

**TO: LAW ENFORCEMENT PERSONNEL
REGARDING PRADER-WILLI SYNDROME**

The person you are dealing with has Prader-Willi syndrome. Because of the unique problems related to children and adults who have the syndrome, it is imperative there you read the following.

Due to a genetic problem, the brain is not working right in people with Prader-Willi syndrome (PWS). This creates several wrong messages to the brain. The legal problems created by three of these “wrong Messages” are:

(1) The message to the brain is always “hunger”, and never registers “full”; thus a person with PWS has an insatiable appetite. Sneaking or stealing food is common, and due to the intense drive to eat, the person with PWS cannot always control themselves. (Anyone who felt that they were starving to death would react in the same way.) Because food is everywhere in our society, it is impossible for a caregiver to always avoid situations where the child/adult with PWS might have the opportunity to steal to get food. No medication to date is effective in curbing this appetite. They will often transfer this stealing to nonfood items.

This does not mean a person with PWS should be allowed to take things, but we do request that you work cooperatively with a parent/caregiver. Our young people with PWS are not in any way “hardened criminals,” and all are functionally retarded in spite of IQ levels.

Food can be dangerous and even life threatening to our young people, and we want to do all we can to prevent food foraging.

(2) Although our young people with PWS are typically mild mannered in personality, the same dysfunctional part of their brain creates stubbornness, illogical thinking, and fits of rage. They can get inordinately upset for the situation and cannot be calmed through discussions or threats. (Often a short “time out” can defuse the situation.) Typically, a law enforcement person becomes involved if the person with PWS: (a) strikes out at another person

-typically this is a caregiver because they are upset over something the caregiver said or did; (b) calls 911 due to being upset with the caregiver and accuses the caregiver of abuse; (c) destroys property. Note: It is also not uncommon for our young people to try to run away when upset or when trying to get at food sources.

(3) Skin picking and some forms of self-abuse are also common; thus sores or scars in various stages of healing are not unusual. This can look like child abuse. This should be taken into consideration when investigating. Call if this is an issue of concern.