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(Original Signature of Member)

119TH CONGRESS
1ST SESSION

H. RES. _____

Expressing support for the designation of November as “Complex Regional Pain Syndrome and Reflex Sympathetic Dystrophy Syndrome Awareness Month”.

IN THE HOUSE OF REPRESENTATIVES

Mr. TONKO submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Expressing support for the designation of November as “Complex Regional Pain Syndrome and Reflex Sympathetic Dystrophy Syndrome Awareness Month”.

Whereas Complex Regional Pain Syndrome, also known as Reflex Sympathetic Dystrophy Syndrome, is a rare, neuro-inflammatory syndrome characterized by intense chronic pain, swelling, vascular changes, and functional impairment of the limbs that may result from simple trauma, injury, infection, or surgery that can lead to disability;

Whereas Complex Regional Pain Syndrome can become debilitating unless diagnosed early and treated appropriately;

Whereas although Complex Regional Pain Syndrome was first identified during the American Civil War, it remains an obscure and poorly understood condition for which there is no single test for diagnosis, and there is no cure;

Whereas Complex Regional Pain Syndrome is more common in women than men with a ratio of 3.5:1, with peak incidence in middle-aged and older adults, especially post menopausal women;

Whereas the incidence of Complex Regional Pain Syndrome is low worldwide, with regional rates generally between 5 and 29 per 100,000 individuals, higher in women and older adults, and even lower in children;

Whereas individuals with Complex Regional Pain Syndrome, 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 Complex Regional Pain Syndrome;

Whereas because the disorder affects multiple systems of the body, a patient with Complex Regional Pain Syndrome often requires access to care from experts across a range of medical specialties;

Whereas to date, there is no treatment for Complex Regional Pain Syndrome that is approved by the Food and Drug Administration (in this resolution referred to as the “FDA”);

Whereas there is a critical need for research and development to advance treatments for Complex Regional Pain Syndrome;

Whereas as a result of the Orphan Drug Act, there have been important advances in research on and treatment for rare diseases, including development efforts in Complex Regional Pain Syndrome;

Whereas the FDA established the Accelerated Approval Pathway in 1992 and Congress codified the pathway in 2012;

Whereas the Accelerated Approval Pathway is an important pathway for rare and ultrarare diseases as it allows for “earlier approval of drugs that treat serious conditions, and fill an unmet medical need”;

Whereas Congress and the FDA have affirmed the importance of incorporating the patient perspective throughout the drug review process through the FDA’s Patient-Focused Drug Development program;

Whereas the Reflex Sympathetic Dystrophy Syndrome Association, a nonprofit organization founded in 1984 to provide support, education, and hope to all affected by the pain and disability of CRPS/RSD, while driving research to develop better treatments and a cure for Complex Regional Pain Syndrome; and

Whereas “Complex Regional Pain Syndrome and Reflex Sympathetic Dystrophy Syndrome Awareness Month” 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

1 *Resolved*, That the House of Representatives—

2 (1) expresses support for the designation of

3 “Complex Regional Pain Syndrome and Reflex Sym-

1 pathetic Dystrophy Syndrome Awareness Month”;
2 and

3 (2) recognizes the importance of, with respect
4 to Complex Regional Pain Syndrome and Reflex
5 Sympathetic Dystrophy Syndrome Awareness
6 Month—

7 (A) improving awareness;

8 (B) encouraging accurate and early diag-
9 nosis;

10 (C) advancing research;

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

13 (E) identifying regulatory pathways for
14 drug development of ultrarare diseases like
15 Complex Regional Pain Syndrome and Reflex
16 Sympathetic Dystrophy Syndrome.