

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.

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It is important to remember that people with PWS are most often very sweet and loving people who, with the help of their parents and other caregivers, are positive and helpful members of their community. Occasionally, however, due to their disability they will experience behavioral problems such as we've described. We hope this information will help you place these behaviors in the appropriate context so that you are able to offer the support and help they need when encountering law enforcement. If you have questions – or we can assist in any way – please do not hesitate to contact us at 800-926-4797 Monday through Friday from 10-5PM EST. We also have many helpful resources available on our website at www.pwsausa.org.

Tips for Working with a Person with PWS in Crisis

While each person with PWS is unique, the following tips will help to create a more successful response to a person with PWS who is in need of police assistance:

- Clearly identify who you are and your role as a helper to the person with PWS.
- If a caregiver or parent is present, before directly addressing the person with PWS, ask the caregiver/parent if they have suggestions for the most effective way for you to approach the person.
- Utilizing a calm voice and non-anxious presence at all times will help to de-escalate a person with PWS who is upset.
- Avoid any threats of jail, punishment, or confrontational tactics. Such negative approaches typically are not effective for people with PWS and actually can significantly worsen the situation.
- Please remember a person with PWS needs your help in understanding what is happening and why you are involved.
- Unless under the most extreme circumstances avoid physical contact or using restraints of any kind. People with PWS will often react negatively if they feel backed into a corner and this can result in physical and verbal aggression and other destructive behaviors.
- PWS is fundamentally a disability that severely impairs a person's ability to self-regulate critical functions such as appetite, emotion, and temper response. It can also create cognitive impairments as well. Therefore your role as a professional is critical in helping a person with PWS manage their emotional or behavioral crisis with minimal harm to self and others.

For additional information about PWS please contact 800-926-4797 or visit www.pwsausa.org. Thank you!