

114TH CONGRESS
2D SESSION

S. RES. 601

Designating September 2016 as “National Dystonia Awareness Month” and raising awareness and understanding of the disorder of dystonia.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 29, 2016

Mr. ISAKSON (for himself and Mr. MERKLEY) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating September 2016 as “National Dystonia Awareness Month” and raising awareness and understanding of the disorder of dystonia.

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

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

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

Whereas symptoms of dystonia may impede the ability of an individual—

- (1) to walk, as in generalized dystonia or limb dystonia;
- (2) to control the posture of the head of the individual, as in cervical dystonia;
- (3) to speak, as in spasmodic dysphonia or oromandibular dystonia;
- (4) to see, as in blepharospasm; or
- (5) to write, as in hand dystonia;

Whereas there are limited treatments and no cure for dystonia;

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

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 the dystonia community is uniting to cooperate on awareness efforts throughout September of 2016; and

Whereas the Benign Essential Blepharospasm Research Foundation, Dystonia, Inc., 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 dystonia;

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

(4) providing support and encouraging individuals 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 Senate—

2 (1) designates September 2016 as “National
3 Dystonia 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 various appropriate cere-
12 monies and activities—

13 (A) to promote public awareness of
14 dystonia; and

15 (B) to foster the understanding of the im-
16 pact of dystonia on patients and their families.

○