Find Your Voice:
Advocating for PWS Health Care Webinar Series

Health Education and Advocacy for Parents and Caregivers

Session 1
OBJECTIVES

- Health Advocacy Strategies
- High Pain Threshold
- Respiratory Concerns
- Temperature Regulation Concerns
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
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.
Advocacy Tips

- **High Pain Threshold**
  - Insist on x-ray
  - Medical Alerts Booklet
  - Monitor Every 4 hours for 24 hours
  - Immediate Need
  - Persistent Pain
Respiratory Issues are the Number One Cause of Death in PWS

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

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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

- Often have low baseline body temperature
- At increased risk for Heat Stroke or Hypothermia
- People with PWS rarely run a fever
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

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