

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

***For Extended Family Members of
a Child With Prader-Willi Syndrome:
Saying "No" may save the life of the child you love!***

Children with PWS process calories more slowly than the general population. Research is still ongoing to determine if this is a problem with metabolism or simply a lack of enough lean muscle mass to burn calories quickly. Regardless of the cause, in order to avoid becoming obese and susceptible to a range of obesity related disorders (diabetes, heart problems, etc.) a child with PWS must have a strictly regulated and monitored calorie intake. A calorie plan should be developed in concert with a dietician and/or medical doctor familiar with PWS. The calorie limits change for each stage in life but in general it is believed about ½ the calorie intake for the general population is appropriate for a child with PWS in order to avoid significant weight gain.

It is very important for family and friends to be aware of the need to consistently support a calorie-reduced diet created for a child with PWS. Sneaking food to a child, for example, might seem like a harmless thing to do but in the long run (and sometimes immediately depending on the amount of food eaten) it can cause serious, even life threatening, medical problems. This is often hard for people outside the immediate family to understand but it is vitally important. A child with PWS will test your ability to say "no". But, saying no will literally keep the child you love safe from short term and long term medical problems.

I would be happy to talk personally with you if you have questions about supporting a calorie restricted child for a child with PWS.

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