

116TH CONGRESS
2D SESSION

S. RES. 717

Expressing support for the designation of September 25, 2020, as “National Ataxia Awareness Day”, and raising awareness of ataxia, ataxia research, and the search for a cure.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 24, 2020

Ms. WARREN (for herself and Mrs. HYDE-SMITH) submitted the following resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

NOVEMBER 12, 2020

Committee discharged; considered and agreed to

RESOLUTION

Expressing support for the designation of September 25, 2020, as “National Ataxia Awareness Day”, and raising awareness of ataxia, ataxia research, and the search for a cure.

Whereas ataxia is a clinical manifestation indicating degeneration or dysfunction of the brain that negatively affects the coordination, precision, and accurate timing of physical movements;

Whereas ataxia can strike individuals of all ages, including children;

Whereas the term “ataxia” is used to classify a group of rare, inherited neurodegenerative diseases including—

- (1) ataxia telangiectasia;
- (2) episodic ataxia;
- (3) Friedreich’s ataxia; and
- (4) spinocerebellar ataxia;

Whereas there are many known types of genetic ataxia, but the genetic basis for ataxia in some patients is still unknown;

Whereas all inherited ataxias affect fewer than 200,000 individuals and, therefore, are recognized as rare diseases under the Orphan Drug Act (Public Law 97–414; 96 Stat. 2049);

Whereas some genetic ataxias are inherited in an autosomal dominant manner, while others are inherited in an autosomal recessive manner;

Whereas ataxia symptoms can also be caused by noninherited health conditions and other factors, including stroke, tumor, cerebral palsy, head trauma, multiple sclerosis, alcohol abuse, and certain medications;

Whereas ataxia can present physical, psychological, and financial challenges for patients and their families;

Whereas symptoms and outcomes of ataxia progress at different rates and include—

- (1) lack of coordination;
- (2) slurred speech;
- (3) cardiomyopathy;
- (4) scoliosis;
- (5) eye movement abnormalities;
- (6) difficulty walking;
- (7) tremors;

- (8) trouble eating and swallowing;
- (9) difficulties with other activities that require fine motor skills; and
- (10) death;

Whereas most patients with ataxia require the use of assistive devices, such as wheelchairs and walkers, to aid in their mobility, and many individuals may need physical and occupational therapy;

Whereas there is no treatment or cure approved by the Food and Drug Administration for ataxia; and

Whereas clinical research to develop safe and effective treatments for ataxia is ongoing: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) recognizes the need for greater public
3 awareness of ataxia;

4 (2) expresses support for the designation of
5 September 25, 2020, as “National Ataxia Awareness
6 Day”;

7 (3) supports the goals of National Ataxia
8 Awareness Day, which are—

9 (A) to raise awareness of the causes and
10 symptoms of ataxia among the general public
11 and health care professionals;

12 (B) to improve diagnosis of ataxia and ac-
13 cess to care for patients affected by ataxia; and

1 (C) to accelerate ataxia research, including
2 on safe and effective treatment options and, ul-
3 timately, a cure;
4 (4) acknowledges the challenges facing individ-
5 uals in the United States who have ataxia and the
6 families of those individuals; and
7 (5) encourages States, territories, and localities
8 to support the goals of National Ataxia Awareness
9 Day.

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