

Find Your Voice:

Advocating for PWS Health Care Webinar Series



Health Education and Advocacy for Parents and Caregivers

.....
Session 3

OBJECTIVES



**Grow confidence in
health advocacy**

**Identify ways to
find information**

**How to come
prepared**

**Grow confidence
in more common
urgent health
issues**

PRIMARY ADVOCATES



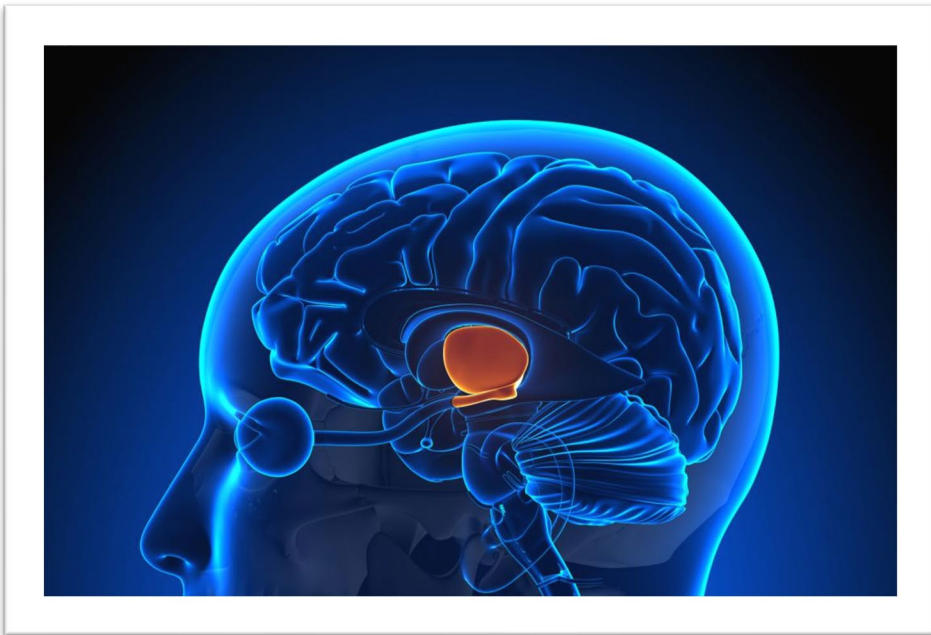
Parents and Caregivers are the primary advocates throughout the life span.

The first step in confidently advocating is becoming informed and educated.

STAYING ENGAGED AND INFORMED



**There are numerous ways
to stay informed**





Concerns for the Hospitalized Person with PWS

- General Information for Patients in the Emergency Department
- Anesthesia and Postoperative Monitoring
- Medication Sensitivity
- Food Security in the Health Care Setting

GENERAL INFORMATION FOR PATIENTS IN THE ED



COMMON REASONS ED IS USED



Choking

GI Issues

**Bone / Joint
Injury**

**Psychiatric
Emergency**

GOALS, TRUTHS, CHALLENGE



Goal?

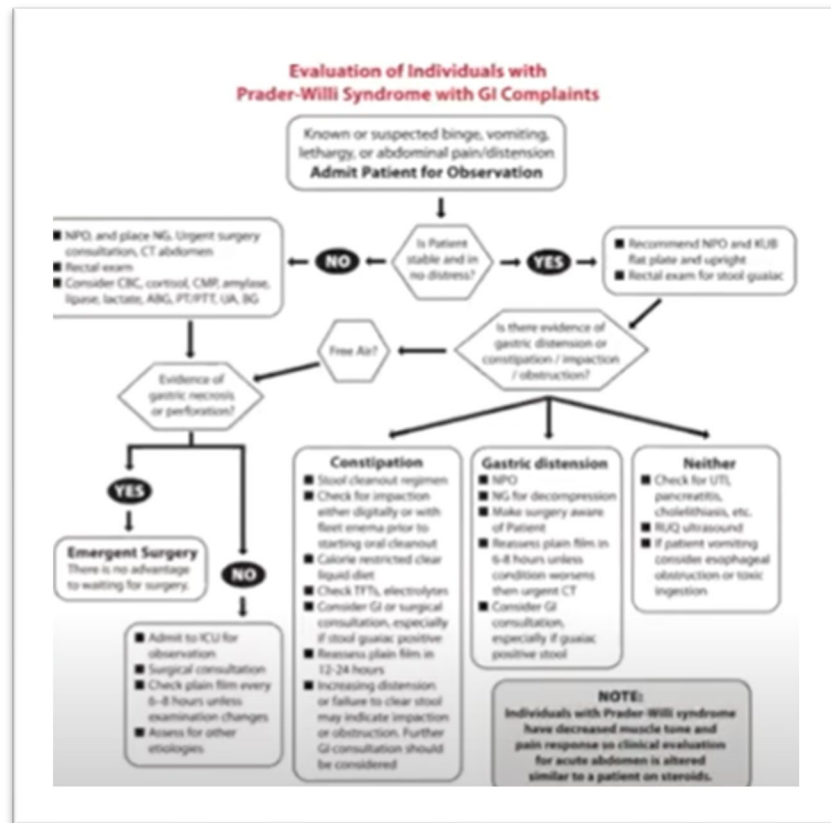
Truths?

Challenge?

- Goal of an Emergency Department
- Truths: People with PWS are a diagnostic challenge
- Biggest Challenge: Making the health care provider believe what you are saying



Things to Keep in Mind



ED staff are
NOT familiar
with PWS

You're the
teacher

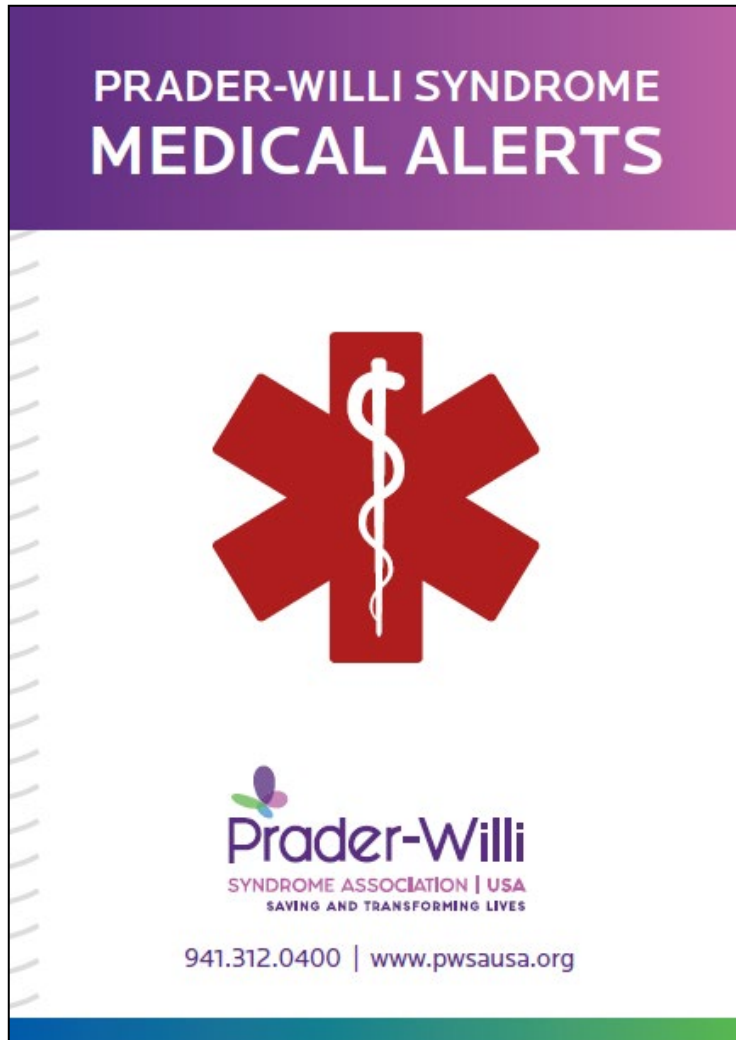
Be Patient

Take GI issues
SERIOUSLY

Get an x-ray

Medical Alerts
Booklet

ADVOCACY TIPS



**Medical
Alerts
Booklet**

GI Algorithm

**Medication
List**

**Physician
Contact Info**

941.312.0400

Up-to-Date

MORE ADVOCACY TIPS



Collaborate

**Calm and
Respectfully
Aggressive**

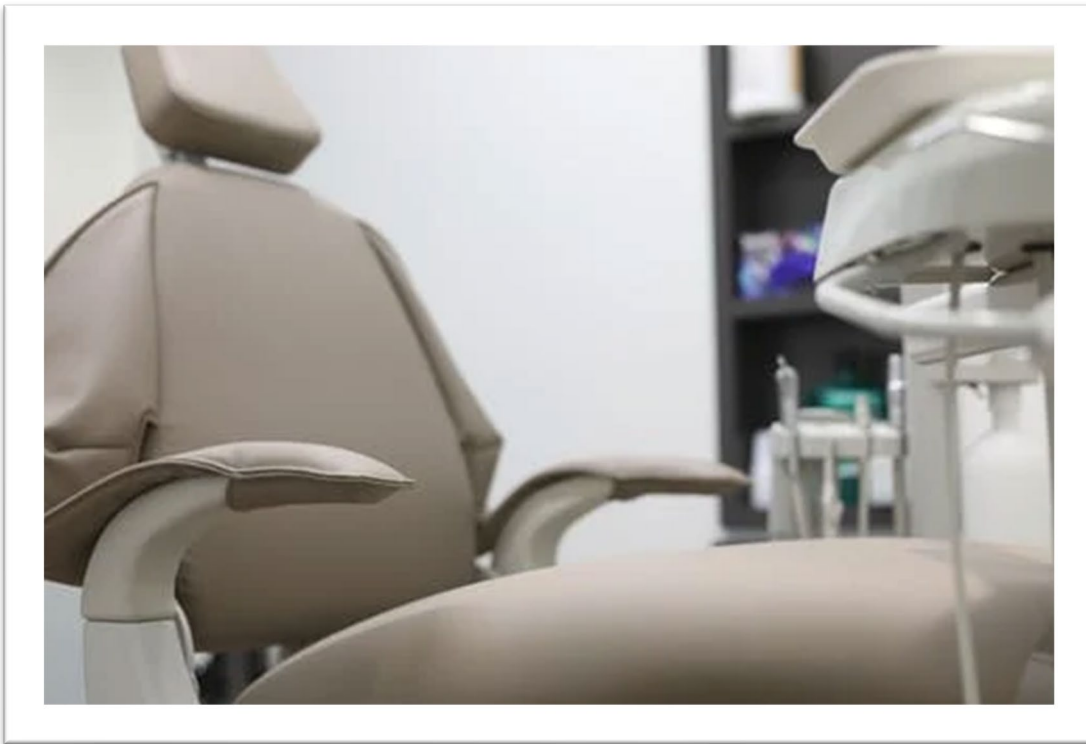
Negotiate

ANESTHESIA AND POSTOPERATIVE MONITORING



People with PWS who need any kind of anesthesia, surgery, or any procedure that requires anesthesia must have close monitoring and need special considerations.

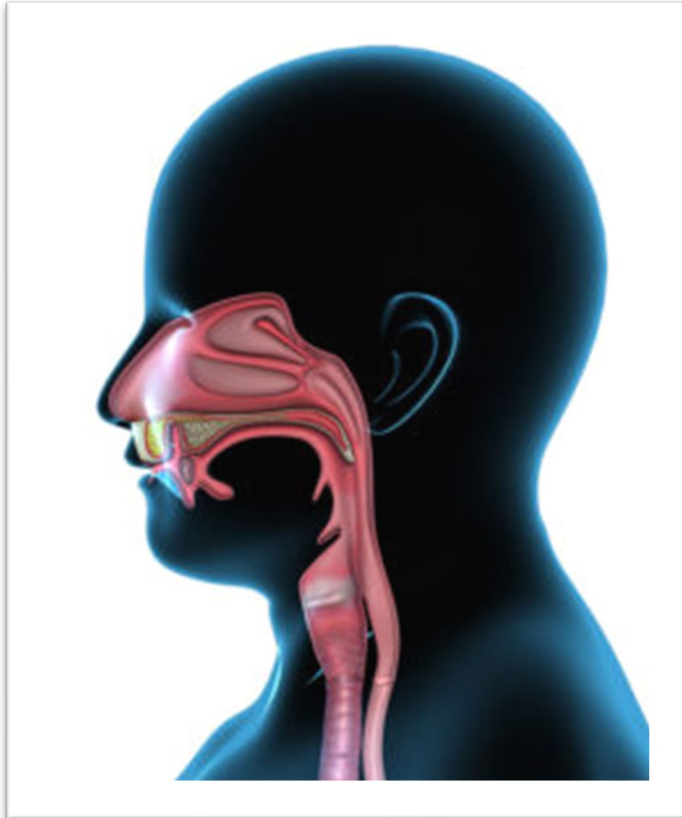
TYPES OF ANESTHESIA



**General
Anesthesia**

**Conscious
Sedation**

SURGICAL AND ANESTHESIA RISK FACTORS



- **Obesity**
 - All people with PWS who are obese are at increased risk of experiencing complications with either type of anesthesia
- **High Pain Threshold**
- **Temperature Instability**
- **Thick Saliva / Narrow Throat**
- **Food Seeking Behaviors**
- **Low Muscle Tone / Respiratory Concerns**
- **Skin Picking**
- **Difficult Starting IV**
- **Behavior Concerns**
- **Slow Recover**
- **Slow GI Movement**

ADVOCACY TIPS



**Address Dental
Concerns Prior
to Surgery**

**Share
Anesthesia
Handout**

**Overnight
Monitoring in
Hospital**



MORE ADVOCACY TIPS



**First Case of
Day**

**Extra
Supervision
when Fasting**

**Respiratory
Therapy**

**Movement /
Walk**

Monitor Tubes

**Most Skilled
Person doing
IV**

**Caregiver
Supervision**

**Communicate
ALL Medications**

Share GI Chart

MEDICATION SENSITIVITY



Things to Know:

- People with PWS are extra sensitive to many medication
- Anesthesia, pain medications and medications used to treat mood or behavior problems are some of the most common medications that can cause an exaggerated response
- Use a slow, conservative approach “start low and go slow”
- Medications that impact the functioning or motility of the stomach and GI tract can also cause a more severe response



ADVOCACY TIPS



**Share a list of
all medications,
including
vitamins and
supplements**

**Share the
Medical Alerts
Booklet**

**Use extreme
caution in using
medications to
treat diarrhea**

FOOD SECURITY IN THE HEALTH CARE SETTING



Managing food security is VERY challenging

Need for Oversight when not mealtime

Binge Episodes

Extraordinary Weight Gain

Water Intoxication

Headaches / Fatigue

Nausea / Vomit

Loss of Consciousness

ADVOCACY TIPS



- Supervision and advocacy in the hospital is very important
- Request a nutrition / dietary consult
- Educate staff of dietary and food seeking needs
- If possible, request a private room to limit the access to roommate's food
- Constant monitoring of food cards with delivery and removal of food
- Block ability to order food by phone
- Limit access to kitchen on the nursing unit
- Check waiting room areas
- If possible, ask that ONE staff be assigned responsibility for providing all food and beverages each shift
- Check weight daily

SUMMARY



- It is very stressful when a person with PWS is hospitalized
- We hope that this presentation has provided you with the information, tips, and resources to help you when your loved one is hospitalized
- YOU are a very important person in helping the person with PWS receive appropriate, prompt evaluation and treatment for their health concern



Open Discussion

Q & A



RESOURCES

PWSA | USA Medical Alert booklet



www.pwsausa.org



Info@pwsausa.org



941-487-6755