

# Find Your Voice:

## Advocating for PWS Health Care Webinar Series



### PWS & Mental Health

*Lauren Schwartz PhD  
University of Washington, Department of  
Rehabilitation Medicine &  
Foundation for Prader Willi Research (FPWR)-  
Mental Health & Behavior Research Programs*



# OBJECTIVES

**Grow confidence in  
health advocacy for  
your loved one**

**Identify ways to  
find information  
about PWS Mental  
Health**

**How to come  
prepared**

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



# PRIMARY ADVOCATES



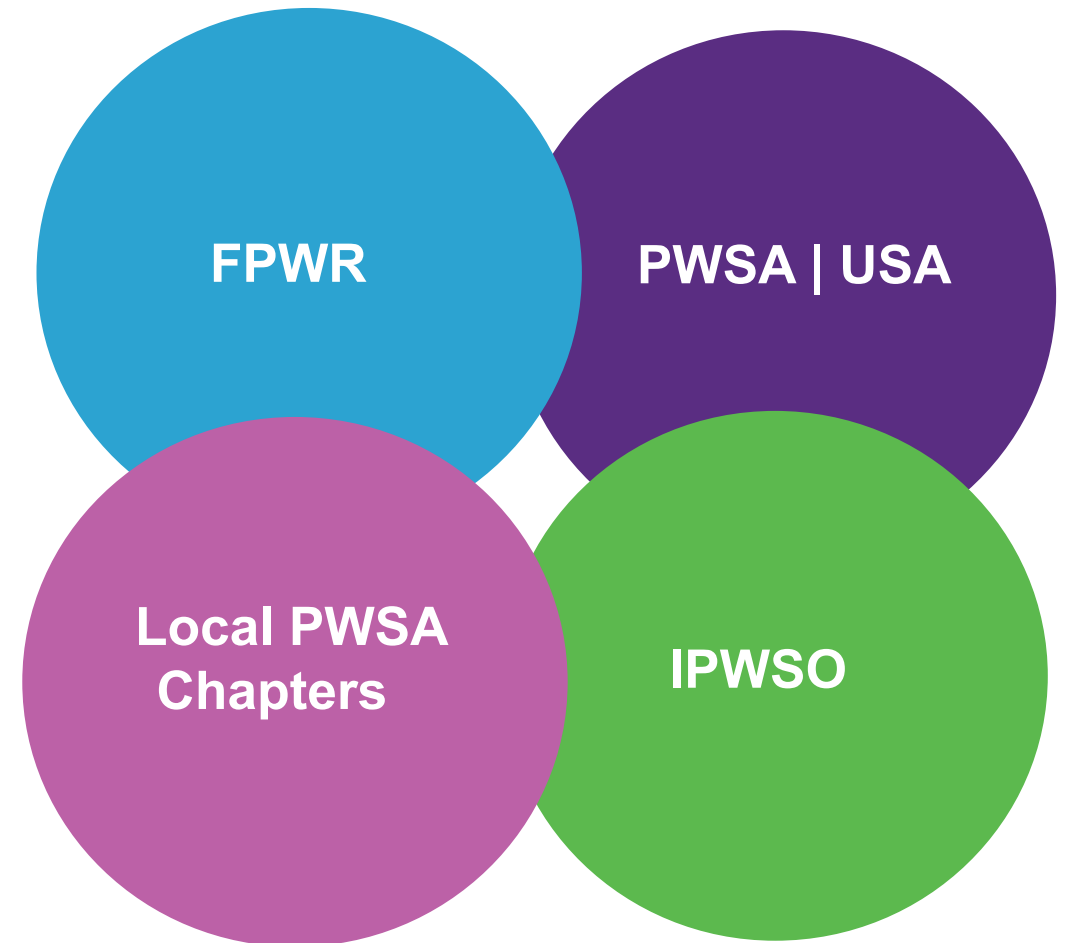
Parents and Caregivers are the primary advocates throughout the life span of the person with PWS.

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



# STAYING ENGAGED AND INFORMED

**There are many ways to stay informed**







# WHY FOCUS ON PWS MENTAL HEALTH?



- Mental health issues are very common in PWS
- They may show up in ways that are unique to PWS
- Parents have told us that it is very difficult to assess, understand and get appropriate treatment for these challenges



# FOCUS FOR TODAY'S SESSION:

What do mental health challenges look like in PWS?

What are early signs and how to best intervene?

When to monitor behaviors and when is it time to get treatment?

Medications and non-medication approaches to treatment





# PWS MENTAL HEALTH GUIDEBOOK

- The Foundation for PWS Research (FPWR) created a Mental Health Guidebook to help parents better understand what to expect, how to identify early symptoms and when to get help
- The Guidebook is based on a qualitative research study involving interviews with parents who's loved one has experienced mental health or severe behavior challenges.
- Clinicians and researchers with extensive experience in PWS mental health also participated in the study and took part in 1-on-1 semi structured interviews





# PWS Mental Health Guidebook

What to Expect and  
How You Can Help



**Note:** The guidebook focuses mainly on serious mental illness in PWS because there are few resources for parents in this area.

**<https://www.fpwr.org/pws-mental-health-guidebook-download>**







# KEY SERIOUS MENTAL HEALTH ISSUES IN PWS

- Clinical depression
- Severe anxiety
- Psychotic Symptoms (auditory/visual hallucinations)
- Bipolar disorder (Mania)
- Severe escalation of core PWS behavioral symptoms to point of crisis

Age of onset: PWS Caregivers reported that mental health symptoms generally started in early adolescence, with 75% reporting significant mental health issues starting after age 12.

# The challenge of identifying mental illness symptoms in PWS

- Often there was difficulty distinguishing typical “PWS behaviors” vs. serious mental illness (which requires intervention)
- Caregivers in the study commented:
  - “at first it just looked like PWS but worse.”
  - “It took us a surprisingly long time to say, gosh, this is mental illness, & we’re not uneducated about these things, but we just didn’t see it.”
- **TIP:** If you suspect mental health issues may be brewing, start to track behaviors
  - *Put check marks on a calendar or notepad indicating frequency and/or intensity of symptoms (0 to 10) you are concerned about (e.g., anxiety, outbursts, sleep patterns).*
  - *Behavior trackers and Apps can be used to track behaviors/ symptoms.*



# BE ON THE LOOKOUT FOR THESE KEY ISSUES

Look for **CHANGES** in the person from their usual behaviors  
(their “baseline”):

- **Eating** – less interest in food, consuming less food than usual
- **Behavior** – more agitation or aggression, more talkative or more withdrawn than usual (spending more time alone, less willing to engage in activities they previously enjoyed)



*If the above changes are not related to physical illness or medication change and have continued for more than 1-2 weeks, schedule a medical/mental health assessment*

A Resource of FWSA | USA | [pwsausa.org](http://pwsausa.org)

# BE ON THE LOOKOUT FOR THESE KEY ISSUES



- Look for **CHANGES** in the person from their usual behaviors
- (considered “baseline”):
- **Sleep** – sleeping less, or a change in sleep pattern
  - Caregiver comments: “the naps just stopped.” “s/he started staying up later and later at night” “s/he was just sleeping ALL the time.”
- **Grooming** – loss of interest in self-grooming (not changing clothes, brushing hair or teeth, showering)



*If the above changes in usual behavior are not related to physical illness and have persisted for more than 1-2 weeks, schedule a medical/mental health assessment*

A Resource of FWSA | USA | pwsausa.org



FOUNDATION FOR  
PRADER-WILLI  
RESEARCH



# SPECIAL CONSIDERATIONS FOR PWS



## Genetic Subtype Differences:

- Research shows that those with PWS by UPD have a high risk for psychiatric symptoms BUT people with the deletion subtype also have an elevated risk compared to the typical population.

## Stress Sensitivity: Most individuals with PWS are highly stress sensitive

- Changes in their environment have the potential to cause or increase psychiatric symptoms
- For example: change in teacher/aide/caregiver, illness in close relative or friend, sibling moving out

## Imaginary Friends:

- *Common for individuals with PWS to talk to themselves and with “imaginary friends.” If the amount of talking significantly increases or this “friend” is being scary or mean, this is cause for concern & would warrant assessment*

- *You can see suggestions in the Guidebook from the experts re: how to ask your child about this or other psychiatric symptoms*

A Resource of PWSA USA | [pwsausa.org](http://pwsausa.org)



FOUNDATION FOR  
PRADER-WILLI  
RESEARCH

# GETTING HELP FOR YOUR LOVED ONE- FIRST STEPS



## Where Can You Go For Help?

- If you don't have an established mental health provider, start with the primary care doctor
- Make sure a thorough assessment is done including potential medical causes of the behavior change (rule out illness, infection, medication reaction, sleep disorder)

## Provide their doctor with information about mental health issues in PWS:

- PWSA-USA & IPWSO have downloads with specific mental health info for providers
- The doctor can call PWSA-USA and request a “peer-to-peer consultation” for PWS mental health concerns
- Give providers the MH Guidebook 1 pager on website
  - <https://www.fpwr.org/serious-mental-health-problems-in-prader-willi-syndrome#definition>

# GETTING HELP FOR YOUR LOVED ONE - MEDICATIONS



- The Golden Rule for Medications in PWS = Start LOW Go SLOW
- Make sure that the doctor prescribing knows **all** the medications & supplements your child is taking
- Ask the doctor how quickly the medication works so you know when you might see changes
- Track target behaviors when starting or increasing a medication

# CAREGIVER PERSPECTIVES ON MEDICATIONS



In our study caregivers tended to be very positive about the use of mental health medications for loved one with PWS

Especially for more serious mental illness, e.g., hearing voices or having symptoms consistent with bipolar disorder

Caregiver comment: *“Don’t be afraid to try medication. But you may have to try a few different ones before you find the right one. Honestly, it really can improve their quality of life A LOT and yours”*



# GETTING HELP FOR YOUR LOVED ONE- PSYCHOTHERAPY



## Psychotherapy

- Caregivers & Experts reported that psychotherapy was helpful for individuals with PWS, but with some caveats and guidelines.
  - Therapist must genuinely appreciate all the great aspects of your loved one's personality
  - Personality match & connection was critical (e.g., “structured but flexible”)
  - Most effective were therapies focused on support, concrete problem-solving & stress management
  - Previous experience working with individuals with intellectual disability and cognitive differences was useful



# NON-MEDICATION APPROACHES – PSYCHOTHERAPY

## Psychotherapy (continued)

- People with PWS can benefit from learning brief relaxation or mindfulness strategies, such as belly breathing or using easy mindfulness Apps (e.g., Headspace, CALM – kid friendly versions)
- Caregiver cueing was almost always needed to help the person with PWS use the coping strategies they learn in therapy and with online mindfulness/relaxation Apps.

# ENVIRONMENTAL INTERVENTION



**Environment:** Escalation of behavior problems and mental health issues may (often) indicate that **the person's environment has become too stressful.**

## The 3 R's:

- *Reduce:* Stress & stimulation by reducing activities
- *Routine:* Be consistent with routines & schedules
- *Review:* Are things improving? What seems to be helping?

## The 3 Areas:

- School & other activities
- Sleep
- Food Security



# ENVIRONMENTAL INTERVENTIONS (CONT'D)

## 1. School & Social activities

- Both experts & parents found that decreasing school/work demands & social activities was important until mood/behavior stabilized
- Short- or longer-term changes may be needed for ongoing mental wellness , e.g., lowering expectations

Caregiver comment: *“He had been doing really well in school, so we just expected that to continue. But high school was very difficult, and the stress of trying to keep up was too much. We started to see more mental health symptoms. We finally realized that we needed to reduce stress, lower expectations and make changes to help him make it through”*

## 2. Sleep

- Regular & consistent sleep schedule to maintain mental wellness (at least 8 to 9 hours of sleep per night, and naps if needed)
- More sleep needed during times of mental health challenges and when adjusting to medications
- Not getting enough sleep for a period of time, especially in combination w/ stress, was a trigger for behavioral challenges and possibly for mental health crisis or relapse





*Be consistent with sleep and rest patterns and decrease school demands and social activities until mood/behavior stabilizes for your loved one.*





# ENVIRONMENTAL APPROACHES (CONT'D)

## 3. Consistent food security

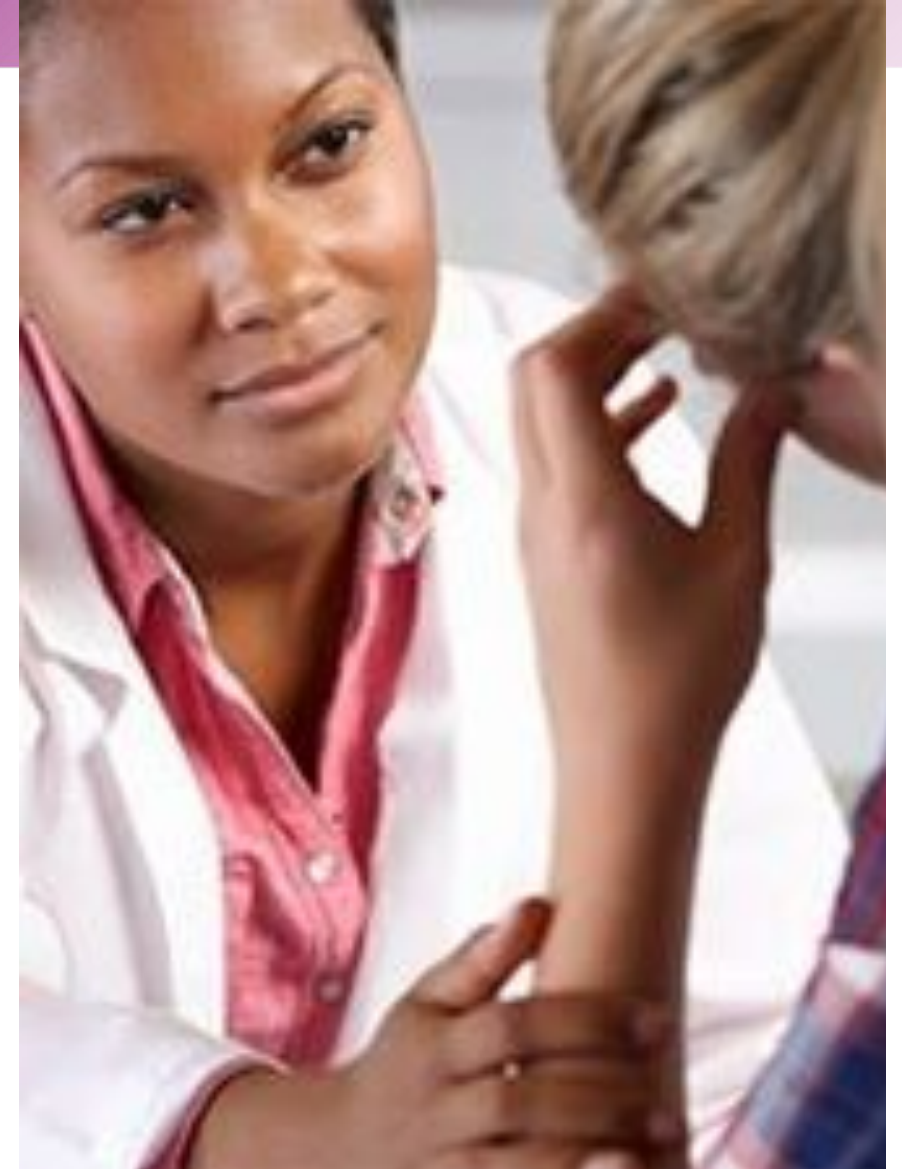
- Inconsistent food security can affect mental health in PWS
- **TIP:** Firm up existing routines/schedules and increase security around food. This can help them feel safer & less anxious.
- *Caregiver comment: “They were doing so well; we were slow to recognize the stress it (lack of food security) was causing. They have a higher IQ for PWS, so we thought we could teach how to manage the food. I came to realize that even if your child with PWS is doing well, they need those boundaries around food!”*
- *PWS Mental health experts reported:*
  - “Not locking up food can increase anxiety to intolerable levels, especially when they’re vulnerable; this can trigger a mental health crisis.”
  - “The person with PWS often wants the greater food security even if they can’t articulate it. They can be silently suffering with the food calling to them.”



# TIP: DON'T WAIT TO FIND A MENTAL HEALTH PROVIDER



- Early in adolescence seek out a local mental health professional to work with your loved one
- Find a provider who is willing to learn about PWS
- Several families shared that if the doctor or therapist was not open to being educated about PWS, find another provider who was
- See tips in the guidebook about how to find a mental health provider



# RESOURCES



## RESOURCES FOR FINDING A THERAPIST/PSYCHOLOGIST

- American Psychological Association — “Find A Psychologist Page”. Enter your zip code and the area of therapist expertise. Choose categories that identify therapists with experience with special needs, e.g., “developmental or intellectual disability,” “autism or ASD”
- Mental Health America — <https://www.mhanational.org/finding-therapy> “Finding Therapy Page”. Non-profit organization focuses on various aspects of mental health.
- Web MD — <https://www.webmd.com/mental-health/features/how-to-find-therapist#1> “How to Find a Therapist Page”. This page offers good information about therapy in general, different therapy providers, and the difference between some therapy approaches.

## RESOURCES: FOR MENTAL HEALTH PROVIDERS & PHYSICIANS (in resource handout)

- Managing Prader-Willi Syndrome: A Primer for Psychiatrists
- The Mental Health of People with Prader-Willi Syndrome with Specific Focus on Mood Disorders and Psychotic Illness





# WORDS OF WISDOM FROM PARENTS

- *“Reach out early if you have concerns, don’t wait or think it’s just a phase. Catching it early can make it easier to treat and easier for them to come back to their normal self. Don’t be afraid to say to their doctor “I’m seeing this .... It might be nothing, but I’m concerned ....”*
- *“I think it is really important for parents to be a team when you are going through something this stressful, you need someone to partner with you even for your own mental health. If this isn’t the other parent, then find a friend or other PWS parent, they can help you think through things, make decisions, bounce ideas off, and listen to you vent. This can really really really help.”*
- *“Sometimes it is hard to realize how bad things have gotten, you get used to it, but you can take a step back and ask for help.”*



# WORDS OF WISDOM FROM PARENTS

*“Remember that it is temporary. One of the hardest things is to watch your child go through something like this, because there is a fear that this is the new normal. For us, it took a few years to get it sorted through. But now we have the right medication, good support, and a stable living situation. Things are going well.....*

*Please make sure you tell the other parents this and that they do come back to you, that sweet kid is in there.”*



- *Caregivers need to take care of themselves too! If you are doing better, your child will do better too.*

# PWS MENTAL HEALTH GUIDEBOOK

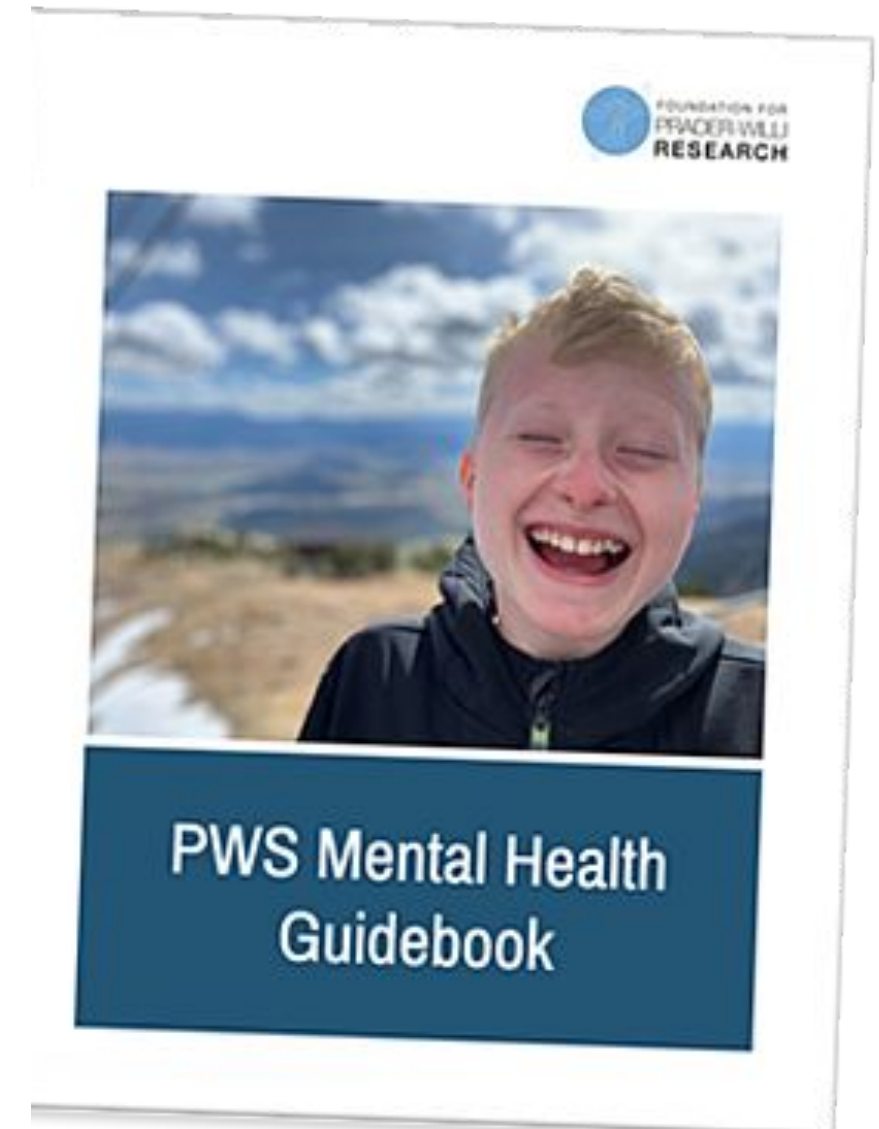


Thank you to the Moriah Foundation for providing grant funding for the Guidebook.

Thank you to all the wonderful and dedicated PWS parents for agreeing to participate in this study and sharing their deeply personal and difficult stories.

Thank you to the PWS mental health experts :

- Laura Bennett Murphy, Ph.D. - Division of Pediatric Psychiatry, University of Utah, PWS Clinic
- Patrice Carroll, M.S. - Director of PWS Services, Latham Centers, Brewster, MA
- Janice Forster, M.D. - Pittsburgh Partnership – Specialists PWS Psychiatry, Consultant to PWSA
- Soo-Jeong Kim, M.D. - Department of Psychiatry, Seattle Children's Hospital, PWS Clinic
- Elizabeth Roof, M.A. – Senior Research Specialist, Vanderbilt University, PWS Initiatives
- Deepan Singh, M.D., FAPA - Vice Chair, Psychiatry Services, Maimonides Medical Center, NY
- Kim Tula, M.A. - Family Support Counselor, PWSA | USA, Sarasota, FL
- Stacy Ward, M.S. - Director of Family/Medical Support, PWSA | USA, Sarasota, FL





# Open Discussion

Q & A

