

# ADVOCACY TOOLKIT






## **ATAXIA ADVOCACY IN ACTION**

The National Ataxia Foundation is taking a more active role in advocacy activities and you can too. NAF is planning to engage with our nation's legislative leaders to raise more awareness for ataxia and increase our partnerships in the fight to end Ataxia. If you have a personal relationship or regular communication with a national or state legislator, then we want to hear from you. Please contact Lori Shogren, Community Program and Services Director at [lorie@ataxia.org](mailto:lorie@ataxia.org) or 763-231-2741.

## SAMPLE LETTER TO REPRESENTATIVE

Senator John Doe  
## Hart Senate Office Building  
Washington, DC #####  
Phone: (202) 333-3333



You can find your representative's contact information on their website

RE: [insert brief subject of your letter; ex. Rare Diseases, Orphan Drug Act Resolution, Meeting Request]

Dear Senator Doe, [insert representative's name; Senator Jones; Congressman Doe]

**Paragraph 1:** The introductory paragraph should include a brief overview of who you are and why you are writing to them. A letter should address only one concern at a time. Address other concerns in subsequent letters. [I am a constituent from [insert town] and I am writing to you today to [i.e. to raise awareness of a disease called ataxia; to urge you to support xyz legislation]

**Paragraph 2:** Describe how your life is impacted by what you are writing to them about. Don't be afraid to give personal stories but remember to stick to one subject and stay on topic. If you are arguing a position on a piece of legislation it is more persuasive to back up your argument with personal examples if available. If you are writing to raise awareness, tell them why raising awareness to legislators is important to you and your family. [I have progressive neurological disease called Spinocerebellar Ataxia (SCA). SCA causes a part of the brain called the cerebellum to degenerate. There is currently no known treatment or cure for SCA which effects around 150,000 people in the US. I urge you to support xyz bill as it would vastly improve my ability to access vital services. In the past while attempting to access abc service...]

**Paragraph 3:** Summarize the overall point of your letter. Thank them for their time and consideration (it is important to be courteous!). [xyz bill is very important to me and the ataxia community, and I urge you to vote yea should this bill come to a vote. Supporting this legislation would improve my ability to access vital healthcare services that would improve my quality of life. Thank you for your time and consideration.]

Sincerely,

[your name]

[contact information]

# PROCLAMATION

## INTERNATIONAL ATAXIA AWARENESS DAY SEPTEMBER 25, 2019

WHEREAS, the National Ataxia Foundation strives to meet the goals of:

- 1) Location of patients and persons at risk. NAF encourages a complete neurological examination to make early and correct diagnoses.
- 2) Increased awareness about Ataxia. NAF assures that accurate information about Ataxia will be available through a variety of educational programs for physicians, allied health officials, and the public.
- 3) Prevention of the spread of these disorders. NAF encourages genetic counseling to help affected individuals and families make informed decisions about family planning.
- 4) Research. In addition to its own research efforts, NAF supports those research projects that are designed to better understand pathology and cause of the Ataxias, or to institute new treatments based upon scientific data. NAF helps coordinate research efforts into the causes and early detection of Ataxia through existing centers throughout the world.

WHEREAS, less than 150,000 individuals are affected by hereditary and sporadic Ataxia in the United States.

WHEREAS, Ataxia is an often fatal degenerative neurological disorder that affects balance, coordination, and speech.

WHEREAS, Ataxia can strike anyone, at any time, without regard to age, gender, race, or creed.

WHEREAS, there is NO known cure, the only defense is research and prevention through education.

NOW THEREFORE, I \_\_\_\_\_, \_\_\_\_\_, of the \_\_\_\_\_ of \_\_\_\_\_ hereby proclaim September, 25, 2019 as INTERNATIONAL ATAXIA AWARENESS DAY in \_\_\_\_\_ and urge all citizens to honor and support those individuals with Ataxia and their caregivers, in the hope that a cure will soon be found.

IN WITNESS WHEREOF, I have hereunto set my hand and have cause the seal of the \_\_\_\_\_ of \_\_\_\_\_ to be hereto affixed this \_\_\_\_\_ day of \_\_\_\_\_, 2019.

# S. RES. XXX

Designating September 25th, 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

December 12, 2018

Mr./Ms. \_\_ Submitted the following resolution; which was referred to the Committee on \_\_\_\_

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## RESOLUTION

Designating September 25th, as “National Ataxia Awareness Day”, to raise awareness of ataxia, support ataxia research, and search for a cure.

Whereas designating “National Ataxia Awareness Day” will raise public awareness of ataxia and the impact it has on patients and their families;

Whereas, ataxia is a clinical manifestation indicating the degeneration or dysfunction of a part of the brain called the cerebellum, which contributes to the coordination, precision and accurate timing of movements;

Whereas, cerebellar ataxia is an umbrella term used to classify a group of neurodegenerative diseases due to cerebellar dysfunction including, but not limited to: Ataxia Telangiectasia, Episodic Ataxia, Friedreich’s Ataxia, Spinocerebellar Ataxia, and Sporadic Ataxia;

Whereas ataxia is estimated to affect less than 150,000 people of all ages, genders, races, and geographic district in the United States;

Whereas ataxia has a catastrophic effect on patients and their families both medically and financially;

Whereas symptoms progress over time sometimes slowly and in others quickly, causing lack of coordination, slurred speech, eye movement abnormalities, difficulty walking, tremors and trouble eating and swallowing;

Whereas most patients with ataxia will require the use of wheelchairs and walkers to aid in their mobility;

Whereas some symptoms can be managed by medication, but there is still no effective treatment or cure for ataxia;

Whereas ataxia generates a fear of the unknown \_\_\_\_\_

Whereas the National Ataxia Foundation is the only organization in the United States dedicated to all types of ataxia and its mission is to—

- I. Support Ataxia Research
- II. Provide vital programs and services for ataxia families
- III. Aid in the search for a cure

Whereas \_\_\_\_\_

*Resolved*, That the Senate—

- (1) designates September 25th as “National Ataxia Awareness Day”;
- (2) supports the mission of National Ataxia Awareness day to raise awareness, support ataxia research, and search for a cure
- (3) understands that there is no effective treatment or cure for ataxia and more research is needed to find a cure.