

Back to School Checklist: For the Student Who Has Prader-Willi Syndrome

(Compiled by Barb Dorn, Consultant on PWS)

We all want a positive, successful educational experience for every student as they return to school. The following checklist is meant to serve as a tool to help the parent do his/her best to make sure this is the case for the student with Prader-Willi syndrome.

- Review the IEP; contact the education case manager (who is typically the special education teacher) to share any changes or updates that may have occurred over the summer break.
- Create a 1-page information sheet about your son/daughter. Include things he/she enjoys; what helps him/her in various behavioral situations (new and/or high anxiety ones); what strategies DON'T work and some information about PWS.
- Share this information sheet with all teachers, aides and other personnel who will be working with your son/daughter. (Not all will have viewed your child's IEP)
- Remember to include what should be done with birthday treats and/or other food-related events.
- Make sure a diet prescription has been obtained from the student's health care professional. This is especially important if the student is participating in the school's breakfast/lunch program. Include the following information:
- Diagnosis: PWS
- Specific number of calories requested for breakfast, lunch and/or snacks that may be provided during the school day.
- Obtain and share information on PWS for educators and school health personnel. (In many schools, the secretarial staff serve as the health aides and provide first aid and/or administer medications).
- Information sheets and brochures are available from Prader-Willi Syndrome Association of WI, Inc. on line at www.pwsaofwi.org or contact us (920) 733-3077

1 week prior to the start of school:

- Visit the school and meet teachers, secretaries, principal and any other people who will be working with your son/daughter.
- Tour the school. Locate the classroom(s), bathroom, and locker. Make the student feel comfortable where things are located when there are few/no students in the building.
- Repeat the tour 2-3 times, especially if the student is new to this building.
- Start preparing for the "Back to School" routine – at least 1 week before school starts.
- Establish bedtime routine and bedtime.
- Prepare clothes, backpack and other school supplies the night before.
- Set up a meeting with teachers and other school personnel to review information about the student with PWS. Keep it short. Distribute information (including brochure, information sheets and information about your son/daughter).
- Contact the transportation company; share information about PWS and review any special requests needed for the student during his/her ride on the bus/van. (These should also be included in the student's IEP).
- Keep a positive attitude no matter how frustrating the preparation process may be. Your attitude is key in communicating cooperation both to educators as well as to your student with PWS.