

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.

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## 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

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## 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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