

Establishing an Ataxia Awareness Day Proclamation



How to Garner Support in Your State or Local Government

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Looking to Raise Awareness of Ataxia in your State or Local Community?

You can submit a proclamation request to your state or local government to ask them to **recognize Ataxia Awareness Day on September 25th**.



01

What is a Proclamation?

A proclamation is an official announcement or declaration made by a government official- in this case likely a governor or mayor- which recognizes a milestone or raises awareness of a cause. Achieving a proclamation in your state or locality is a wonderful way to introduce your community to Ataxia to foster awareness of our cause. This process can also be a great way to form a relationship with your government!

How to Submit a Proclamation Request



Step One: Decide Who to Contact

You can choose to submit your proclamation request to your state, county, or city. You can decide this based upon the impact you wish to have, the process requirements, or personal preference. You could also choose to submit a request to more than one level of your government, but this is not required.



Step Two: Figure Out the Requirements for Submission

Search the term 'proclamation' on the webpage of the entity you will be submitting your request to. Larger governments will likely have their guidelines posted to their website. You may need to contact a member of the staff to find the guidelines for a smaller entity, like a city.

We have included draft language that you can use in an email to request a proclamation. You will also likely need to fill out a form with information about the request and provide draft language for the proclamation.



Step Three: Draft Your Proclamation

You will be asked for draft language for your proposed proclamation. See below for an example of language that you can use for designating September 25th as Ataxia Awareness Day. You may have to edit this template to meet the specific requirements for your submission. Reach out to NAF for help making any necessary edits.



Step Four: Submit Your Proclamation Request

Following all of the requirements, submit your proclamation request! You may need to include this information with your request:

- Your name and contact information
- The date for your request (September 25th for Ataxia Awareness Day)
- The purpose of your proclamation (to raise awareness of Ataxia)
- A brief personal story of your experience with Ataxia
- Affiliated organization (National Ataxia Foundation)

Be sure to note any deadlines that you may have to meet! For example, some governments require that proclamation requests are submitted at least 30 days before the awareness day. Start this process early so you don't miss your opportunity.



Step Five: Publicize Your Achievement!

1. Let NAF know about your success so we can highlight your win! We would love to receive and circulate any photos you get.
2. Request an in-person signing. This may or may not be granted depending on a variety of factors, so don't be discouraged if they say no.
3. If you feel comfortable, reach out to local news outlets to gain some additional awareness through media coverage. NAF is happy to provide a quote if they run a story.



Subject: [Insert brief subject of your email, ex.) Rare Disease Awareness]

Dear [Government official's name],

My name is [your name] and I live in [where you live.] In addition to being one of your constituents, I am also a rare disease patient. Specifically, I have [type of Ataxia], a rare neurodegenerative disease that affects thousands of people across the country. Ataxia can cause debilitating symptoms including trouble balancing, incoordination, and trouble speaking and swallowing. [Include a few sentences about your symptoms, your diagnosis journey, etc. to make the email personal to you.]

September 25th is International Ataxia Awareness Day. The recognition of this day provides an opportunity for education and awareness of Ataxia and a way for our [city/state/county] to show support for those in our community who are also affected by this disease. Thousands of people across the country are affected by a form of Ataxia, yet most people I encounter have never heard of this disease. Establishing a local Ataxia Awareness Day would provide meaningful visibility for this disease to help people understand the effects of Ataxia.

I would be honored if you would sponsor an official proclamation to recognize September 25th as Ataxia Awareness Day in [state/city/county.] An official proclamation would underscore the importance of educating the public about Ataxia and show your support for the rare disease community. I am enclosing the text from a U.S. Senate Resolution designating September 25th as National Ataxia Awareness Day, which may help your office draft this [state/city/county] proclamation.

If your office has any questions, please [email/call/text] me at [phone number/email address.] Thank you for your consideration of this request.

Sincerely,
[Your name]

119TH CONGRESS
1ST SESSION

S. RES. _____

Designating September 25, 2025, 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

Mrs. HYDE-SMITH submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Designating September 25, 2025, 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, 2025, as “Na-
5 tional Ataxia Awareness Day”;

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

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

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

13 (C) accelerate ataxia research, including on
14 safe and effective treatment options and, ulti-
15 mately, 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.