

# 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.



## **How to Obtain a Proclamation or Resolution**

Proclamations and Resolutions are formal statements issued to recognize a person, organization, event, or cause to increase public awareness. Proclamations are issued by a mayor or governor and are valid for that year only. Resolutions are passed by State Representatives and become state law; they do not need to be reissued.

### **Steps to Obtain a Proclamation or Resolution**

1. Send a letter and a sample proclamation/resolution to your mayor, governor, or state representative.
2. Schedule a meeting with the individual that you mailed the request to.
3. If the proclamation/resolution is granted, schedule a time to accept and take photos.

### **Quick Tips**

- Use the samples provided as a starting point.
- Personalize the sample letter. Tell your story. Explain how Ataxia impacts you.
- Contact NAF for assistance or to let us know about your efforts.
- Be persistent. Follow up with the major, governor, or state representative as needed.
- Send a formal thank you letter to the individuals involved in the process.
- Keep in touch with the representatives that you developed a relationship with by sharing Ataxia news and events in your area.

## Sample Proclamation/Resolution Letter for IAAD

[Governor, Mayor, or State Representative Name]

[Address]

[City/State/Zip]

Dear [Title and Name],

I am writing to express my gratitude for your support of vital healthcare initiatives and invite you to issue a [Proclamation/Resolution] designating September 25 as International Ataxia Awareness Day (IAAD). The National Ataxia Foundation (NAF) believes this is essential to build awareness for this rare disease in [Your City/State].

IAAD is a coordinated awareness effort from individuals and Ataxia organizations around the world to help shed light on and fight to end this rare disease. NAF is committed to leading the way on this outreach effort – but we need your help! We need more individuals and partner organizations to join us in recognizing International Ataxia Awareness Day to help us achieve our goals: 1) Raise awareness, 2) Support Ataxia research, and 3) Advocate for those impacted by the disease.

Ataxia is a neurological disease that gets worse over time; it affects all ages. Many symptoms of Ataxia can mimic those of being drunk – slurred speech, stumbling, falling, and incoordination. All are related to degeneration of the cerebellum, the part of the brain that is responsible for coordinating movement. Complications from the disease are serious, oftentimes debilitating, and life-shortening.

NAF's primary purpose is to support Ataxia research, provide vital programs and services for Ataxia families, and provide education about the disease. NAF works closely with the world's leading Ataxia researchers, promoting exchanges of ideas and innovation in Ataxia discovery.

We strongly believe that this [Proclamation/Resolution] will continue the advocacy efforts needed to improve the lives of the persons and families affected by Ataxia. We must work together to end this relentless and cruel disease. We must break down the isolation barriers that those with Ataxia face, in large part because the disease is rare and unknown to most.

I will be following up by phone with your scheduling offices to coordinate a meeting with you. I look forward to our continued communication and partnering to designate September 25 as International Ataxia Awareness Day.

Sincerely,

[Your Name]

[Contact Information]

Office of the  
[Mayor/Governor]  
[City / State] of  
[City/State Name]

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# SAMPLE 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, as many as 150,000 individuals are affected by hereditary and sporadic Ataxia in the United States.

WHEREAS, Ataxia is often a 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.

# SAMPLE RESOLUTION

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

Whereas designating “International 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 the cerebellum, the part of the brain which controls coordination, precision, and accurate timing of movements;

Whereas, 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 as many as 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 “International Ataxia Awareness Day”;
- (2) supports the mission of International 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.