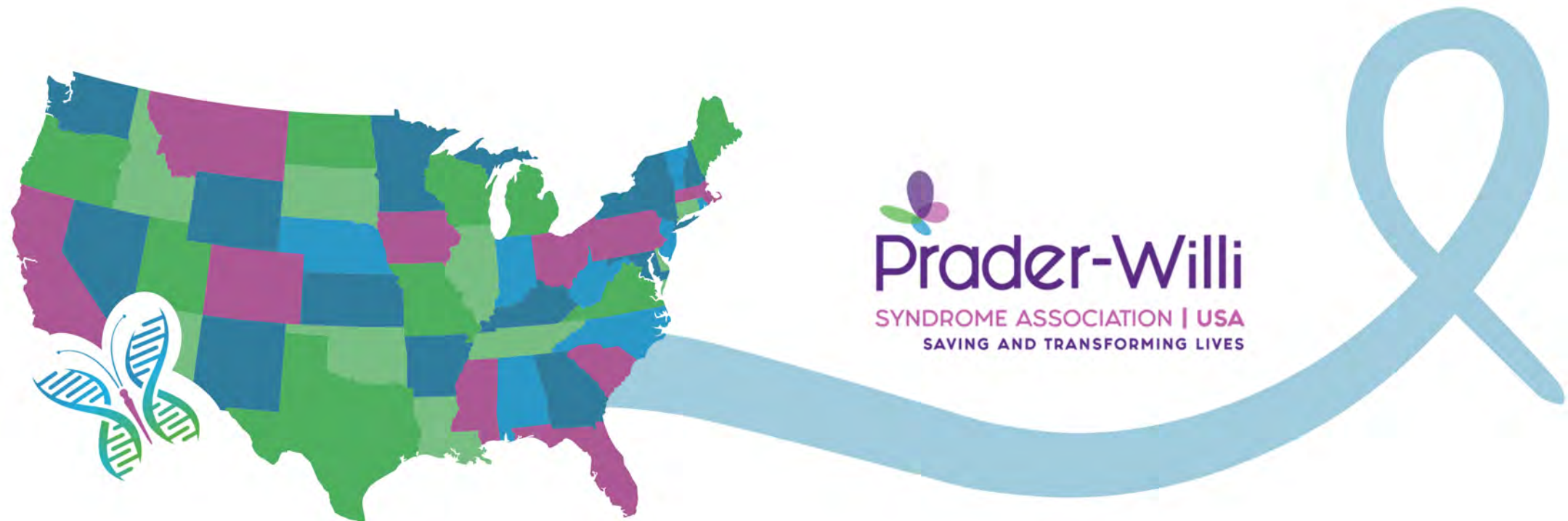
FACT #24



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.

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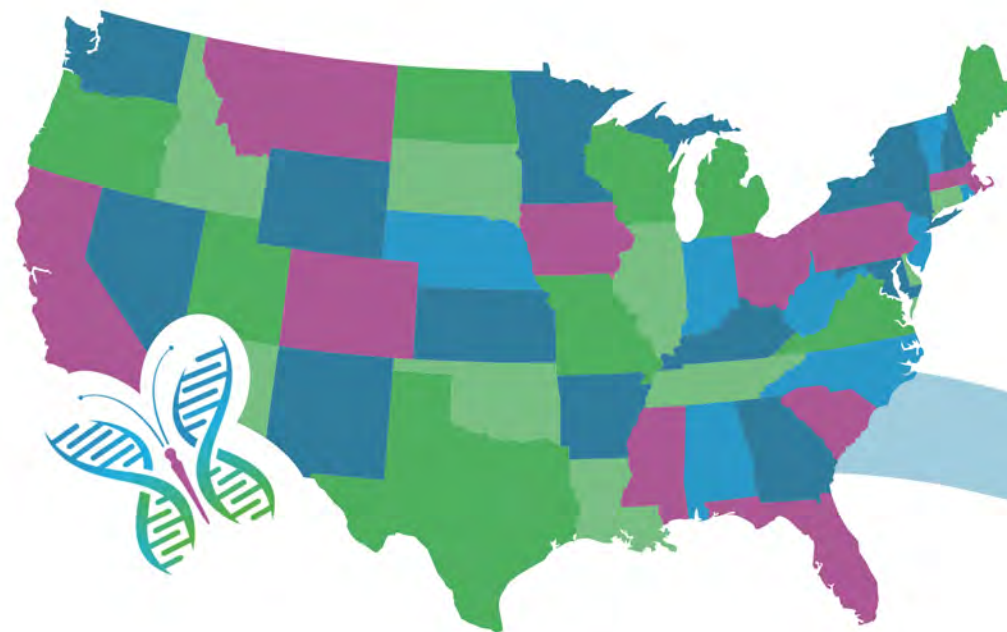
FACT #25



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

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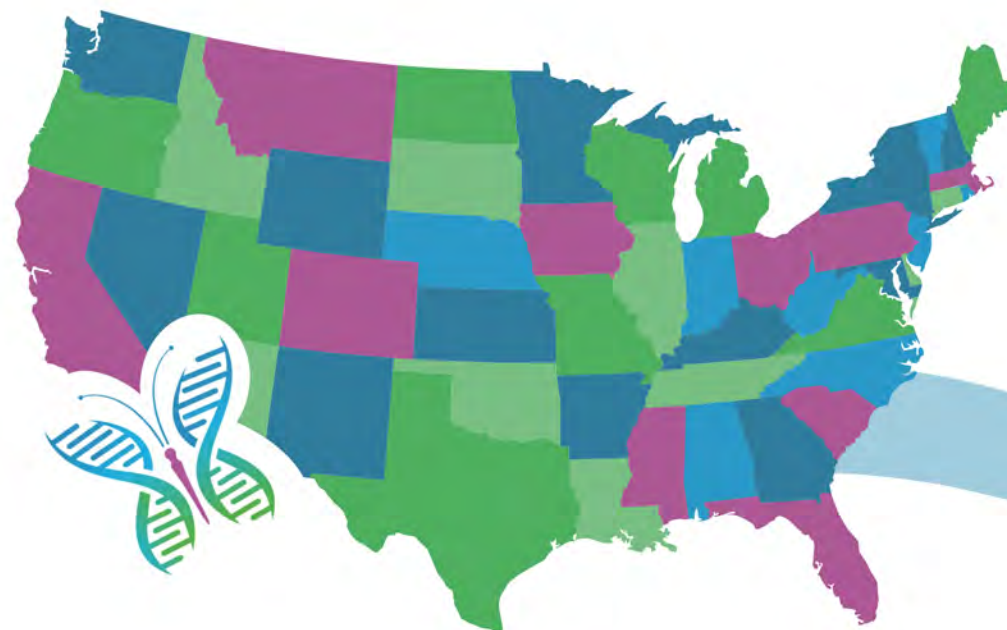
FACT #26



Hyperphagia symptoms commonly begin between ages 3 and 8. Many families utilize cabinet and refrigerator locks to keep their loved ones safe and decrease anxiety. There are drugs in clinical trials that show promise in treating hyperphagia.

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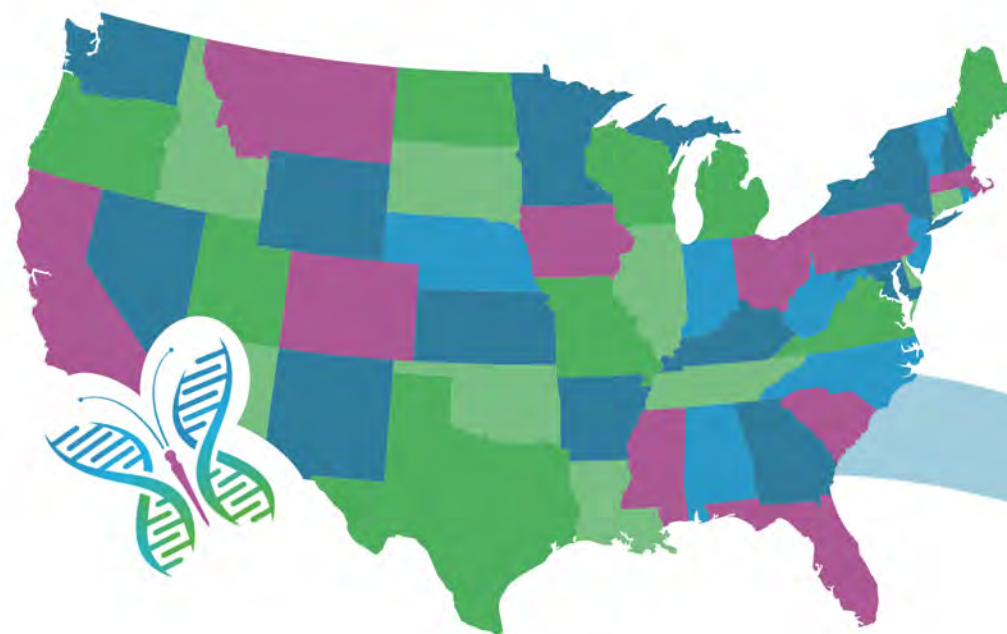
FACT #27



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

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FACT #28

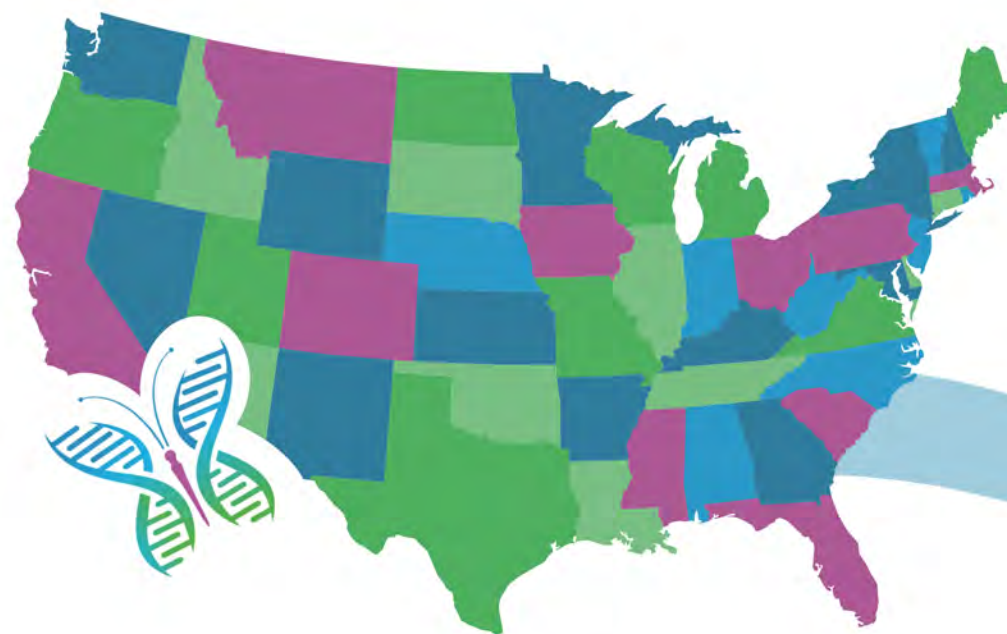


Many families utilize cabinet and refrigerator locks to keep their loved ones safe and decrease anxiety.



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FACT #29

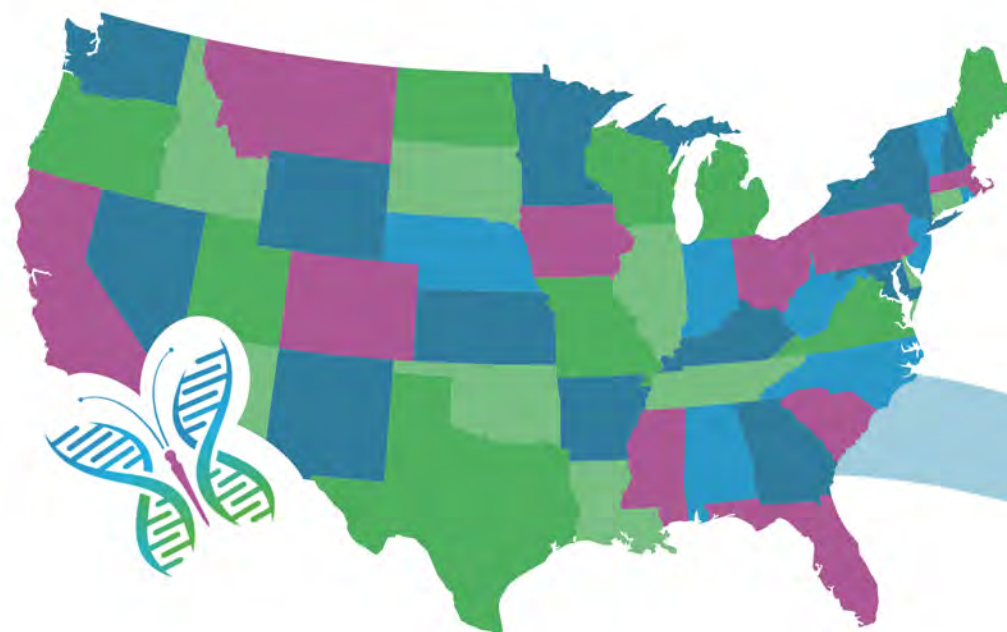


Many individuals with PWS have poor impulse control, placing them at risk of injury or harm. The use of social stories and therapy may improve impulse control.

<p>1 On the weekends I go to the park to play.</p>	<p>2 Sometimes I like to play with other kids.</p>	<p>3 I can ask them, "Do you want to play with me?"</p>
<p>4 If they say "yes" I can play with them.</p>	<p>5 If they say "no" I cannot play with them.</p>	<p>6 That's okay. I can ask someone else to play or I can play by myself.</p>

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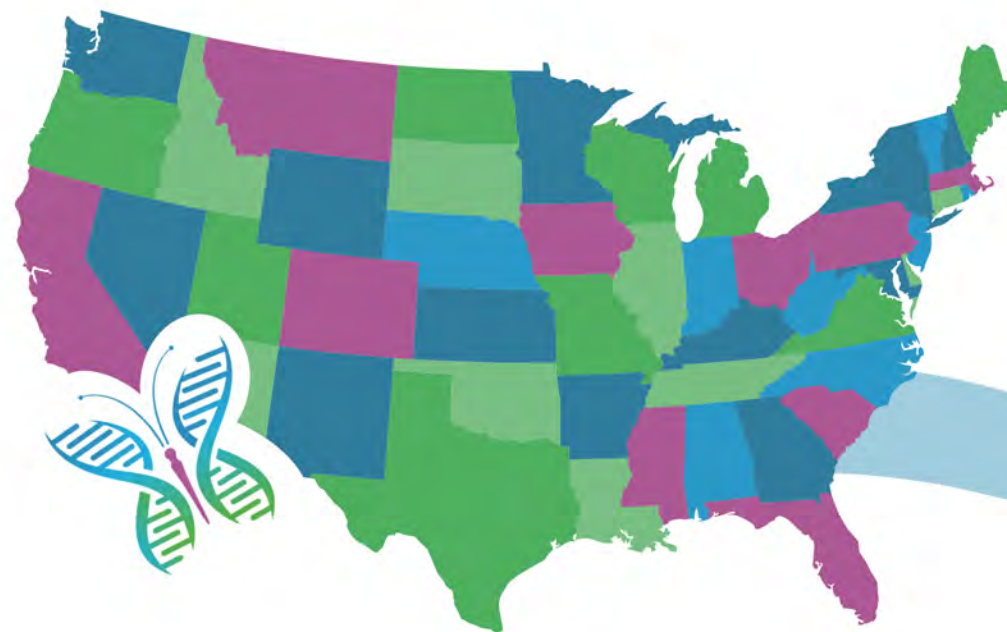
FACT #30



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

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FACT #31



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



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