



Prader-Willi

SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Find Your Voice:

Advocating for PWS Health Care Webinar Series



Health Education and Advocacy for Parents and Caregivers

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Session 1

OBJECTIVES



**Health Advocacy
Strategies**

**High Pain
Threshold**

**Respiratory
Concerns**

**Temperature
Regulation
Concerns**

HEALTH ADVOCACY- STRATEGIES, TOOLS & RESOURCES



**Get
Educated**

**Stay
Educated**

RESOURCES



Prader-Willi Syndrome Association | USA
Website:

www.pwsausa.org

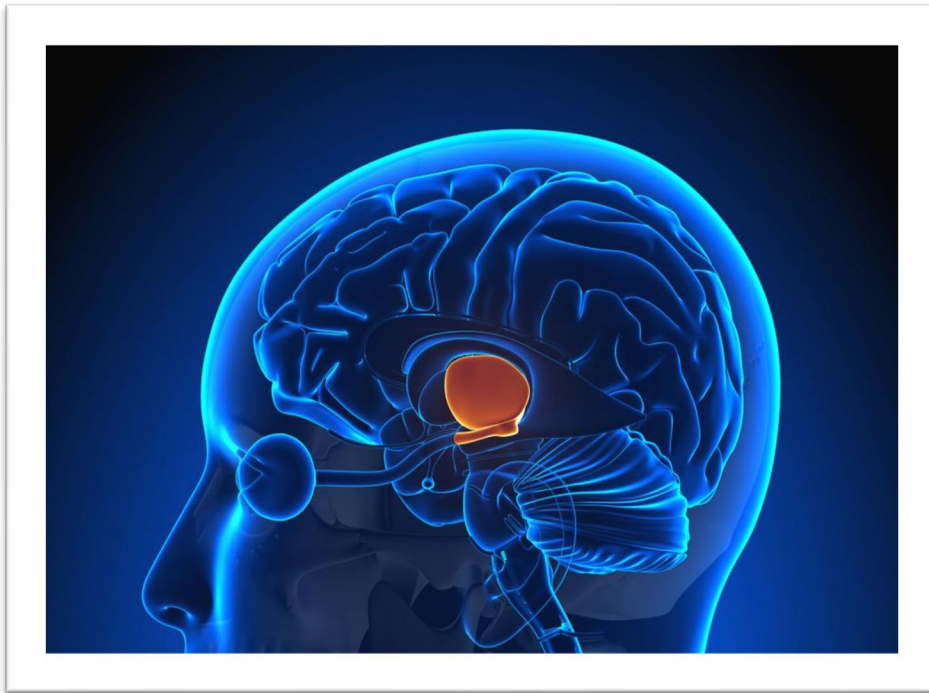
Foundation for Prader-Willi Research Website:

www.fpwr.org

PWS State Chapter:

<https://praderwillinews.com>

HEALTH ADVOCACY – STRATEGIES, TOOLS & RESOURCES



**Share &
Educate**

**Written
Materials**

**PWSA | USA
Crisis Line
941.312.0400**

Up-to-Date



HIGH PAIN THRESHOLD

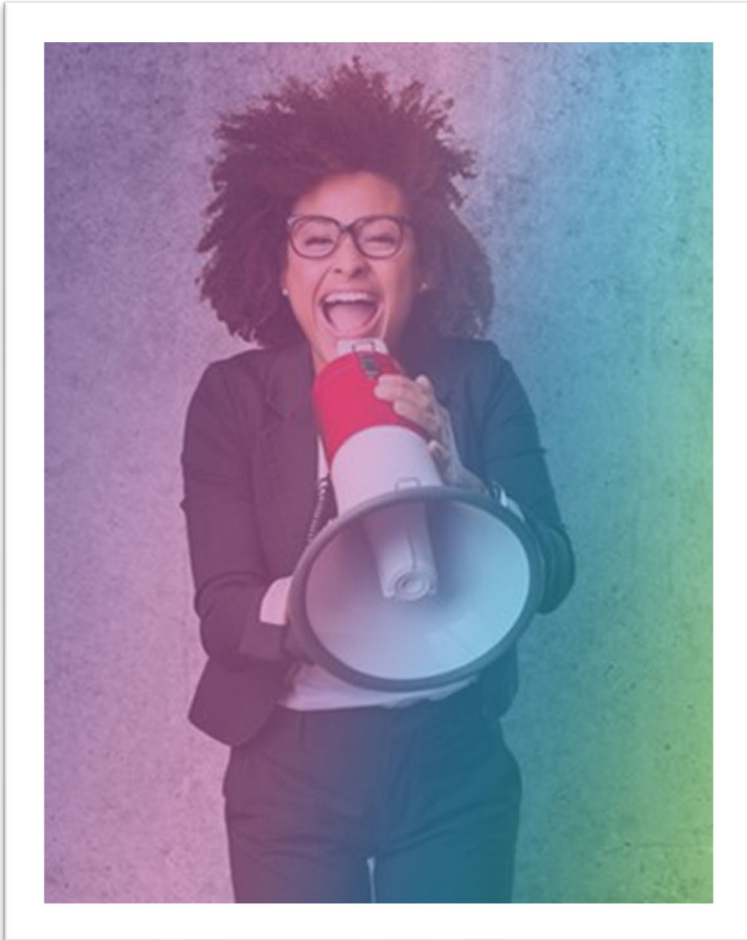


- Individuals with PWS do not feel pain accurately, and may not complain
- Take all complaints of pain seriously and have them evaluated
- Behavior changes may be the first indication of illness or injury. Always rule out medical causes before implementing behavior management procedures



HIGH PAIN THRESHOLD

Advocacy Tips



Insist on x-ray

**Medical Alerts
Booklet**

**Monitor Every
4 hours for 24
hours**

**Immediate
Need**

**Persistent
Pain**

RESPIRATORY CONCERNS



Respiratory Issues are the Number One Cause of Death in PWS



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- Obesity
- Sleep Apnea
- Weak Chest Muscles
- Scoliosis
- Medications
- Choking

RESPIRATORY CONCERNS



Advocacy Tips



**Manage
Weight**

Food Security

Sleep Studies

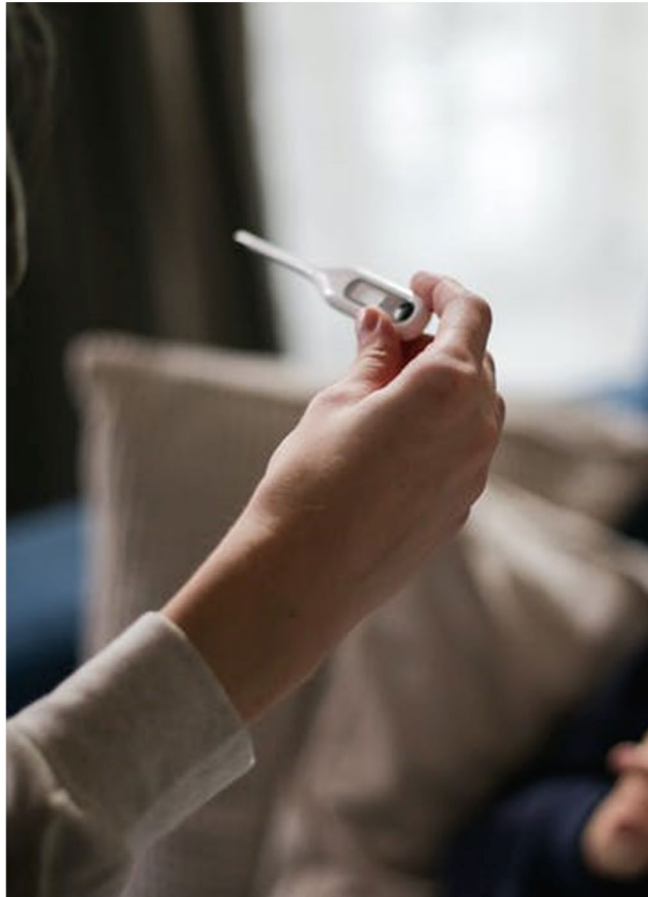
CPAP/Bi-PAP

Pulse Oximeter

**Start Low &
Go Slow**

Peer-to-Peer

TEMPERATURE REGULATION PROBLEMS



**People with
PWS rarely run
a fever**

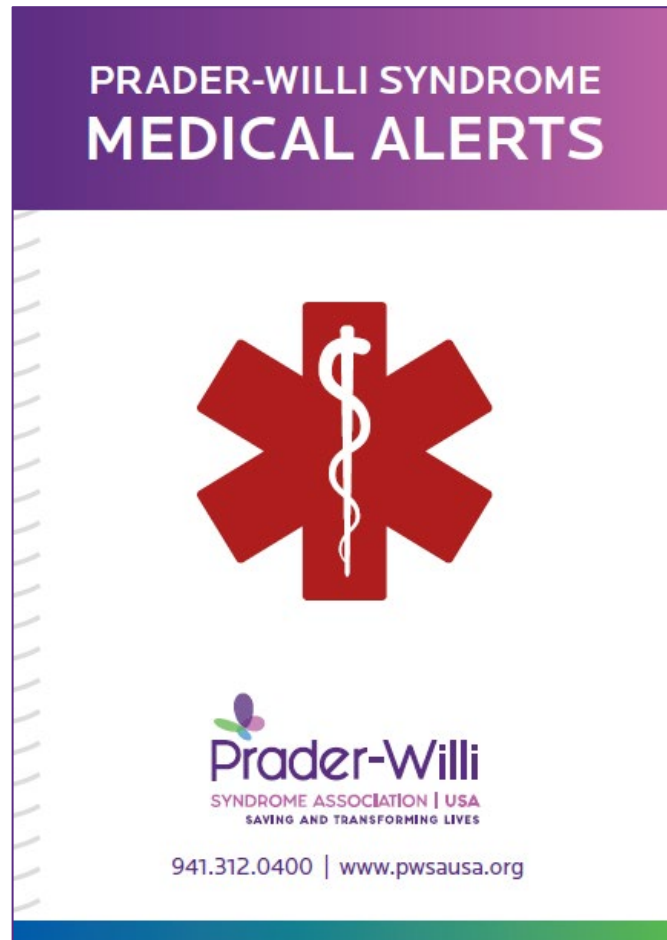
**Often have
low baseline
body
temperature**

**At increased
risk for Heat
Stroke or
Hypothermia**

TEMPERATURE REGULATION PROBLEMS



Advocacy Tips



- Always have a copy of the Medical Alerts Booklet handy
- PWS is a spectrum disorder – not everyone will react the same way to temperature
- Request a complete blood count (CBC) to assess for infections
- Encourage weather appropriate clothing
- Keep the thermostat at a temperature that addresses their need
- Know their baseline temperature



Open Discussion

Q & A



RESOURCES

PWSA | USA Medical Alert booklet



www.pwsausa.org



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