

## **To: Law Enforcement Personnel Regarding Adults with Prader-Willi Syndrome**

This person has Prader-Willi syndrome (PWS). Because of the unique behavioral and emotional characteristics related to this rare syndrome, it is imperative that you read the following information in order to better understand the situation you've encountered. PWS is a genetic disorder that causes the brain to function in a way that is not typical of other people. This brain dysfunction can cause problems that often lead to the involvement of law enforcement because:

1. The brain of a person with PWS sends a message of constant hunger due to an inability to register a feeling of "fullness" after eating regardless of the amount of food ingested. As a result, sneaking or stealing food is common and due to this intense drive to eat, a person with PWS cannot always control themselves around food. The reality is that any person who felt the same way would react in a similar manner. No medication, to date, is effective in curbing the insatiable appetite of a person with PWS. Food can be dangerous and even life threatening for people with PWS so parents and caregivers do all that they can to prevent exposure to food that is not secured. But, because food is everywhere in our society, it is impossible for a person with PWS to always avoid situations where they might have an opportunity to "steal" or take food so theft of food can occur. In addition, people with PWS may also steal nonfood items (i.e., money) usually in an attempt to buy or trade for food. When theft occurs, PWSA | USA encourages you to work cooperatively with the parent(s) or caregiver to resolve the situation through implementing new positive behavioral and environmental supports. Especially because when a person with PWS engages in theft of any kind it is a manifestation of their disability rather than an indication of willful criminal intent.
2. The same part of the brain that regulates appetite (the hypothalamus) also regulates temper and emotional response. As a result, it is not uncommon for a person with PWS to experience significant temper tantrums and behavioral outbursts. Such outbursts are a feature of PWS. We encourage you in response to allow the person with PWS the space to work their way out of a tantrum if they do not pose a threat to self or others. Responses such as over talking, threats or other punitive approaches will most often cause an escalation of behavior. In addition, due to respiratory features of PWS, injury and even death can occur if improper physical restraint is applied.
3. Over consumption of food can be medically dangerous and even life threatening for a person with PWS. For this reason, parents and caregivers are encouraged

to practice strict food security in their household. This food security practice can include locking refrigerators, cabinets, and any other place food is kept. It is very important to understand that such measures are not an indication of abuse. These precautions are taken to safeguard a person with PWS and are not signs of a “bad” or punitive parent. Such food security practices are encouraged by PWSA | USA and other medical and professional PWS experts.

4. Since behavioral instability can be a feature of PWS there are other unusual behaviors that can be the cause of police attention including:
  - a. Calling 911 when upset with a caregiver. This can include accusations of abuse or some type of mistreatment by a parent or caregiver.
  - b. Destruction of property when upset – most often when denied food.
  - c. Elopement or “running away” behavior often for no identifiable reason - although in some cases it is to pursue food.

These behaviors, while actively discouraged by parents and caregivers, should also be treated as a manifestation of the person’s disability rather than a criminal act. Appropriate responses include working with the parent(s) and or caregivers to develop positive behavioral solutions in each situation to discourage repeat incidents in the future. PWSA | USA is happy to serve as a resource in these situations to make behavioral suggestions based on best practices when caring for a person with PWS.

5. Skin picking and some forms of self-abuse are also common, so it is not unusual for a person with PWS to exhibit sores and scars in various stages of healing. At first glance this can look like the signs of possible caregiver or parental abuse. And, while we encourage all potential situations of abuse to be appropriately addressed, it is important to take this information into account when investigating potential abuse involving a person with PWS.