

116TH CONGRESS
1ST SESSION

H. RES. 557

Expressing support for designation of September 2019, as “National Dystonia Awareness Month” and raising awareness and understanding of the disorder of dystonia.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 13, 2019

Mr. LEVIN of Michigan (for himself, Mr. SMITH of New Jersey, Ms. SCHA-KOWSKY, and Mr. FITZPATRICK) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for designation of September 2019, as “National Dystonia Awareness Month” and raising awareness and understanding of the disorder of dystonia.

Whereas dystonia is the third most common movement disorder, affecting no fewer than 250,000 people in the United States and millions worldwide;

Whereas dystonia is a neurological disorder presenting in various forms, characterized by involuntary muscle contractions causing abnormal, often repetitive movements and postures;

Whereas symptoms of dystonia may impede the ability to—
(1) walk (as in generalized dystonia or limb dystonia);

(2) control the posture of the head (as in cervical dystonia);

(3) speak (as in spasmodic dysphonia or oromandibular dystonia);

(4) see (as in blepharospasm); and

(5) write (as in hand dystonia);

Whereas there are limited treatments for dystonia, and there is currently no cure;

Whereas dystonia is commonly misdiagnosed, delaying access to appropriate medical care for those affected;

Whereas trauma like that experienced by military service-members can lead to the onset of dystonia;

Whereas countless friends, loved ones, spouses, and caregivers must shoulder the physical, emotional, and financial burdens that dystonia causes;

Whereas the severity of the symptoms of dystonia and the limited public awareness of the disease cause many patients to be isolated;

Whereas National Dystonia Awareness Month will raise public awareness and understanding of the disorder of dystonia, a disorder affecting people of all ages, races, ethnicities, genders, and backgrounds;

Whereas National Dystonia Awareness Month will also foster understanding of the impact the various forms of dystonia have on those affected and their families;

Whereas the dystonia community is uniting to cooperate on awareness efforts throughout September; and

Whereas the Benign Essential Blepharospasm Research Foundation, the Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, and the

National Spasmodic Torticollis Association are dedicated to—

(1) conducting research to find treatments and a cure for dystonia;

(2) fostering public awareness and understanding of the disorder;

(3) educating patients and their families about dystonia to improve their treatment and care; and

(4) providing support and encouraging people to become advocates, including by sponsoring annual patient education conferences, school-based educational programs, and local events to raise funds for dystonia research, education, advocacy, and awareness: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports the designation of “National Dys-
3 tonia Awareness Month”;

4 (2) supports the goals and ideals of National
5 Dystonia Awareness Month to raise public awareness
6 and understanding of dystonia;

7 (3) recognizes the need for additional research
8 to find a cure for all forms of dystonia; and

9 (4) encourages all people in the United States
10 and interested groups to support National Dystonia
11 Awareness Month through activities to promote pub-
12 lic awareness of dystonia and foster the under-

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- 1 standing of the impact of dystonia on patients and
- 2 their families.

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