

Prader-Willi
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Congress Establishes Prader-Willi Syndrome Awareness Month

WASHINGTON, D.C. – December 10, 2009 – House Resolution 55, introduced in the House of Representatives by Reps. Ed Royce (R-CA) and Jane Harman (D-CA), passed today in a majority vote with bipartisan support. The resolution establishes a Prader-Willi Syndrome (PWS) awareness month. PWS is a rare life-threatening genetic condition affecting one in 15,000 people and is the most common known genetic cause of life-threatening obesity that has been identified. The resolution also recognizes the importance of early diagnosis and the efforts and commitment of patient advocacy groups.

“This is a significant development for those affected by Prader-Willi syndrome,” said Kim Weinberg, executive director of Prader-Willi Syndrome Association (USA). “PWSA (USA) is a strong advocate for national recognition of PWS, launching PWS Awareness Month, and will continue to promote the agenda of the PWS community.”

Janalee Heinemann, M.S.W. and PWSA (USA)'s director of research and medical affairs, said, “PWS research has wide ramifications beyond the PWS community and is a significant key to unlocking the mystery of obesity as well as to gaining a better understanding of autism.” In June, Heinemann co-chaired the First International Conference on Hyperphagia (the uncontrolled desire to consume food) bringing together multi-disciplinary experts studying hyperphagia across different syndrome groups, government and pharmaceutical representatives to accelerate discoveries of new, effective treatments and a cure. “This Congressional recognition shines a light on an important area of study for a perplexing disease and on those who are dedicated to finding answers, such as the NIH and others in the scientific world,” Heinemann added.

“House Resolution 55 is a great step toward a brighter future for those with PWS,” said Weinberg. “The entire PWS community is appreciative to Reps. Royce and Harman for their work and support.”

PWS is a complex genetic disorder affecting appetite, growth, metabolism, cognitive function and behavior. Although considered a rare disorder, PWS is one of the most common conditions seen in genetics clinics. Currently there is no cure and, to date, no medications or procedures are successful in staving off the relentless hunger, although growth hormone treatment has great benefit.

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PWSA (USA) is a 501(c)(3) charity that helps children and adults with PWS and their families through every stage of life via support, education, advocacy and research funding. For more information, visit www.pwsausa.org.

still hungry for a cure.