119TH CONGRESS
1ST SESSION

H. RES. 253

Expressing support for the designation of May 15, 2025, as "Prader-Willi Syndrome Awareness Day" to raise awareness of and promote research on the disorder.

IN THE HOUSE OF REPRESENTATIVES

MARCH 25, 2025

Mr. TONKO (for himself and Ms. SALAZAR) submitted the following resolution; which was referred to the Committee on Energy and Commerce

---

RESOLUTION

Expressing support for the designation of May 15, 2025, as "Prader-Willi Syndrome Awareness Day" to raise awareness of and promote research on the disorder.

Whereas Prader-Willi syndrome (PWS) is a rare genetic disorder and the most common of the genetic disorders that cause life-threatening obesity in children;

Whereas PWS usually results from problems on chromosome 15;

Whereas PWS is a complex genetic disorder that occurs in approximately 1 out of every 15,000 births;

Whereas, in the United States, there are approximately 10,000 to 20,000 living individuals with PWS;

Whereas PWS affects—

(1) males and females with equal frequency; and

(2) all races and ethnicities;

Whereas PWS causes an extreme and insatiable appetite, often resulting in severe obesity;

Whereas severe obesity is the major cause of death for individuals with PWS;

Whereas one of the main symptoms of PWS is the inability to control eating and constant hunger, and other symptoms include low muscle tone and poor feeding as an infant, delays in intellectual development, and difficulty controlling emotions;

Whereas PWS causes cognitive and learning disabilities and behavioral difficulties, including obsessive-compulsive disorder and difficulty controlling emotions;

Whereas PWS affects many aspects of the person's life, including eating, behavior and mood, physical growth, and intellectual development;

Whereas PWS can affect hormone production and cause other health complications;

Whereas PWS can lead to obesity and related complications such as heart issues, diabetes, and high blood pressure;

Whereas studies have shown that individuals with PWS have a high morbidity and mortality rate;

Whereas individuals with PWS, like many other rare disorders, experience challenges with obtaining a diagnosis, limited treatment options, and difficulty finding and accessing treatment centers and physicians with expertise in PWS;

Whereas there is no known cure for PWS;

Whereas early diagnosis of PWS allows families to access treatment, intervention services, and support from health professionals, advocacy organizations, and other families who are dealing with PWS;

Whereas discovered treatments, including the use of human growth hormone, are improving the quality of life for individuals with the syndrome and offer new hope to families, but many difficult symptoms associated with PWS remain untreated;

Whereas increased research into PWS—

(1) may lead to a better understanding of the disorder, more effective treatments, and an eventual cure for PWS; and

(2) is likely to lead to a better understanding of common public health concerns, including childhood obesity and mental health;

Whereas there is a critical need for research and development to advance treatments for PWS;

Whereas studies have shown that individuals with PWS have a high morbidity and mortality rate;

Whereas the Prader-Willi Syndrome Association, a nonprofit organization established in 1975, provides parents and health care professionals with a national and international network of information, support services, and research endeavors to expressly meet the needs of children and adults with PWS and their families;

Whereas the organization comprises parents, professionals, and other interested individuals who are taking active roles in improving the lives of people with PWS;

Whereas the goals of the organization include—

(1) normalizing life for people with PWS and their families;

(2) improving communication and education; and

(3) acting as a lifetime advocate for affected individuals;

Whereas the association also supports research, interdisciplinary communication, and increased professional knowledge of treatments; and

Whereas ''Prader-Willi Syndrome Awareness Day'' is expected to be observed in the United States for years to come, providing hope and information for patients, caregivers, and families around the country: Now, therefore, be it

Resolved, That the House of Representatives—

(1) supports the designation of ''Prader-Willi Syndrome Awareness Day'';

(2) applauds the efforts of advocates and organizations that encourage awareness, promote research, and provide education, support, and hope to those impacted by Prader-Willi syndrome;

(3) recognizes the commitment of parents, families, researchers, health professionals, and others dedicated to finding an effective treatment and eventual cure for Prader-Willi syndrome; and

(4) recognizes the importance of, with respect to Prader-Willi syndrome—

(A) improving awareness and educating the public;

(B) encouraging accurate and early diagnosis;

(C) advancing research;

(D) developing new treatments, diagnostics, and cures; and

(E) identifying regulatory pathways for drug development of rare diseases like Prader-Willi syndrome.

○