



# PRADER-WILLI SYNDROME

Facts

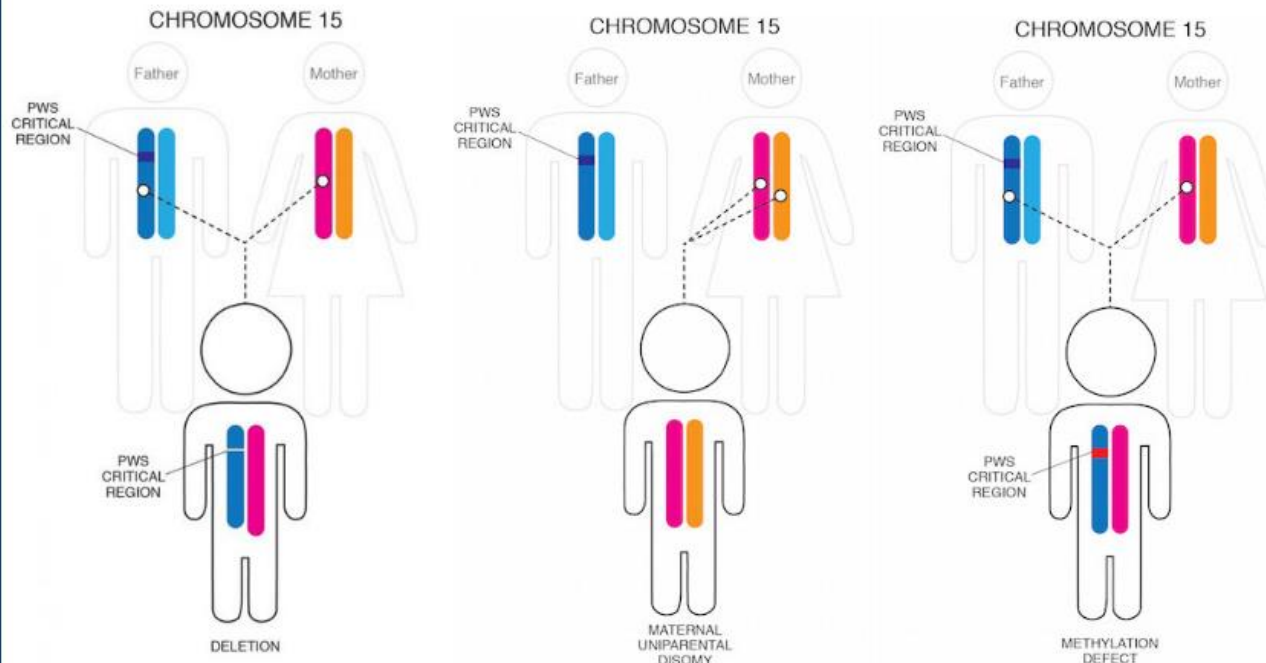
May is Prader-Willi Syndrome Awareness Month

Prader-Willi syndrome (PWS)  
is a rare genetic disorder  
affecting approximately **1 in**  
**15,000** people. It affects all  
genders and races equally.



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## 3 Genetic Causes of PWS



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Our success is only made possible by the cumulative efforts of volunteers from around the world.

Thank **YOU** for taking **ACTION!**



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**#PWSawareness**

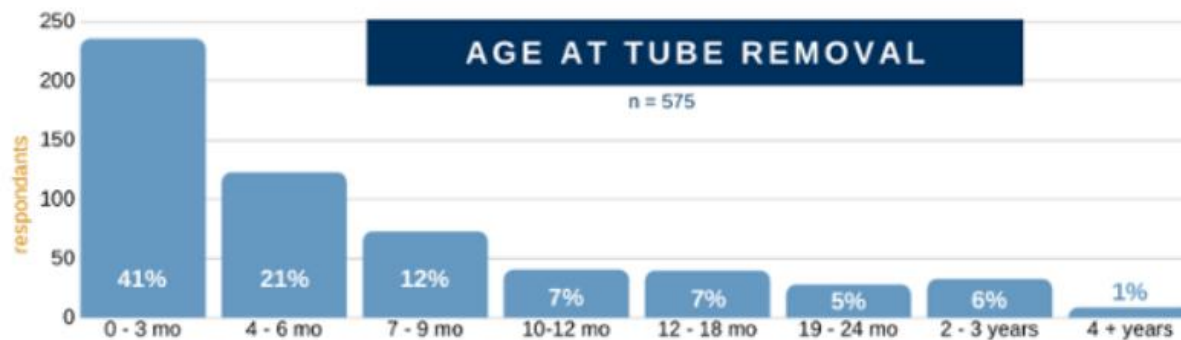
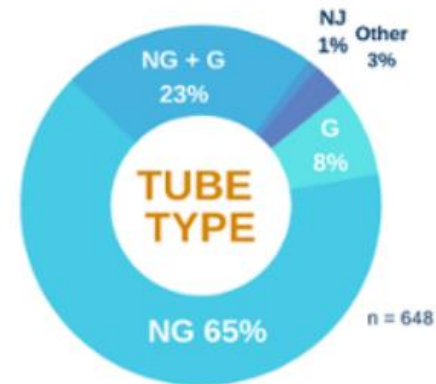
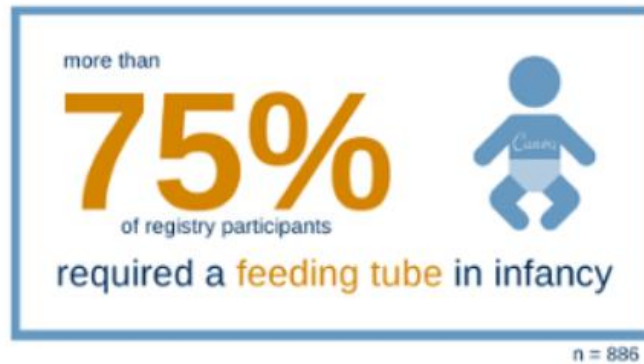
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PWS is recognized as the  
most common genetic  
cause of life-threatening  
childhood obesity.



# May is Prader-Willi Syndrome Awareness Month



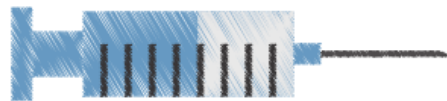
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## May is Prader-Willi Syndrome Awareness Month

In multiple studies, **growth hormone** (HGH) has been found to be beneficial for those with PWS. In addition to positive effects on growth and body composition, studies suggest positive effects on development and behavior.



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PWS was first reversed in  
2017 in neurons in a dish.  
This discovery could lead  
to treatments or even a  
cure for PWS.



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Symptoms of PWS change over time. Symptoms of hyperphagia commonly begin between 3 and 8 years of age.

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Currently, there are  
**no treatments** for the most  
debilitating challenges of  
PWS. We are working to  
change that.



## May is Prader-Willi Syndrome Awareness Month



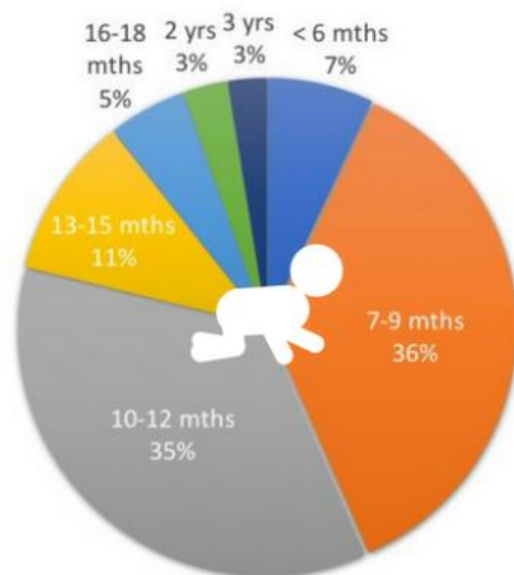
People with PWS may have an increased risk of developing dangerous blood clots.



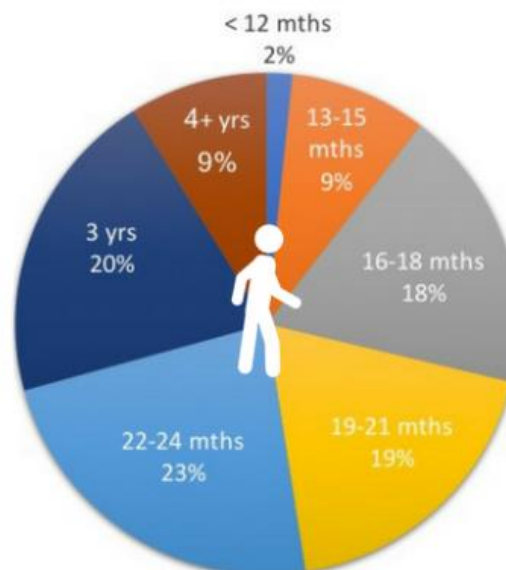
# May is Prader-Willi Syndrome Awareness Month

## MILESTONE AGE

### CRAWLING AGE



### WALKING AGE



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**41%** of students  
have received 1:1 aid  
at school.



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**18%**

OF REGISTRY PARTICIPANTS HAVE  
**CHOKED**



**50%**

OF CHOKING INCIDENTS WERE  
SEVERE ENOUGH TO REQUIRE THE

**HEIMLICH**



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Individuals with PWS are at high risk for mental illness such as depression, bipolar disorder, and psychosis.

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Currently there are many  
PWS clinical trials are  
currently recruiting patients  
**ages 3 - 65 years old**

Caregivers of people of  
Prader-Willi Syndrome  
often experience  
compassion fatigue.

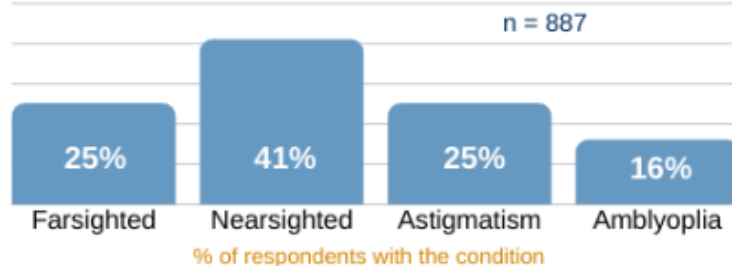


# May is Prader-Willi Syndrome Awareness Month

**40%** of registry participants have had **strabismus**

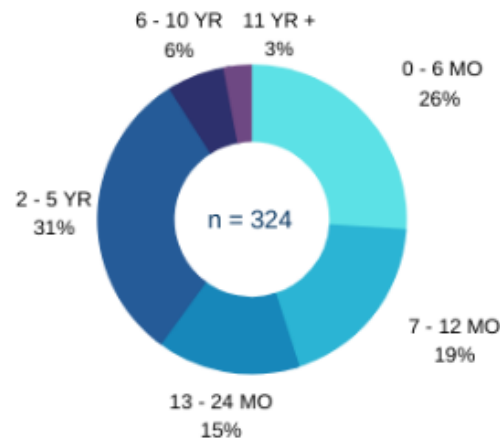
*There is no statistically significant difference in strabismus among PWS subtypes.*

## Frequency of Other Eye Conditions

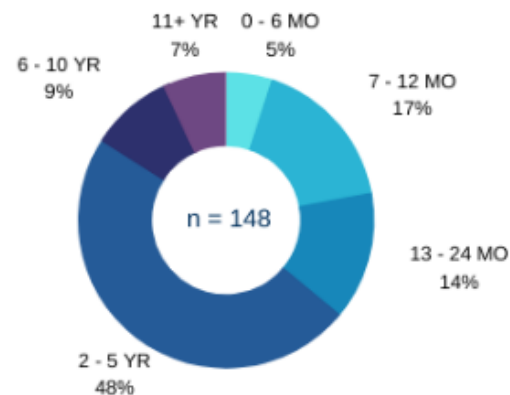


**48%** of strabismus patients go on to have corrective surgery

## Age At Strabismus Diagnosis



## Age At Strabismus Surgery



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Individuals with PWS typically exhibit cognitive challenges, with measured IQs ranging from low normal to moderate intellectual disability.

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## ORTHOPEDICS OF PWS

14%



OF REGISTRY PARTICIPANTS HAVE BEEN DIAGNOSED WITH

**HIP DYSPLASIA**

## SCOLIOSIS



46%

OF REGISTRY PARTICIPANTS OVER  
THE AGE OF 2 REPORT HAVING A

**SPINAL  
DEFORMITY**



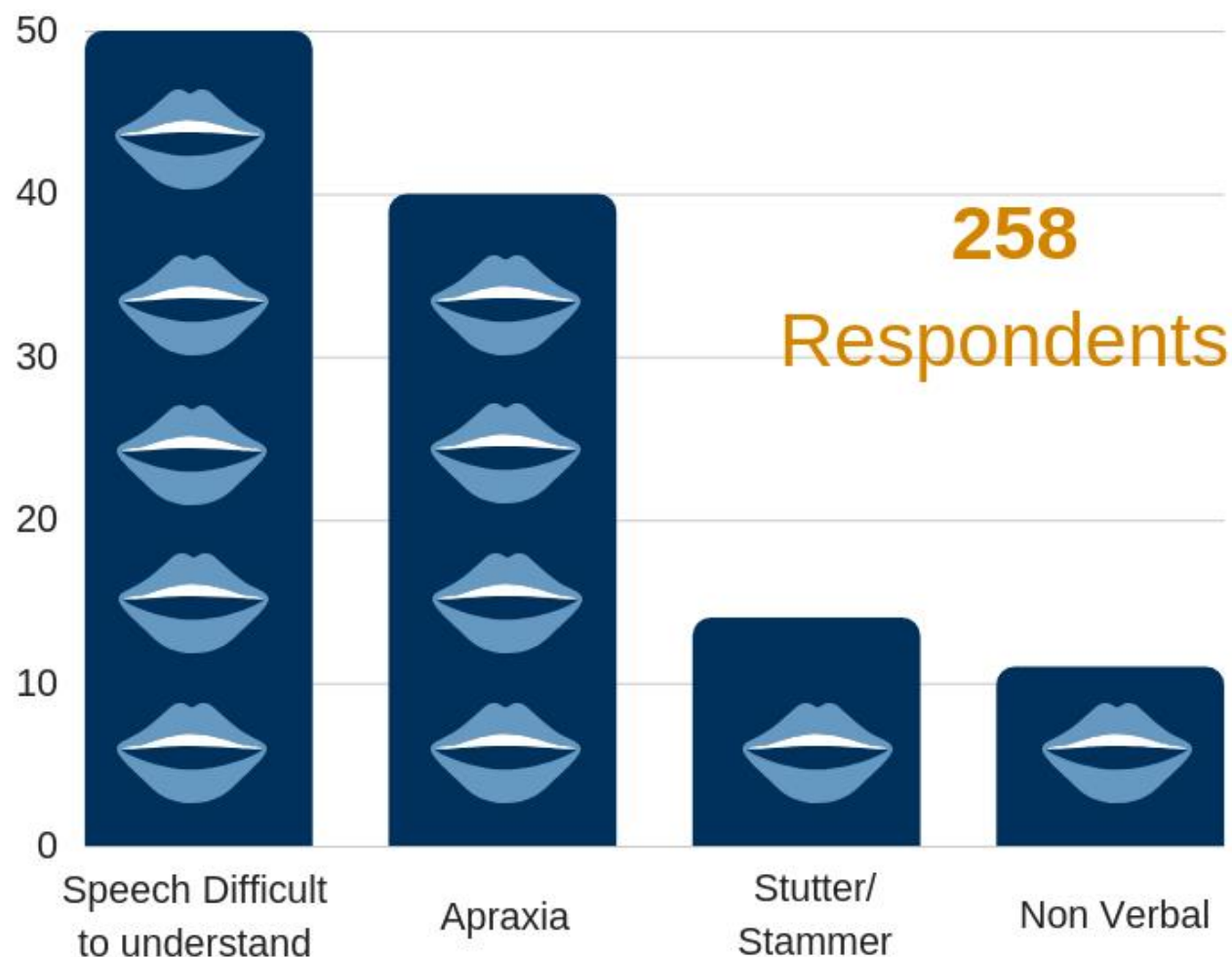
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# May is Prader-Willi Syndrome Awareness Month



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A newborn screen for PWS  
is currently under  
development which will allow  
individuals with PWS to have  
standard-of-care therapies  
right from the beginning.

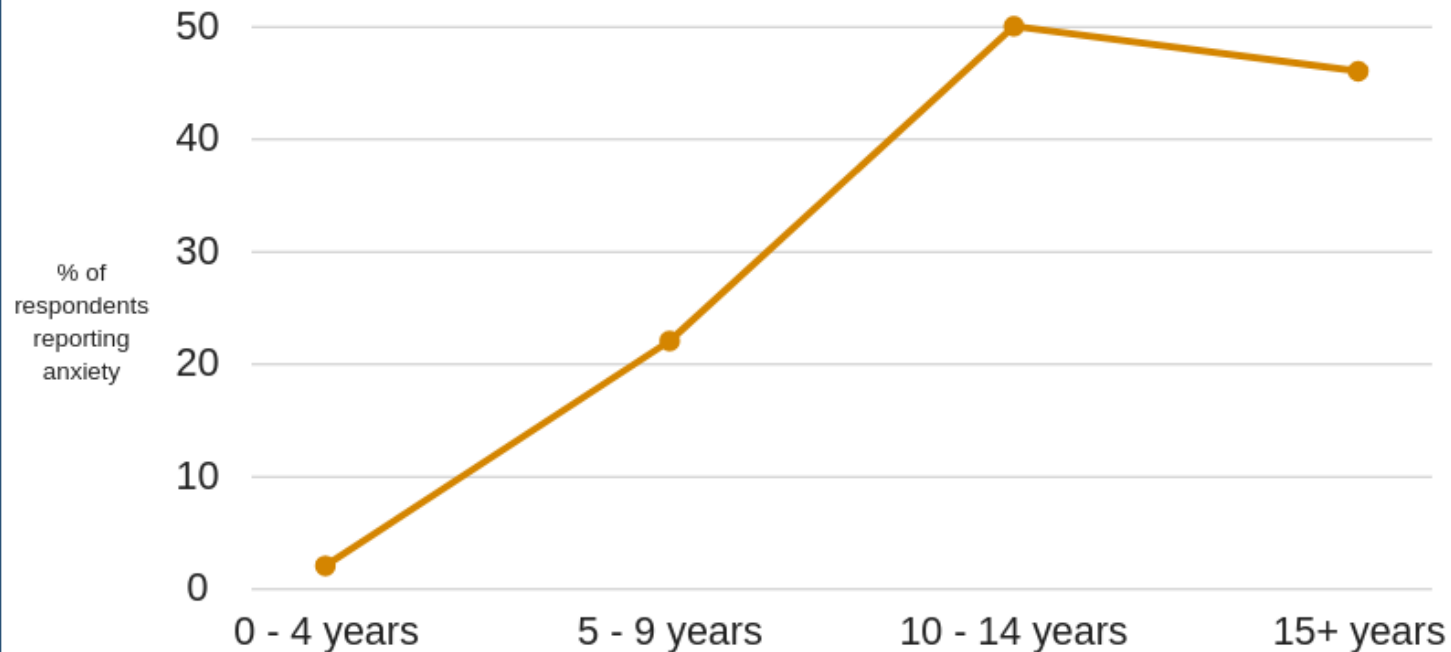
**41%** of children  
with PWS

were reported to be  
displaying outbursts  
**by the age of 3**



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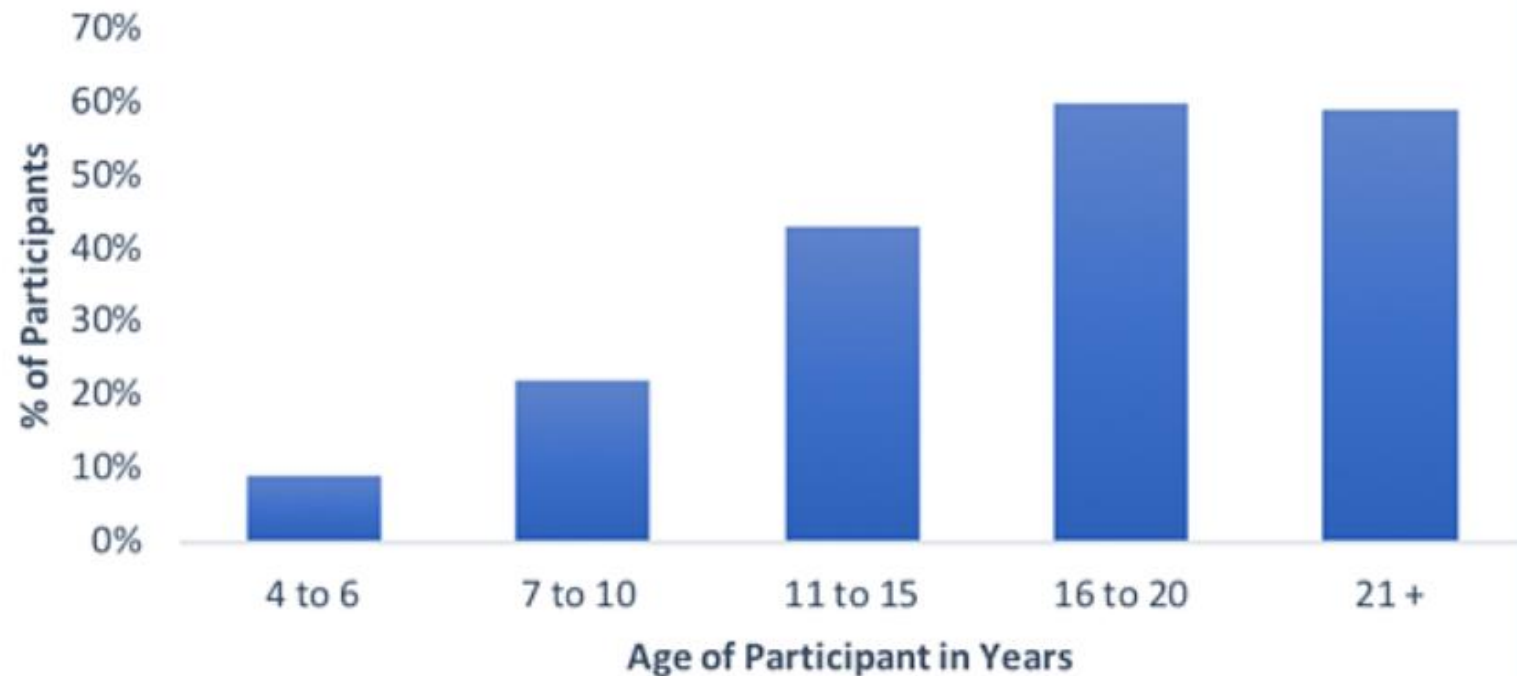
## PREVALENCE OF ANXIETY IN PWS



**Schaaf-Yang Syndrome**  
is caused by a mutation  
on one of the genes  
(MAGEL2) in the PWS  
region.

# May is Prader-Willi Syndrome Awareness Month

## % of Participants Whose Friends ALL or Mostly Have Special Needs





**Mindfulness** practices  
can improve behavior  
challenges in PWS as  
well as caregiver fatigue.



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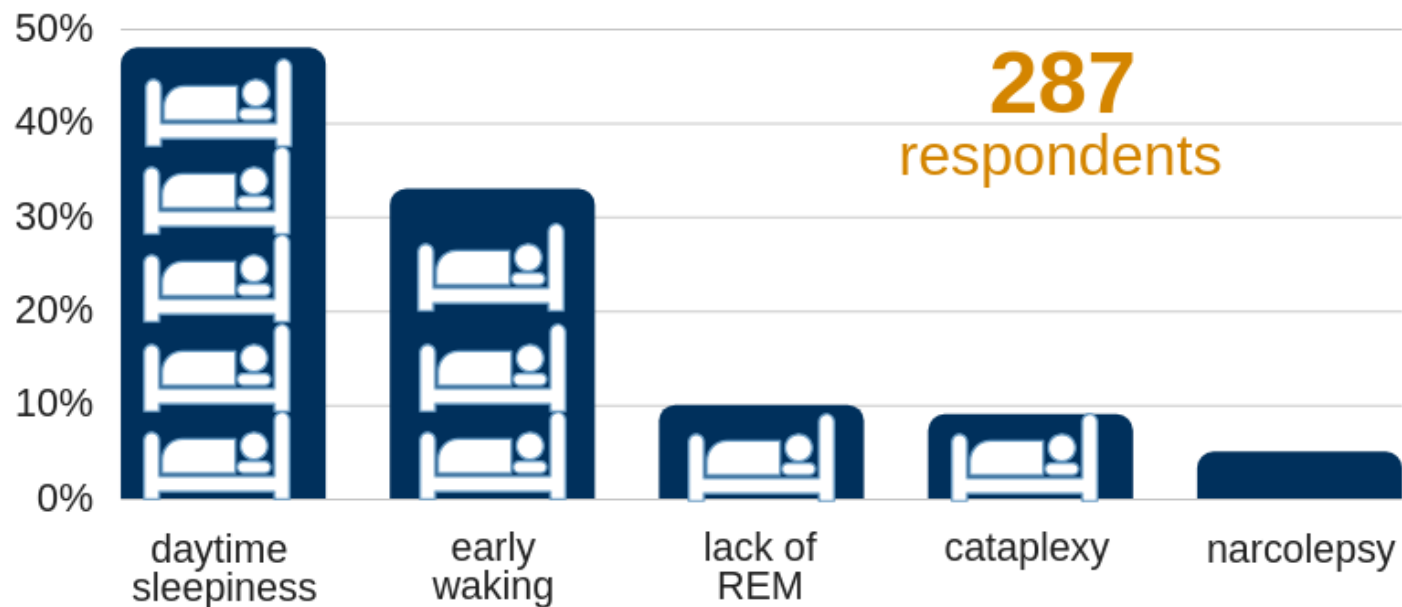
A promising study finds that  
**4 out of 5** participants had  
a reduction in temper  
outbursts after wearing an  
activated **vagus nerve**  
**stimulation device**

Parenting a child with  
PWS can be tough, but  
with the support of the  
PWS community,  
**you never have to go  
through it alone!**



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## FREQUENCY OF SLEEP ISSUES



## IMPACT

**2014:** FPWR co-funded the Phase 1 study of Diazoxide Choline Controlled Release (DCCR).

**2019:** Destiny-PWS began its Phase 3 clinical trial in the US and UK and we have hopes it will go on to receive FDA approval in 2020.

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We can change the future for  
our loved ones with PWS.

*It starts with US!*



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