



FOOD FIGHTS AT SCHOOL

Addressing Food Issues at School for Students with PWS

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1. If you have not yet told the school district the basic facts about Prader-Willi syndrome (PWS), do it now. The more educated school personnel are about PWS, the more help they can provide to your child.
2. Get brochures and booklets about PWS and education issues from PWSA and give them to every person who has contact with your child at school – from the regular education teacher to the principal to the special education teacher to aides to the music teacher to the cafeteria worker to the gym teacher to the janitor. Everyone should be informed. Obviously, a simple brochure or a one-page FAQ (Frequently Asked Questions) sheet you put together is plenty for most people to know, but teachers will probably need more information. Once you have educated the major players in your child's educational environment, it's time to seriously address food issues.
3. Address food issues at the IEP (Individualized Education Plan) meeting with all team members present.
4. Tell the team that your child should never be given food as a reward (it might surprise you to know how often this happens in many classrooms).
5. Tell the team that your child should never be punished by deprivation of food. Sometimes if students misbehave, they are not allowed the same snack as everybody else. Usually, this means they get a healthier snack, but it's still treated as a punishment.
6. Discuss a behavior management plan in the event that your child steals. Food stealing/hoarding is a manifestation of PWS and should not necessarily be subject to the typical disciplinary rules.
7. School meal programs, both breakfast and lunch programs, are administered at the federal level by the U.S. Dept. of Agriculture (USDA). USDA reimburses schools for every meal served to students. Schools are required to make a reasonable effort to provide special meals to students whose diets are restricted due to their disabilities. 7 CFR § 15b.26(d)(1). These meals are provided at no charge. You pay the same price that is charged for the typical meal served. To be eligible for the modified meals (these can be low calorie, low fat, or smaller portions, or any combination), a student must have a letter from a physician that includes a brief description of PWS, the need for dietary restrictions to prevent morbid obesity, what kind of meal modification you want, the caloric content you desire, and foods that are or are not acceptable. You can write the letter and just have your doctor sign it. Put this modification in the IEP.
8. *Monitor!*