FOUNDATION FOR PRADER-WILLI RESEARCH
Working Toward an Independent Future

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MAY IS PRADER-WILLI SYNDROME AWARENESS MONTH

Parents of children with rare disease share stories of hope online

WALNUT, CA _ On May 1, the Foundation for Prader-Willi Research will kick off Prader-Willi Syndrome Awareness Month by sharing inspiring stories of hope about children with PWS at fpwr.org/pwam. These stories from parents, friends, and caregivers will raise awareness and generate the funding needed for **research to help loved ones with PWS lead more healthy and fulfilling lives**. The page also features videos, downloads, and social media graphics to share with the hashtag **#PWSawareness**.

"For the PWS community, research gives us a reason to believe our loved ones will one day live full and independent lives," said FPWR Executive Director Susan Hedstrom. "PWS Awareness Month is a great opportunity to raise awareness and support for our 5-year research plan, which accelerates PWS research and brings us closer to that goal."

Since May of 2010, PWS Awareness month has mobilized the PWS community to raise awareness and educate others in their communities and across the country.
Parents involved with FPWR will host events throughout the month including One SMALL Step walks and golf tournaments, which are listed on the web page.

Prader-Willi syndrome is a rare, non-inherited genetic disorder affecting approximately 1 in 15,000 people. Nearly every system in the body is affected by a PWS diagnosis but the hallmark symptom is extreme hunger. A person with PWS never feels full. To make matters worse, this is coupled with a slow metabolism where the person with PWS only needs about 60% of the calories of their typical peers. Other common symptoms include behavioral challenges, obsessive compulsive disorder, anxiety, sleep problems, scoliosis, and much more.

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The Foundation for Prader-Willi Research was established in 2003 by a small group of parents who saw the need to foster research that would help their children with Prader-Willi syndrome lead more healthy and fulfilling lives. Today, FPWR is composed of hundreds of parents, family members, researchers, and others who are interested in addressing the many issues related to PWS, including childhood obesity, developmental delay, psychiatric disorders, and autism spectrum disorders.

The mission of FPWR is to eliminate the challenges of Prader-Willi syndrome through the advancement of research and therapeutic development. High-quality research will lead to more effective treatments and an eventual cure for this disorder. By working together, we intend to free our loved ones from the burdens of PWS, allowing them to lead full and independent lives.

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Photos of individuals with PWS and their families are available for use in the media upon request.