

International Ataxia Awareness Day 2018



Fight Ataxia

Awareness Campaign Toolkit

#IAAD18

www.ataxia.org

NAF National Ataxia
Foundation

Campaign at a Glance

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.

The theme of our 2018 IAAD campaign is Ataxia symptoms.

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 recognize Ataxia as a disease and better understand its symptoms.

Need Help?

If you have questions about the campaign, we're here to help!
Contact Stephanie Lucas:
stephanie@ataxia.org
763-231-2744

This is Your Guide

This campaign guide is for anyone - anywhere. If you have an interest in getting involved with spreading awareness, this guide can help get you started. The more people and organizations that participate - the more Ataxia awareness we spread.

If you work in government, healthcare, non-profit, or the media - we want you involved! If you have Ataxia, are a parent, friend, spouse, sibling, or son/daughter of someone with Ataxia - we want you involved!



What We Hope to Achieve

The overall goal of this campaign is simple: spread awareness about Ataxia. In doing so, we aim to:

- Inform the general public about Ataxia, its symptoms, and how it affects a person's quality of life.
- Help people with Ataxia gain confidence through increased public awareness.
- Allow individuals, government, organizations, and media to participate in raising awareness.

What is Ataxia?

Ataxia is a neurological disease. It is an umbrella term used to classify a group of complex diseases, many of which are genetically inherited. All result in damage to the part of the brain called the cerebellum.

Ataxia causes individuals to appear drunk, as they gradually lose their ability to walk, talk, and use fine motor skills. For some types of Ataxia, the disease can lead to an early death.



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

An estimated 150,000 people in the U.S. are affected by Ataxia.

The Campaign Core

This campaign is designed to spread recognition of Ataxia and its symptoms. This will lead to an increased understanding in the general public and lessen chances of misdiagnoses in the medical community.

Talking with others about Ataxia will reduce misunderstandings and embarrassment caused by symptoms, ultimately leading to improved quality of life for persons with Ataxia.

We appreciate your help in changing lives for people affected by Ataxia.



The Slogan

The campaign slogan is: **Fight Ataxia.**

Target Audience

Everyone! Ataxia can affect anyone, at any age. Symptom onset is unpredictable. Everybody should know about the disease to recognize early signs/symptoms. NAF believes that education and understanding of this disease

are vital for everyone. We've provided materials that anyone can use when planning awareness campaigns and events.

Overarching Messages

- Ataxia is a rare disease that affects up to 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.

Living with Ataxia requires drastic lifestyle changes.

How to Get Involved

Use these campaign materials

Adapt the materials and select messages that fit your needs/goals for your awareness campaign. Use the handouts, 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 on and around IAAD 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 **#IAAD18** but we also encourage the use of **#FightAtaxia**. Tell your story and what you do to fight back against the disease.



www.facebook.com/ataxiafoundation



www.twitter.com/NAF_Ataxia



www.youtube.com/NatlAtaxiaFound

Help Us Trend on IAAD!

Let's Trend!

Use **#IAAD18** for every post on social media about International Ataxia Awareness Day. Together, we can trend! And don't forget to tell people how you **#FightAtaxia** too!

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

I want you to **#FightAtaxia** for International Ataxia Awareness Day. Ataxia is a rare disease with symptoms that worsen over time. Help spread the word! **#IAAD18**

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. **#IAAD18**



Sample Twitter Posts

#FightAtaxia for Intl Ataxia Awareness Day. Ataxia is a rare disease with symptoms that worsen over time. Spread the word! **#IAAD18**

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. **#IAAD18**

Join the #FightAtaxia Social Media Campaign!

The Premise

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 want to recognize the things that people do to **#FightAtaxia**.

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

Show Us How You #FightAtaxia

Hold up a **#FightAtaxia** sign or send us a picture that shows us how you **#FightAtaxia**! Is it working out to stay strong? Hanging out with your friends to stay positive? Being daring to live life to the fullest? Finding ways to keep doing the things that you love? We want to see it! Send your pictures* to stephanie@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 awareness campaigns:

- Awareness Poster
- Press Release
- Ataxia Awareness Day Proclamation
- 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!

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

Contact:
NAF Communications Manager
Stephanie Lucas
stephanie@ataxia.org | 763-231-2744

Fundraising Tools

Interested in raising more than awareness? Support the NAF mission with an IAAD fundraising campaign!

Participate in the Virtual Fundraiser

You don't have to host an event to make an impact. You can use a letter writing, word of mouth, or social media campaign to help support NAF.

Mail cash or check donations:

National Ataxia Foundation
Attn: IAAD
600 Highway 169 S., Suite 1725
Minneapolis, MN 55426-1205

Online donations:

<https://ataxia.donorpages.com/2018IAAD/>

Get a Fundraising Page for Your Event

Hosting an IAAD event? Do you want your participants to have the ability to donate online? Contact NAF. We can set up a fundraising page for you.

Contact:
Development Director
Joel Sutherland
joel@ataxia.org | 763-553-0020

