



INTERNATIONAL  
**ATAXIA**  
AWARENESS DAY  
SEPTEMBER 25

# United Against Ataxia

## Awareness Campaign Toolkit



#IAAD19

[www.ataxia.org](http://www.ataxia.org)

**NAF** National Ataxia  
Foundation

**International Ataxia Awareness Day (IAAD)** is celebrated on September 25th every year. It is an effort from Ataxia organizations and individuals around the world to spread awareness about the disease and inspire action towards a cure.

Ataxia can affect anyone, at any age. It is a degenerative neurological disease that affects a person's ability to walk, talk, and use fine motor skills. It impacts every aspect of a person's life - making simple tasks difficult to complete.

Oftentimes, one of the most frustrating aspects of having Ataxia is the lack of disease recognition outside of the medical community. Isolated feelings can be prevented by helping others learn about Ataxia and better understand its symptoms.

As many as 150,000 people in the U.S. are affected by Ataxia.



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### Need Help?

If you have questions about the campaign, we're here to help!

Contact Lori Shogren:

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## What is Ataxia?

Ataxia is a degenerative disease of the nervous system. Many symptoms of Ataxia mimic those of being drunk, such as slurred speech, stumbling, falling, and incoordination. These symptoms are caused by damage to the cerebellum, the part of the brain that is responsible for coordinating movement. Ataxia treatment involves a combination of medication to treat symptoms and therapy to improve quality of life.

## Symptoms:

Ataxia symptoms worsen over time and may include:

- Lack of coordination
- Difficulty walking
- Poor balance
- Slurred speech
- Trouble eating and swallowing
- Deterioration of fine motor skills
- Gait abnormalities
- Tremors
- Eye movement abnormalities
- Cognitive difficulties
- Heart Problems

## Quick Facts:

- Ataxia is a rare disease that affects as many as 150,000 people in the United States.
- Ataxia is a neurological disease with symptoms that worsen over time.
- Everyone is at risk of Ataxia - it can be inherited or occur sporadically.
- Symptoms of Ataxia can cause a person to appear as if they are drunk, such as slurred speech, clumsiness, and stumbling.
- Lack of public awareness about Ataxia makes coping with the disease more difficult for those who have it.
- Symptoms can be managed, but they oftentimes make everyday tasks difficult to complete for a person with Ataxia.
- Talking about Ataxia with others is a first step to finding a cure.
- More awareness will lead to more support for research.

## How Do I Get Involved?

### Use these campaign materials

Adapt the materials and select messages that fit your needs/goals for your awareness campaign. Use the brochures and images at your event and in your campaign.

### Organize an activity

Plan an event, activity, or fundraiser to help raise awareness about Ataxia. Organizing your event on or around September 25th will help build the strength of the effort and draw media attention. Activities can be small or large, social or educational, informational or fundraiser - the possibilities are endless!

### Share information on social media

Check NAF's social media channels in September for shareable messages. Feel free to use our suggested social media messages and graphics on your own as well. The primary hashtag for this campaign is **#IAAD19**. Tell your story; every story and action matters.



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[www.facebook.com/ataxiafoundation](https://www.facebook.com/ataxiafoundation)

[www.twitter.com/NAF\\_Ataxia](https://www.twitter.com/NAF_Ataxia)

[www.youtube.com/NatlAtaxiaFound](https://www.youtube.com/NatlAtaxiaFound)

## Help Us Trend on IAAD!

### Let's Trend!

Use **#IAAD19** for every post on social media about International Ataxia Awareness Day. Together, we can trend! And don't forget to tell people how you are **#UnitedAgainstAtaxia**.

### Use Our Sample Posts

Want to post on social media for IAAD but don't know how to start? Use our sample posts! Take them word for word, or use them to get you started. Any post at all will help spread awareness. No matter what you post, don't forget to use the hashtags to help IAAD trend!

### Sample Facebook Posts

We are **#UnitedAgainstAtaxia** for International Ataxia Awareness Day. Ataxia is a rare disease with symptoms that worsen over time. Help spread the word! Learn more at [ataxia.org](http://ataxia.org) **#IAAD19**

It's International Ataxia Awareness Day! Ataxia symptoms can make a person appear as if they are drunk. Degeneration in the brain gradually makes it difficult to walk and talk. Learn more at [ataxia.org](http://ataxia.org) **#IAAD19**

### Sample Twitter Posts

**#UnitedAgainstAtaxia** for Intl Ataxia Awareness Day. Ataxia is a rare disease with symptoms that worsen over time. Spread the word! Learn more at [ataxia.org](http://ataxia.org) **#IAAD19**

It's Intl Ataxia Awareness Day! Ataxia symptoms can make a person appear as if they are drunk and makes it hard to walk and talk. Learn more at [ataxia.org](http://ataxia.org) **#IAAD19**

## Join the #IAAD19 Social Media Campaign!

### The Premise

We welcome you to participate in this year's 4 week United Against Ataxia series in recognition of IAAD. We fight Ataxia every day - in our own ways. Some by learning to live with the disease, some by teaching others about Ataxia, some by raising money for research, and others by working relentlessly on the science to understand and treat the disease. Together, that fight will lead to a cure.

We will be sharing community-submitted photos throughout our IAAD awareness campaign. Join us in raising awareness and encouraging others to be **#UnitedAgainstAtaxia** too!

### Show Us How You Are #UnitedAgainstAtaxia

Show us the people in your life that are **#UnitedAgainstAtaxia**! Send us a picture of your group holding hands or locking arms. You could get together with family, friends, coworkers, or your medical care team. Be creative! We'll use these photos for our IAAD social media campaign. Send your pictures to [mollie@ataxia.org](mailto:mollie@ataxia.org).



\*Submitting a picture gives NAF the right to use your photo on social media and other marketing materials.

## Awareness Campaign Tools

In addition to this toolkit of information, NAF will provide the following items to aid in your local awareness campaigns:

- Sample Press Release
- Ataxia Awareness Day Proclamation How-To
- IAAD Logo
- Social Media Graphic

### Promote Your Event/Campaign

Register your IAAD event with NAF to get it listed on our website. Then reach out to local media to pitch your story. Feel free to use the sample press release, or create your own. Contact NAF if you would like any assistance. Want to take it one step further? Reach out to local government to request a proclamation for Ataxia Awareness Day in your area.

### We're Here to Help!

If you have questions or would like assistance in adapting any of the awareness tools provided, we're here for you.

Contact:

NAF Community Program & Services Director

Lori Shogren

lori@ataxia.org | 763-231-2743