

118TH CONGRESS
2D SESSION

S. RES. 794

Designating September 25, 2024, 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

AUGUST 1, 2024

Mrs. HYDE-SMITH (for herself, Mr. MURPHY, Mrs. CAPITO, and Ms. STABENOW) submitted the following resolution; which was referred to the Committee on the Judiciary

RESOLUTION

Designating September 25, 2024, 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 in the United States 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 addiction or misuse, 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 can 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 many patients with ataxia require the use of assistive devices, such as wheelchairs and walkers, to aid in their mobility, and many individuals with ataxia may need physical and occupational therapy;

Whereas few treatments and no cures have been approved 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) designates September 25, 2024, as “Na-
5 tional Ataxia Awareness Day”;

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

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

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

13 (C) to accelerate ataxia research, including
14 on safe and effective treatment options and, ul-
15 timately, a cure;

16 (4) recognizes the individuals in the United
17 States who face challenges due to having ataxia, and
18 the families of those individuals; and

- 1 (5) encourages States, territories, and localities
- 2 to support the goals of National Ataxia Awareness
- 3 Day.

