


Supporting People with Prader-Willi Syndrome



PWCF Presents

## How to Prepare for the New School Year

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### Welcome Parents!

- Our goals are:
  - To provide you with strategies to help prepare your child for the new school year
  - To help you provide critical information to your child's teachers and all school staff
  - To provide you with helpful handouts to share with your child's educators and support team

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### Our Approach

- There is no "one right way" to advocate for your child! This webinar reflects both best practices as well as our personal experiences.
- What worked for our child may or may not work well for you, your child, or your family. Take what may work and tuck the rest away.
- Our guiding principles have been and continue to be based upon what we believe is in the best interest of our child and our family as a whole.
- You are the expert of your child. School personnel are the experts of the educational system. The goal is to work together as a team for the educational and emotional benefit of your child. Some schools make this easier than others!

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## Preparation Starts Now!



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## Preparation Starts Now

Summer break often means more lax bed time and wake up routines.

- **Create School Day Routines**
  - At least a week before school begins, start going to bed and waking up according to the new school schedule.
  - Schedule 7-9 hours of sleep per night
- **Paint the Picture of the New Routines**
  - Walk or drive the route to the school site
  - Visit the school site and walk the campus.
  - Visit lockers, the library, office, nurse's office, counselors offices, the P.E. room and field, cafeteria.
  - Learn how the lunchroom is run and Paint this Picture for your child.
  - Meet teachers and staff who are available to meet with you

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## Preparation Starts Now con't

- **Request your child's class schedule** before school begins, if possible
  - Preface with your child this is a *temporary schedule that may change*
  - Review the Food Schedule in detail.
  - Do a dry run of the school day according to the schedule, starting from parking the car, entering the school, accessing the locker, walking from class to class, to pick up location.
- **Affix the final schedule to your child's notebook**

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### Preparation Starts Now con't

• **Schedule a PWS Training**

- Ask your IEP Coordinator to schedule a 60-minute PWS training to introduce how PWS may affect your child in the school environment.
- Ensure that as many people who will interact with your child attend the training. More later!
- Provide the training yourself or request PWCF to provide the training for you.
  - Provide helpful handouts
    - One page introduction to your child
    - PWS Synopsis
    - How PWS affects your child
- Remind everyone that a PWS training makes the year more successful – especially if Training is provided *before* school starts!

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### Preparation Starts Now con't

• **Review your IEP**

- Review all of your IEP again for accuracy, especially the Accommodations and Modifications page.
- Have new symptoms appeared or worsened that require changes to the IEP?
  - Do you need 1:1 support this year when you didn't last?
    - If non-food related aide support is needed, you may need to request a Functional Behavioral Analysis (FBA) to support your request.
- Have previous goals been reached? Do new goals need to be created for this school year? Are teacher goals realistic given your child's processing skills?

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### Review Class Rules

- **Talk with your child about class rules** that teachers will likely expect in the classroom, in the hallways, in the library, in the cafeteria, and on the playground.
  - Class rules might include:
 

- Be respectful	- Be punctual
- Be responsible	- Be organized
- Follow directions	- Be a self-starter
	- Be prepared
  - Ask your child what behavior they can display that *demonstrates* each class rule.

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## Develop Good Relationships

- **Cultivate a cooperative relationship with your school.** From the moment you make your first phone call to the school or step onto the campus, cultivate a good working relationship with everyone you meet. Express your gratitude for their support (even if you don't always feel it!).
- **Educate the Educators.** PWS is a rare disorder; school staff will likely know nothing about it. Be proactive to educate them about how PWS affects your child's learning and behavior.
  - Work with teacher regarding the importance of restricting access to unauthorized food, not allowing food be eaten in the classroom, where to store all students' snack and lunchboxes, food options at class parties and holiday celebrations (birthdays, Halloween, Valentine's Day, etc.). Would a handout about PWS distributed to other students' parents be helpful?
  - Might an age-appropriate presentation about PWS to the whole class be helpful?
- **Aides need your extra special training and support!**
  - Direct communication is critical (texts and phone calls).
  - Maintain congenial, supportive relationship with aide - no matter how frustrated you get! Request an alternate aide if necessary.
- **Be as accessible and supportive as possible.** Can you volunteer in the classroom? Volunteer during field trips? Donate classroom supplies?

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## Stress Reducing Routines



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## Reduce Morning Stress

- **Develop nighttime routines to reduce morning stress:**
  - Decide *with your child* the evening before each school day what clothing they'd like to wear. Lay it out for easy dressing in the morning.
  - Help your child pack their backpack the night before.
  - Wake up and be ready earlier than your child so that you can be solely focused on helping your child be ready on time.
  - Offer 2-3 preferred choice options for breakfast
  - Create a visual schedule of each task that must be accomplished in order to walk out the door on time.
  - Praise, praise, praise tasks that are completed in a timely manner. You are teaching life-long tools to help your child be successful in *all* settings!

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## Develop Good After-School Habits

- **Create after school routines**
  - Decide *with your child* what the after school routine will be:
    - First snack, then homework OR
    - First snack and 30 minutes relaxation, then homework OR
    - A different plan
- **Create a homework area**
  - Decide *with your child* where to create a homework and study area.
  - Create a space near the homework area for placing their backpack, books, lunch box, and all school-related supplies.
  - Use visual or auditory aides to help with time management
  - Post a whiteboard or corkboard for schedules, reminder notes, etc.<sup>33</sup>

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## Develop Good After-School Habits con't

- **Create and post a wall calendar** that incorporates the school calendar (early dismissal, no school days), class field trips, etc. Talk about daily, weekly, and monthly schedules. Write in doctor and therapy appointments. Write in extracurricular activities, after school activities, etc. The greater input your child has on the schedule and the more you make it visible, the more likely they'll adhere to it.
- **Monitor how much time and/or frustration is expended on homework.** If necessary, work with the teacher(s) to adjust homework quantity and/or type.
- **Find a Tutor.** Many high schools maintain a list of students who are available for free or low fee to help tutor younger or same-age students. If your child may benefit from tutoring, or if you battle with your child over homework, find a tutor. It can also be a nice social experience for your child!

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## Keep 'Em Busy!

**Keep your child busy** but not over scheduled.

- Schedule fun after-school activities that also offer social opportunities:
  - Homework club or after-school tutoring
  - Library visits or book clubs
  - Art classes
  - Drama class
  - Dance class
  - Music class
  - Sensory-based exercises to help regulate sensory integration

Note that aide support is generally *not available before and after* school hours so you will need to identify alternate means of supervision.

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## Daily Physical Activity is Critical

Physical activity is especially critical for all individuals with PWS for physical and emotional well-being.

- **Schedule some physical activity every day**
  - Walk around the track after school with your child
  - Walk around your block at home with your child
  - Walk the mall with your child
  - Sign up for:
    - Dance lessons
    - Martial arts
    - Zumba
    - Special needs baseball, soccer, basketball
  - Gym membership
  - Swim classes
  - YMCA activities

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## The Importance of PWS Training



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## PWS Training

- Whether you provide your PWS Training or you ask PWCF to provide it, training that occurs before school begins is the most effective.
- Additional training will be helpful when any new staff begins, if the IEP is not being followed, if there is food acquisition and/or weight gain, when new symptoms develop, or if there are behavioral issues.
- Invite as many people who will interact with your child including:
  - Teacher(s)
  - Aide(s)
  - Principal and Vice Principals
  - Counselor
  - School Nurse
  - Related Services Providers:  
OT, PT, SLP, APE
  - PE Coaches
  - Librarian(s)
  - Cafeteria Workers
  - Janitorial Staff
  - Bus driver(s)

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## Key Elements of a PWS Training

- **Physical and neurocognitive symptoms** that may impact your child at school.
  - If there are any hyperphagia symptoms then 1:1 supervisory support is required for the health and safety of the student.
- **Behavior Management Strategies**
  - PWS Environmental Basics with focus on Food Security
  - Empathy as Intervention
  - Manage Expectations: Paint the Picture, Fix a Past Goof, transition prompts
  - Manage Disappointment: Preferred Choices, Allow for Rightness, Disguise the No's
  - Positive Reinforcement: Motivate externally, no punishment
- **PWCF Contact Info:** 800-400-9994 | info@pwcf.org

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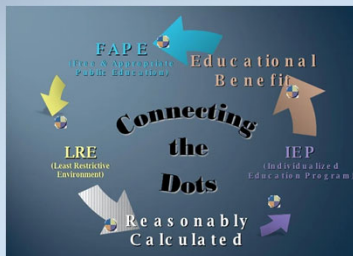
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## IEP Tips for Success



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## Start of School Year IEP Tips

- **Review the IEP to assess any new/different needs for support**
  - Are there new symptoms that require new supports?
  - Are there goals that need to be updated or amended?
- **Check-in with the new teacher(s), aide(s), related service provider(s)** if necessary or helpful.
- **If not already in your IEP, document the need for PWS Training.** Request and document in the IEP that a brief PWS Training will be held for school staff prior to or as close to the start of the school year as possible.
  - Provide training yourself or ask PWCF to provide it for you.

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## Start of School Year IEP Tips con't

- **Needs drive supports.** When you request supports, provide enough reasons and/or documentation to support the need for your ask.
  - Provide handouts about PWS to document and validate why you ask for supports.
  - Provide the *Physician's Note Symptom and Treatment Checklist* to document physiological symptoms and needs for supports.
  - Provide reports from any private therapists
- **Be organized!**
  - Create a 4" IEP Binder to house all documents for this "season" of school: Elementary School | High School
  - Save, print, or document any and all requests, correspondence (e.g., email, handwritten notes, conversations with teacher, etc.)
  - Write down and/or send a follow-up email regarding anything said to you verbally that may be important later.

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## IEP Meeting Tips

- **Guiding Principles:**
  - You are the expert in your child. School personnel are the experts in the educational environment. The law gives you equal voice in creating your child's Independent Educational Plan (IEP).
  - Build relationships. Be respectful, congenial, assertive, focused on what is in the best interest of your child.
    - School Districts are not obligated to provide your child with the "best" education. Your child is "only" entitled to a free appropriate public education (FAPE) in the least restrictive environment (LRE), that meets his or her educational needs.
  - Approach every discussion and meeting as an opportunity to educate about PWS.
  - Become educated about the language and legalities of IEPs.
    - Wrightslaw has awesome resources
    - Attend PWCf-sponsored school trainings; view PWSA | USA video resources

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## IEP Meeting Tips con't

- **Before the Meeting**
  - Come to the IEP Meeting prepared
    - Request that all assessments and reports be given to you a week or at least a few days *prior* to the IEP meeting. Follow-up your verbal request for reports in writing!
    - Review the reports and ask the report's author questions so you are prepared to discuss at the meeting.
    - Pre-discuss progress and goals with the teacher and related service providers.
    - Any requests should be followed up in writing or documented.
  - Decide *ahead of time* if it is in your child's best interest and if your child is capable of appropriately participating in some or all of the IEP meeting.
    - If "none", why not?
    - If "some" or "all", prepare your child by Painting the Picture. E.g., Share your desires with the team, then return to class.
    - If "some" or "all", can it be a student-led IEP?

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### IEP Meeting Tips con't

- **At the Meeting**
  - Listen carefully.
  - Take notes.
  - Ask questions respectfully, use the Columbo approach.
  - Be organized.
  - Be flexible. E.g., "1:1 Aide" vs. "1:1 dedicated support"
  - Watch the time and do your best to move the meeting along if spending too much time on less important matters.
  - Don't be intimidated into agreeing to something you don't agree with.
  - The IEP is a legal agreement; if it's not in writing, it didn't happen!
  - Don't sign the IEP in the meeting! Take it home, read it carefully, sign when all is correct. Sign only the Attendance page.
  - Utilize resources avail from Parent Training Info Centers, Family Empowerment Centers, Family Resource Centers (only birth – 3 years).

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### IEP Meeting Tips con't

- **After the Meeting**
  - Express your gratitude and thanks for a successful meeting
  - Follow up with a thank you note, if appropriate
  - Turn in your signed IEP as soon as you know it's accurate
  - Print your IEP and place it in your IEP Notebook binder
  - Stay organized for the next successful IEP meeting!

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### Handouts

- PWS Synopsis brochure
- Information for School Staff
- Food is Never OK in the Classroom
- 1:1 Support for the Student with PWS
- Food Security in School
- Food in the Classroom – PWSA
- Neurocognitive Skills Deficits & Management
- Behavior Tool Kit
- Empathy is a Powerful Intervention
- Homework: A Lesson in Frustration
- Health Concerns for the Student with PWS
- Medical Overview for School Nurses
- Medical Alerts Booklet 2022
- Wrightslaw IEP Checklist
- Physician's Note Symptom & Treatment Checklist
- SCDD Educational Resources
- Educational Support Resources List
- PWCF Education & Training Services brochure

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# Questions?



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## Contact PWCF!



Looking for more resources?

- PWCF Website: [www.PWCF.org](http://www.PWCF.org)
- PWSA | USA Website: [www.pwsausa.org](http://www.pwsausa.org)
- Wrightslaw: [www.wrightslaw.com](http://www.wrightslaw.com)
- State Council on Developmental Disabilities: <https://scdd.ca.gov>

Need to learn how to schedule a training at your school? Need help at your next IEP? Contact PWCF: 800-400-9994 | [info@pwcf.org](mailto:info@pwcf.org)

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