

USA PRADER-WILLI SYNDROME ASSOCIATION

Still hungry
for a cure.

PRADER-WILLI SYNDROME MAY IS PWS AWARENESS MONTH

Our son Reagan Seely was diagnosed at infancy with Prader-Willi Syndrome (PWS). He will turn four this coming June, and we are so proud of the progress that he has made thus far. He has worked so very hard!!

Prader-Willi Syndrome Association (USA) has designated May as a month long effort to promote awareness of PWS. This is a complex syndrome affecting appetite, growth, metabolism, cognitive function, and behavior. The hallmark characteristics of PWS that typically begin around age three to five include:

- An insatiable appetite that cannot learn to be controlled because of a dysfunction of the hypothalamus region in the brain.
- Rapid weight gain on few calories because of a malfunctioning metabolic system. Therefore a closely monitored diet must be maintained to restrict calorie intake.
- Ironically, babies typically show no interest in eating and have difficulty sucking, breathing and swallowing. This is known as "failure to thrive" stage.
- Those with PWS need strict external controls, including access to food. Possibly to the extent of padlocking food. This may be necessary as a life-saving intervention. Children as young as three have died of weight related problems. These problems are life threatening and include perforation in the lining in

**Reagan is ready for his 1st day of
the stomach from sudden eating binges.
pre-school at Eli Pinney.**

It is estimated that PWS affects one in 12,000 to 15,000 births. This syndrome affects both males and females and all ethnic groups. Currently there is no cure to date, no medications or procedures are successful in staving off the relentless hunger. However, growth hormone has been effective in increasing height, improving body mass and metabolism, and boosting strength and energy.

Reagan is a very sweet boy with an incredibly infectious smile! We are fortunate for an early diagnosis, along with a handful of specialists and daily therapies. The biggest factor in our success has been the growth hormone therapy, a daily injection that he will need for the rest of his life. Although we are not experiencing the food seeking issues at this time, we know that the road ahead will be challenging for him as the second phase of this syndrome emerges.

Please help us in our efforts to activate PWS knowledge & to enlighten others about this syndrome. To learn more about PWS visit the website of PWSA (USA) at: www.pwsausa.org



Thank you for support, The Seely Family