

Prader-Willi
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**Prader-Willi Syndrome Association (USA) Praises Congress for Postponing
Vote on Bills Restricting Access to Human Growth Hormone**

*Abuse of Human Growth Hormone Generates Legislative Attention, Further
Consideration*

March 19, 2008 (Sarasota, FL)—Two bills drafted to reclassify human growth hormone (HGH) as a Schedule III controlled substance under the Controlled Substance Act were temporarily removed from Congressional fast track consideration early March. After a flurry of constituent concerns was registered with bill sponsors, U.S. Senator Charles Schumer (D-NY), pulled S. 877 from the unanimous consent calendar and U.S. Representative Stephen Lynch (D-MA), sponsor of H.R. 4911, promised to revisit his legislative language if his bill moves forward.

Patients with Prader-Willi syndrome (PWS), hypoglycemia and other conditions who use HGH as a recognized and valued treatment for their conditions urged the bill sponsors to take time to fully understand the legitimate medical uses of HGH.

"Fortunately, the bill sponsors have indicated a willingness to amend their language to address the abuse issues while preserving access to the HGH that our populations requires," said Craig Polhemus, executive director of Prader-Willi Syndrome Association (USA).

The bills are a direct result of recent abuses by professional athletes which have put the use and distribution of growth hormones under the scrutiny of Congress. Unfortunately, the health of patients who legitimately use the hormone are put at risk by more stringent policy.

Prader-Willi syndrome is a non-inherited genetic disorder of chromosome 15 which causes children to have a constant sense of hunger, slower metabolic rates, learning disabilities, speech issues, and weak muscle tone. Currently, there is no cure for PWS and 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. It is the only Federal and Drug Administration (FDA)-approved drug with major life-improving and life-saving benefits for patients with PWS.

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still hungry for a cure.

Growth hormone has many benefits for those with PWS aside from increasing linear growth and muscle mass. According to PWSA (USA), newer research is finding that growth hormone increases energy, redistributes fat in the body for a healthier body composition, helps to keep weight down, allows more intake of calories in a very restricted diet, and may improve cognition.

PWS occurs in approximately 1 out of every 12,000-15,000 births and equally affects both males and females and all ethnic backgrounds. PWS symptoms are caused by a dysfunction of the hypothalamus in the brain which regulates hunger and many other systems in the body. Individuals with PWS feel hungry most (if not all) of the time and yet can only eat about half the calories without gaining weight. PWS is the most common known genetic cause of life-threatening obesity in children.

Organizations like PWSA (USA), whose populations rely on growth hormone for improved quality of life, point out that many families already find it difficult to obtain access to and insurance coverage for growth hormone. In their appeals to Congress, PWSA (USA) asked that reclassification be a joint determination by the FDA and the Drug Enforcement Administration (DEA) that will not restrict access to or insurance coverage of HGH for those with PWS, hypoglycemia, or other conditions for which the hormone is a recognized treatment.

“We applaud Senator Schumer and Congressman Lynch for taking a step back and considering the medical repercussions of their legislation,” Polhemus continued. “For our population, the best scenario of all would be Congressional passage of legislation requiring insurance coverage for growth hormone for those with PWS, hypoglycemia, or other qualifying conditions. HGH deficiency is very serious and access to life-enhancing medication should not be one of our daily trials.”

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Prader-Willi Syndrome Association (USA) is a 501(c)(3) not-for-profit organization that helps children and adults with PWS and their families through every stage of life. Headquartered in Sarasota, FL, the organization funds PWS research and provides PWS support, education and advocacy. Hospitals, physicians, and parents from all over the world consult with PWSA (USA) with medical emergencies and questions daily.

For more information about PWS, visit www.pwsausa.org.