

### Helpful Tips to Maintain Food Security

Make sure lunch is placed with a bus driver and/or an assistant on the ride to school.

Educate and inform *all* people working with the student including bus drivers, custodians, secretaries and volunteers.

If the student states he has not had breakfast call the parents or caregiver *before* giving food. The child may have already eaten a healthy breakfast and is hoping to obtain more food.

Supervise the lunchroom and all food related areas. In some cases the student may need to eat in his classroom with a peer or friend.

Many children require supervision in hallways or near unlocked lockers at all times.

Avoid allowing the student to have money. Lock up all sources of money including purses. Money buys food!

Address any stealing or trading of food in private. Never be punitive—this is the syndrome!

Never try to take food out of the child's hand unless it is spoiled or dangerous as this may lead to meltdown behavior. Instead, inform the parents of the eaten food and secure against a reoccurrence.

Follow parental guidelines for treats or eating of extra food. Communication with home is very important.

If a special calorie diet is needed and served by the school, a prescription must be obtained from a health care provider and should be a part of the student's educational plan.

Don't delay snack or lunch; if this is necessary discuss ahead of time with the child.

Limit availability and visibility of food. Be aware of candy dishes or sources of food. Do not offer a food treat to another child in the presence of the child with PWS who cannot also enjoy that food treat.

Do not use food as a reward, incentive, or punishment. Instead, the use of other systems of reward or incentive are encouraged such as stickers, small toys, tokens for the "purchase" of small toys, etc.



Be aware of food aromas. There is nothing like the smell of popcorn or cookies to make a student with PWS agitated.

When going on a field trip or other outing discuss all food-related issues *ahead* of time. Will you bring a snack along or will it be purchased? If purchased, what will it be? Will the outing interfere with the typical timing of a meal?



Obtain weekly weight by school nurse if indicated.

Daily exercise should be a part of the student's schedule.

Praise situations where the student does not take food when you see he could have. The use of praise in general will go a long way for the typical child... and even longer for the child with PWS.

### For More Information about PWS

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 PWS please visit the PWCF website at [www.PWCF.org](http://www.PWCF.org) or call the PWCF toll-free in California at 800.400.9994 or outside California at 310.372.5053.

*Prader-Willi California Foundation is a non-profit 501(c)(3) charitable corporation established in 1979. An affiliate of Prader-Willi Syndrome Association (USA), PWCF is dedicated to supporting individuals with Prader-Willi syndrome, their families, and the professionals who serve them.*



*Supporting People with Prader-Willi Syndrome*

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## Food Security at School

## for the Student with Prader-Willi Syndrome



*Supporting People with Prader-Willi Syndrome*

## Prader-Willi Syndrome Causes an

### Insatiable Appetite

Prader-Willi syndrome (PWS) is a non-inherited genetic disorder. PWS causes a host of symptoms including hyperphagia, or insatiable appetite. Persons with PWS do not feel satiated or “full” no matter how much they eat; the brain continuously and relentlessly drives someone with PWS to seek out and eat more food. At the same time, the body metabolizes food at generally half the normal rate, so someone with PWS will gain weight at a tremendous rate on few calories.

*Food Security in the school setting at all times and in all circumstances is imperative.*



There is no known treatment or appetite suppressing medication to eliminate or even reduce the hyperphagia caused by PWS. It must be understood that for the child with PWS there is no "behavior modification" in regard to food. It is not realistic to expect that the student with PWS can “learn to control himself” and not eat food that is available. While some children may be able to manage their 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 knowing that he should not, will attempt or succeed at eating excess food. Individuals with PWS know they’re not supposed to eat “unauthorized” foods; they simply cannot overcome their biochemical drive to eat. For the child with PWS the emphasis is always on prevention. *The key to managing the hyperphagia caused by PWS and reduce the incidence of food-related behavior issues is to maintain Food Security within the school environment.*

### But Just “One” Can’t Hurt... Can It?

For the child with PWS, just “one” or just one food binge *can* hurt... It can even be deadly. Here’s why:

## Rapid Weight Gain

Due to a reduced metabolic rate and other endocrine issues persons with PWS can quickly gain large amounts of weight on very few calories. A diet considered healthy for a child without PWS can cause rapid weight gain for the child with PWS. The daily caloric intake of the child with PWS must be strictly monitored; even just one cookie or one extra slice of pizza every now and again can mean the difference between a healthy weight and a tip of the scale into morbid obesity. If a child is known to have obtained extra food during the school day parents must be notified so that they may compensate and reduce the child’s caloric intake for the remainder of the day or week.

## Choking

Choking is a particular hazard for persons with PWS. Children with PWS often eat much too quickly and do not adequately chew their food before swallowing. Sneaked or stolen food will be eaten very, very quickly to avoid detection or loss of the forbidden item. Low muscle tone and poor coordination exacerbates the choking risk.

## Severe Gastric Illness

Abdominal distention or bloating, pain, and/or vomiting may be signs of life-threatening gastric inflammation or necrosis and is more common in PWS than in the general population. Thinner individuals appear to be at even greater risk. Rather than localized pain the child may complain of a general feeling of unwellness. If a child with PWS has these symptoms, especially following a known or suspected binge-eating episode, immediate parental notification and hospitalization is warranted as this may be a life-threatening situation.

## Lack of Vomiting

Vomiting rarely occurs individuals with PWS. Emetics may be ineffective and repeated doses may cause toxicity. The presence of vomiting may signal a life-threatening illness.

## PWS’ Impact in the Classroom

It is unrealistic to expect a child with PWS to maintain focus on the task at hand when he knows that a food or beverage is or may be obtainable; the drive to eat is too strong and will affect behavior and school performance. For most kids with PWS, having *any* food *anywhere* in the classroom will impede their ability to concentrate and learn. Maintaining Food Security will help improve learning and the overall behavior of the student with Prader-Willi syndrome.



## Food Security

Food Security, a term coined by PWS experts Linda Gourash, M.D. and Janice Forster, M.D., refers to “the ready availability of nutritionally adequate and safe foods with an assured ability to acquire acceptable foods in socially acceptable ways.” The Principles of Food Security are:

**No Doubt** when meals will occur and what foods will be served plus

**No Chance/Hope** to obtain anything different from what is planned equals

**No Disappointment** related to false expectations.

Some ways to achieve Food Security include:

- Secure access to food across *all* settings:
  - Controlled access to all food sources including the cafeteria, lunch boxes, hallways, vending machines and money
  - Avoid any spontaneity related to food: no snacks on demand, no food left out, absolute portion control
- Supervise food exposure at all times
- Post the schedule for snack and lunch times

### The Hand is Quicker Than the Eye

Regardless of cognitive function, a child with PWS can be quite adept at obtaining food. Educators should be aware that children with PWS have been known to:

- Take food out of someone else's lunchbox
- Take food from someone else’s lunch tray
- Trade valuable items such as jewelry and money for food
- Eat their own packed lunch and attempt to obtain more food from the cafeteria
- Steal food from the cafeteria, other children, the teacher’s lounge
- Take half-eaten or discarded food from the trash
- Take food from backpacks left in corridors while on the way to the restroom
- Eat all of their lunch on the bus while on the way to school

There is no end to what PWS may drive a child to do to obtain food. Children with PWS may not be truthful about whether or what they’ve eaten regardless of the “evidence.” It is generally recommended not to ask “Did you eat that?” but rather presume food was eaten and notify the parents.