

To: Law Enforcement Personnel Regarding Children with Prader-Willi Syndrome

The child of this parent 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 children. This brain dysfunction can cause problems that often lead to the involvement of law enforcement because:

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:

1. The brain of a child 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 child 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. And because food is everywhere in our society, it is impossible for a parent to always avoid situations where their child with PWS might have an opportunity to "steal" food so theft can occur.
2. Over consumption of food can be medically dangerous and even life threatening for a child 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 child abuse. These precautions are taken to safeguard a child 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.
3. 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 child with PWS to experience significant temper tantrums and behavioral outbursts. Such outbursts are a feature of PWS. If the child you encounter is experiencing a tantrum or emotional meltdown, we recommend allowing the child space to work their way out of the tantrum if they do not pose a danger to self or others. Responses such as over talking and apply punitive approaches will most likely result in an escalation of behavior. In addition, due to respiratory features of

PWS, injury and even death can occur if improper physical restraint is applied. Often the parent(s) of a child with PWS can help you with the best suggestions for how to respond to their child when they are upset. Typically, it is important to remain calm and use clear and simple directions with the child.

4. A small portion of children with PWS exhibit “running” or elopement behavior often for no identifiable reason (although in some cases it is to pursue food). For this reason, some parents will need to utilize motion detectors and/or locks to keep their child from leaving home without supervision. Again, this is a practice put into place for the safety of a child – not as a punitive or abusive action.
5. Skin picking and some forms of self-abuse are also common, so it is not unusual for a child 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 child with PWS.
6. Some children with PWS will also call 911 when upset with their caregiver.

It is important to remember that children with PWS are most often very sweet and loving children who, with the help of their parents, 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 (941) 312-0400 Monday through Friday from 9:00 – 5:00 p.m. EST. We also have many helpful resources on our website at www.pwsausa.org.