

Raise Awareness for FA: Proclamations

What Is A Proclamation?

A proclamation is an official declaration issued and signed by a person of authority, typically an elected official, that recognizes a certain group of people or organization in your community. They are most often used to highlight various awareness days, weeks, and months, and they can be issued at the local, state, and rarely the federal level.



Image of FARA Ambassador, Mary Nadon Scott (middle), at a proclamation signing ceremony with Vermont Governor, Phil Scott for Rare Disease Day!

Proclamations generally consist of:

- An explanation of your cause (i.e. a brief explanation of what FA is and how it affects patients and families).
- Relevant statistics, in particular up-to-date and state/locality-specific statistics if possible.
- 4-6 “Whereas” clauses followed by a “Therefore” clause.
 - An example of this structure can be found below.
- A specific date or range of dates associated with the request.

The proclamation process is state/locality specific! Every state/locality has a different process for requesting proclamations. So, it is important to double check your state's rules, which you can find attached below, and ensure that your request is compliant.

However, proclamations are typically:

- Only able to be requested by individuals, groups, or organizations located in the jurisdiction of the elected official (i.e. state, city, county, etc.).
- Only able to be requested by individuals or non-profit entities.
- Recognizing a broad group of people within the state or locality (i.e. no recognition for individuals, individual organizations, etc.).
- Recognizing a day, week, or month for awareness purposes.
- State/locality-specific.
- Around 200-250 words and no more than one standard page in length with 12-point font.

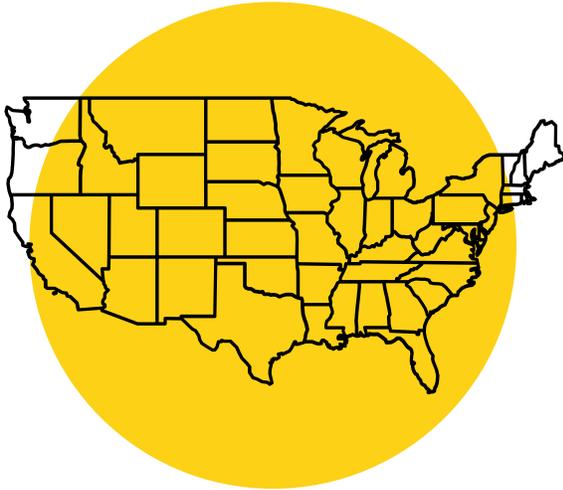
Some states may also have additional requirements and procedures, like:

- Requiring a state agency to sponsor a request.
- No proclamations related to medical conditions.
- Charging a small fee.
- Limiting the number of proclamations completed by a particular individual/organization.
- Having certain requirements for including and citing any statistics.

Why Are Proclamations Important?

Most people don't know much, if anything, about FA and how it impacts people in their community. Raising awareness can help the public learn more about the condition, as well as educate lawmakers so that they can take actions that support the community.

How Can You Get A Proclamation Signed In Your Community?



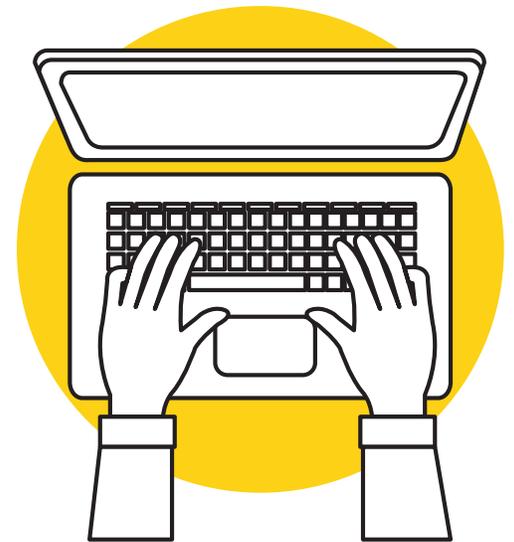
Step 1:
Figure Out Your State's/City's Process

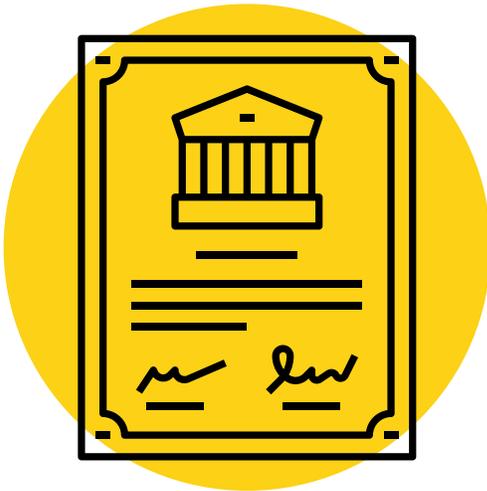
Each state has a different process, timeline, and rules associated requesting proclamations. So, it's important to know what the rules in your state are! You can find all of that information in this [spreadsheet](#).

***Note that the spreadsheet only contains information regarding states. If you are interested in a local proclamation, you will need to find that information on your own.**

Step 2: **Draft Your Proclamation Language!**

You can find draft language below. Usually, you will be able to submit your request with this language. However, if you need to alter it to your city's/state's guidelines, please reach out to the FARA advocacy team for help. Your elected official may also have a staffer who can assist you with amending the language.





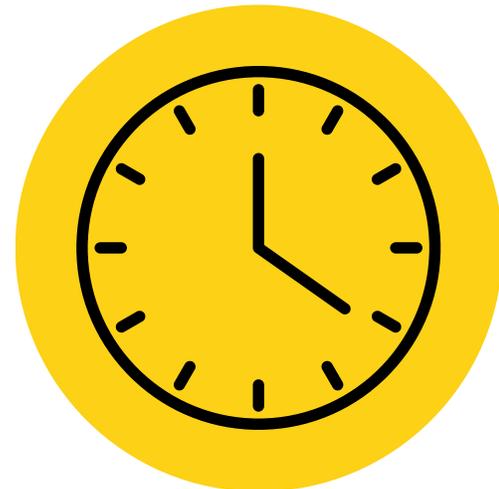
Step 3: Submit Your Proclamation Request!

Using your particular state's process and rules, submit your request. To do this, you'll likely need to fill out a form or email your governor's office with:

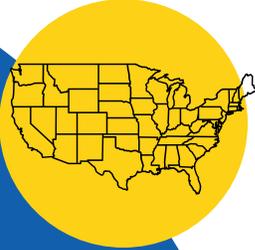
- Your name & address
- The date/range of dates associated with your request
- Draft language
- The name of an affiliated non-profit (FARA/NAF)

Step 4: Wait For A Response!

- You will need to submit your request several weeks ahead of the date you want recognized. The amount of time until you get a response will vary. There are four possible responses:
 - They accept your proclamation!
 - They accept with edits.
 - Someone else submitted a similar request so they will not grant yours. They may send you a copy of the other proclamation.
 - They will not grant your proclamation.



Other Information & Advice



1. **Start as early as you can!**

- Make sure that you're aware of your state/locality's timeline requirements and send in your proclamation early within that timeline.

2. **Consider asking for an in-person signing.**

- Please note, only limited in-person signings are granted.
- Otherwise, you can ask that a copy be sent to you in the mail.

3. **Request a copy be sent to FARA!**

- Not all states will send copies of proclamations to non-profits located out-of-state. However, some will!

4. **If you're comfortable doing so, send a picture and/or a link of the proclamation to FARA!**

- We would love to share your hard work in our Advocacy Newsletter, on social media, or elsewhere!

5. **Don't be afraid to reach out for help!**

- Not only can FARA staff help if you are having trouble, but many FARA Ambassadors and other FA advocates have requested proclamations before and may be able to give great advice!

Draft Language

Below is an example of a proclamation request for **National Ataxia Awareness Day**. Please review your state/locality's requirements (i.e. citation requirements, content requirements) and adjust the language accordingly before submitting. You may also want to work with staffers in your state/local government to do this as well. You can also find a link to draft language [here](#).

NATIONAL ATAXIA AWARENESS DAY PROCLAMATION

WHEREAS, ataxias are a group of both hereditary and acquired degenerative neurological conditions that affect both children and adults. There are more than 70 different types of ataxia affecting up to 150,000 people in the U.S.

WHEREAS, ataxias are often characterized by stumbling, lack of coordination, slurred speech, difficulty walking, and other symptoms, such as trouble eating and swallowing and heart problems. These symptoms interfere with activities of daily living and can be life-shortening;

WHEREAS, there is no cure for ataxia. While there is currently one FDA-approved treatment available to patients for Friedreich's Ataxia (FA), the most common form of hereditary ataxia, there are not treatments to address the root cause of any hereditary ataxias;

WHEREAS, lack of awareness about ataxia in [insert city/state] and throughout the world limits access to a timely diagnosis, adequate clinical management, and research to help expedite potential cures;

NOW, THEREFORE, BE IT RESOLVED THAT the [city/state] of [name of city/state] hereby declares September 25, 2025, as National Ataxia Awareness Day.

X 



Draft Language

Below is an example of a proclamation request for **FA Awareness Day**. Please review your state/locality's requirements (i.e. citation requirements, content requirements) and adjust the language accordingly before submitting. You may also want to work with staffers in your state/local government to do this as well. You can also find a link to draft language [here](#).

FRIEDREICH'S ATAXIA (FA) AWARENESS DAY PROCLAMATION

WHEREAS, Friedreich's ataxia (FA) is a rare, genetic, progressive neuromuscular disease that affects over 5,000 people in the United States and 15,000 people globally. FA typically presents in childhood or adolescence, but may present later in life.

WHEREAS, FA is characterized by issues with balance and coordination of movement, both of which lead to life-altering loss of mobility. The disease may also cause other symptoms, such as fatigue, serious heart conditions, scoliosis, speech difficulties, and diabetes, among others;

WHEREAS, FA is a life-shortening condition, causing tremendous pain for those affected and their loved ones;

WHEREAS, there is no cure for FA. While there is currently one FDA-approved treatment available to patients, this therapy only slows progression and does not address the root cause of the disorder;

WHEREAS, lack of awareness about FA in [insert city/state] and throughout the world limits access to a timely diagnosis, adequate clinical management, and research to help expedite potential cures;

NOW, THEREFORE, BE IT RESOLVED THAT the [city/state] of [name of city/state] hereby declares May 17, 2025, as Friedreich's Ataxia (FA) Awareness Day.

X 

