PRADER-WILLI SYNDROME ASSOCIATION

Attention Teachers:

For the Student with Prader-Willi Syndrome Food Is *Never* OK in the Classroom

For most if not all kids with Prader-Willi syndrome (PWS), having any food anywhere in the classroom will impede their ability to concentrate and learn because their mind will be more focused upon how to obtain that food item rather than attending to the task at hand.

Prader-Willi syndrome is a serious medical disorder that interferes with the body appetite-control centers. Individuals with PWS do not recognize feeling satiated or "full" after they eat. The signals to the brain continuously and relentlessly drive someone with PWS to seek out and eat more food. People with Prader-Willi syndrome metabolize their food at generally half the rate their peers do, so someone with PWS can easily gain weight at a tremendous rate on just a few extra calories. In addition, people with PWS can experience severe gastric illnesses which can, particularly after overeating or binge eating, lead to life-threatening conditions (thinner individuals may be at even greater risk). Keeping food items out of sight and inaccessible is imperative.

It must be understood that for the child with Prader-Willi syndrome there is no "behavior modification" or "learning" to control oneself in regard to food. It is not realistic to expect that a child with PWS can modify his behavior about taking the bag of chips out of someone else's lunch or eating the entire lunch if that food is available to him, no matter how many tokens or



prizes or incentives are given the child not to take food. While the child with PWS may be able to manage his behavior for a day or even a week or two, this does not constitute genuine modified behavior. There will come a day when the child, despite his knowing that he should not, will take that bag of chips or eat other lunches and eat them as quickly as he can, thus also creating a choking risk, in addition to putting himself at risk for severe gastric illness. Individuals with PWS know



they're not supposed to eat "out of bounds" foods; they simply cannot overcome their biochemical urge to eat.

If teachers provide snack items during the day, those snack items must be kept in another area, such as another classroom or the office until use, or kept within the same classroom in a cupboard or storage area that is clearly locked. Children's backpacks which contain their lunch boxes or snacks should be kept in an area that is not visible or accessible to the student with PWS. Some teachers keep lunch boxes in one large, closed trash barrel outside the classroom. It is realistic and manageable to make these relatively minor changes to accommodate the student with PWS in order to free his mind to learn.

While there may be a few children with PWS who do have the limited ability to manage their behavior around food, having any food visible to them while in the classroom will severely interfere with their ability to focus, concentrate, and learn. It is therefore far better to err on the safe side and get all food products out of the classroom setting.

For more information about Prader-Willi syndrome or to speak with someone about how to organize or manage your classroom to assist your student with Prader-Willi syndrome, please visit Prader-Willi Syndrome Association (USA)'s website at www.pwsausa.org or call 800-926-4797.