

International Ataxia Awareness Day

September 25, 2017



The ATAXIA's are rare, progressive disorders of the nervous system affecting balance and coordination. People of all ages and races are affected.

For further details, help, and support, please contact the National Ataxia Foundation at the address below, or visit our website at www.ataxia.org.



National Ataxia Foundation
2600 Fernbrook Lane Suite 119 • Minneapolis, MN 55447-4752
Phone: 763.553.0020 • Fax: 763.553.0167
Email: naf@ataxia.org • Website: www.ataxia.org
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International Ataxia Awareness Day is an outreach of the National Ataxia Foundation. Thank you for participating

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Introduction

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Thank you for your interest in International Ataxia Awareness Day and the National Ataxia Foundation. This awareness kit is your guide to promoting International Ataxia Awareness Day in your community. 2017 is the 18th year that

an international public awareness campaign has been implemented. We are very excited about this year's activities and, with your help, we will better inform many more people about the ataxias.

What is International Ataxia Awareness Day?

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The "International Ataxia Awareness Day" is an international effort from ataxia organizations around the world to dedicate September 25th as International Ataxia Awareness Day. Each participating country, state, or individual may have a specific plan for this event. The goal of IAAD is for every individual to participate in some activity, creating awareness about ataxia. You could share something you know about ataxia with one other person who has never heard of it, educate a group of people by speaking at a school or civic group, contact the media, or raise financial support.

Participation in International Ataxia Awareness Day has grown over the years. Suggested activities for involvement are listed under the Opportunities & Ideas for Involvement section of this guide. We welcome you to share your experiences and ask you to submit information about your successful activities and events so that we may include them in future guides, giving inspiration and direction to others as they get involved in IAAD.

We encourage you to participate in this year's activities and make IAAD 2017 the most successful awareness campaign yet!

~ The National Ataxia Foundation

The National Ataxia Foundation is dedicated to improving the lives of persons affected by and at risk for ataxia through support, education, and research.

Awareness Guide “Kit”

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Each of the documents on Pages 4 – 6 are available for you to reproduce and can aid you in contacting others and spreading the word about ataxia. Following is a description of each and how they can be used.

Press Release:

On Page 4 is a press release regarding International Ataxia Awareness Day. Please fill in the blanks in the press release and send it to your local newspapers, radio stations, and television stations. Sharing additional items such as posters, brochures, bookmarks, and buttons may bring a better response (see order form on Page 8). Many times, meeting with a reporter or editor will enhance the likelihood of printing an article, coupled with the fact that many times a local article may be written about how ataxia has affected you, your family, or your friends. Cable access stations have community event bulletins that will promote this project.

Proclamation:

On Page 5, you will find a proclamation, declaring September 25th as “International Ataxia Awareness Day”. Please feel free to make copies of this document, and use it to approach your local city, county, parish, or state elected officials. Your local mayor, for example, would sign this proclamation. This would be an excellent time to coordinate the signing of the proclamation with your local newspaper to provide a “photo op” and a newspaper article.

Awareness Poster:

On Page 6, there is a poster promoting IAAD. You can make copies or request additional copies from NAF (limited number available), and post them in your local community. Some places for display are stores, churches, synagogues, hospitals, businesses, office buildings, libraries, and alike. If allowed, a stack of brochures placed near the poster would allow for additional information. You may wish to use the blank space near the bottom to announce your local event. Please note: Always ask permission before displaying the poster or other materials.

For Immediate Release

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For Immediate Release

Dated Material

National Contact: Joel Sutherland
Executive Director
joel@ataxia.org
(763) 553-0020

Local Contact:

EIGHTEENTH ANNUAL INTERNATIONAL ATAXIA AWARENESS DAY

Chances are that you have never heard of ataxia. That is why the National Ataxia Foundation and other ataxia organizations throughout the world have declared September 25, 2017 as “International Ataxia Awareness Day” to help get the word out about ataxia.

Ataxia is a group of rare and often fatal degenerative neurological disorders. An estimated 150,000 people in the United States are affected by ataxia. Symptoms are progressive and often impact coordination, hearing, vision, and speech. Ataxia affects both genders and all ages, but too often ataxia strikes children and young adults. At this time, there is no effective treatment or cure for ataxia.

“The National Ataxia Foundation was established in 1957 and is dedicated in serving ataxia families through research, education, and support services,” says Joel Sutherland, the Executive Director of the National Ataxia Foundation. Sutherland continued, “Ataxia can affect anyone at any time and is caused by either a recessive or dominant gene. There are also sporadic forms of ataxia which have no known genetic link or family history.”

In the dominant forms of ataxia, each child born has a 50/50 chance of developing the disorder. In the case of recessive forms, each child born has a 25% chance of being affected, a 50% chance of being a carrier, and only a 25% chance of not being affected or a carrier of the gene. In the recessive forms of ataxia, many times people do not know that they carry an ataxia gene until their child begins to display signs of in-coordination.

(Please share your personal story on how ataxia has impacted you and your family as part of this press release.)

To find out more about ataxia, visit the National Ataxia Foundation’s website at www.ataxia.org. You may also write the Foundation at 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752, email at naf@ataxia.org, or call (763) 553-0020.

Proclamation

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International Ataxia Awareness Day September 25, 2017

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 diagnosis.
- 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 professionals, 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, the NAF supports those research projects that are designed to better understand the pathology and cause of the ataxias, or to institute new treatments based upon scientific data. The NAF helps to coordinate research efforts into the causes and early detection of ataxia through existing centers throughout the world.

WHEREAS, an estimated 150,000 individuals are affected by hereditary and sporadic ataxia in the United States.

WHEREAS, ataxia is an often fatal degenerative neurological disorder that affects balance, coordination, and speech.

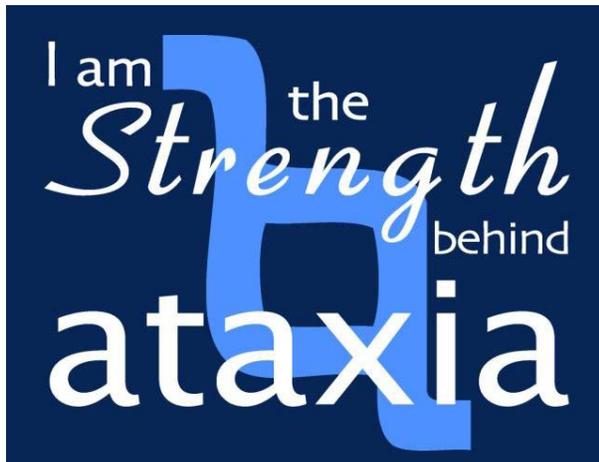
WHEREAS, ataxia can strike anyone at any time, without regard to age, gender, race or creed.

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, 2017 as INTERNATIONAL ATAXIA AWARENESS DAY in _____ and urge all citizens to honor and support those individuals with ataxia and their care givers, in the hope that a cure will soon be found.

IN WITNESS WHEREOF, I have hereunto set my hand and have caused the seal of the _____ of _____ to be hereto affixed this _____ day of _____, 2017.

International Ataxia Awareness Day September 25th



The ATAXIA's are rare progressive disorders which affect speech, balance and coordination. People of all ages, race, and gender are affected.



For further details, help, and support please contact the
National Ataxia Foundation at:
2600 Fernbrook Lane N Suite 119, Minneapolis, MN 55447
Phone: 763-553-0020 Fax: 763-553-0167
E-mail: naf@ataxia.org
www.ataxia.org



IAAD Items Available @ www.ataxia.org

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Buttons:



A 2.5 inch in diameter button depicting the IAAD logo is available from the National Ataxia Foundation. These are great for giving out as a memento of an event. Another use is to sell them as a fundraiser. Buttons are \$1 each or 6 for \$5.

Bookmarks:



These bookmarks, showing the National Ataxia Foundation's IAAD logo, serve as a wonderful handout at an awareness / informational booth. These bookmarks list facts about ataxia on one side and information about the National Ataxia Foundation on the other.

IAAD T-Shirts:



Available in sizes small – 3X, these black t-shirts with the IAAD logo are available for purchase at \$10.00 each. These make a great awareness tool, and could also be used as a fundraiser.

Magnets, Wrist Bands, and Bags:

These make a great awareness tools, and could also be used as a fundraiser. Magnets are \$4 each or 3 for \$10. Wristbands are \$2 each or 3 for \$5. Drawstring Backpacks are \$5 each.



“Ataxia is not a Foreign Cab” Items

T-Shirts and Sweatshirts:



Available in sizes small – 3X, these ash gray shirts, with the Ataxia is not a Foreign Cab logo on them, are available for purchase at \$10.00 each for t-shirts, and \$20.00 each for Sweatshirts. These are great items that get people asking “What is Ataxia?”, opening up the opportunity for you to share what you know.

Bumper Stickers & Window Clings:

Available for \$1.00 each.

Opportunities & Ideas for Involvement

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NAF's IAAD Walk n' Roll – Getting Started

There are 150,000 Americans and their families affected by ataxia. Just think if each of us participated in the NAF IAAD Walk n' Roll. Together we could significantly increase awareness about ataxia and raise much needed dollars to support the important work of the Foundation. IAAD is a celebration of hope and a unification of the ataxia community. The NAF Walk n' Roll represents a voice for greater awareness and a vessel to fund important programs and services.

Family, friends, co-workers, and neighbors joining together for one cause, one purpose...ataxia. It is through this unity that a closeness and kinship is created. The NAF Walk n' Roll brings people together to have fun and at the same time creates hope, understanding, and a promise for a brighter future. Walk, roll, skip, or jump, it does not matter how you get there, what only matters is that you participate.



In starting any fundraiser, you should first get a few people together to form a committee to help plan and organize the event. Each person should be assigned specific duties to work on the project. Activities such as publicity, looking into local city ordinances, site location of event, donated items, identifying volunteer needs, and alike are all integral parts into a successful fund raiser. The chair of the committee should periodically check with each committee member to evaluate the status of their progress and to also see if they need additional help in completing their tasks.

In order to help raise awareness about ataxia on International Ataxia Awareness Day (IAAD), there are a number of ideas given in the IAAD kit. One idea to help raise awareness and to support the important work of the Foundation is to host your own NAF IAAD Walk n' Roll or participate in the Global Online Walk ' Roll for Ataxia.

The event will bring greater awareness about ataxia in your local community and gives everyone an opportunity to participate. Walking or using a wheelchair, we can all join in and get the word out about ataxia by participating in the NAF IAAD Walk n' Roll. Let's get started... the items listed below are ideas in creating your own NAF IAAD Walk n' Roll. You may certainly modify or add to these steps depending upon your particular event needs. For more Information about Walk n' Roll events please visit [NAF's Walk n' Roll Kit](#) or contact the National Ataxia Foundation.

Community Garage Sales:

In order to help raise awareness and increase funding through International Ataxia Awareness Day, a number of fundraisers can be used. One that has seen great success by a number of NAF Support Groups as well as individual members is an Ataxia Garage Sale.

The Ataxia Garage Sale is just like any other garage sale, but with a few twists. It is a combination of neighbors, friends, relatives, and local businesses donating items for your garage sale. The proceeds from the sale are forwarded to the National Ataxia Foundation. As the host of the Ataxia Garage Sale, you can choose if you would like those funds to be used for research, programs, or general support.



How is it done? – Set a date for your sale. This year, IAAD is on a Friday. You could choose to hold a multi-day sale, running Thursday – Saturday, or just one day, depending on the number of items you have and the time commitment you and/or your volunteers are willing to give. Begin contacting your friends, relatives, local businesses, civic groups, and others, and ask for donated items for this event. Prepare an ad for placement in your local newspaper to advertise your sale. At the same time, ask them if they would run an article about ataxia and your awareness effort.

What kinds of items are good for a garage sale? – Any items will sell at a garage sale: clothes, tools, furniture, equipment, knickknacks, sporting goods, toys, etc. The list is unlimited.

How do I get donations? – Ask your friends, relatives, neighbors, local businesses, civic groups, churches, synagogues, and others to donate items for your Ataxia Garage Sale. Items donated are tax deductible. Stress to potential donors that proceeds from donated items will help support important ataxia programs.

How do I get Media Coverage? – Let your local newspaper and radio stations know about the event. Paid ads and/or a newspaper article about ataxia and your event will help to promote it. Posters can be posted around town...remember to ask permission first. Potential places to display posters would be grocery stores, gas stations, Laundromats, offices, schools, clinics, hospitals, movie theatres, video stores, and other local businesses. This will help get the word out. Make sure your ads and posters have some of the “special items” listed that will be available at your garage sale.

Help with Packaging and Pricing – You should receive all of the donated items at least one week prior to your sale. You will need this time to price and package the items. Masking tape or colored stickers with handwritten prices work well. You may also wish to use labels and a word processor, if that is easier. Pricing on some items can be difficult, but if it doesn’t sell, you can always reduce the price. You may want to consider offering a half price sale the last hour of your Ataxia Garage Sale.

How can I Promote Ataxia? – At the Ataxia Garage Sale, PROMOTE ATAXIA! Have information available to anyone asking about the fundraiser. You may want to insert a fact sheet with each

purchase at the sale. Also, banners or posters at the event are a good idea. This is also a wonderful opportunity for a local paper to do a photo shoot at your event.

About Volunteers – Make sure you get plenty of volunteers to help you with the promotion of the sale, packaging and pricing items, and sales.



When and Where? – Garage sales can be a one-day or multiple day event. The number of days for your sale depends on the amount of items you have and the number of volunteers you have available. The best time to start is in the morning, around 8:00 a.m.; smaller garage sales normally last for 5 – 6 hours. Selling coffee, soda, and baked goods can increase your sales.

Thank you – After the garage sale, it is always a good idea to publicly thank your donors, volunteers, and participants through a thank you ad in your local newspaper. This not only tells them thank you now, but sets the tone for when you ask them for future support.

Let us know about your sale – Please tell us about your Ataxia Garage Sale, so we can share your story with others through the Foundation’s quarterly news publication, “Generations”.

Have Fun!! – The Ataxia Garage Sale is away to raise awareness and funds for ataxia. It is also a way to share your story and interest of ataxia with others. It is fun work for a worthy cause. Thank you for your support.

Candle Lighting Ceremony:

One option for an event on International Ataxia Awareness Day has been to hold a candle lighting ceremony. Blue and white candles have been used to represent hope and unity. Invite friends and relatives, business associates, local civic groups, members of your church congregation, and others to participate. Don’t forget to invite your local media! You may consider having a potluck dinner before or after the ceremony. Locations for this event could include your county fairgrounds, Community Park, church parking lot or any other appropriate location.



Ask each person to bring a blue and white candle. At the lighting ceremony, each candle will be lit. This is where you can use some creativity in planning your event. One suggestion is to have a “Walk of Hope and Unity” where each person has a lit candle and walks for a designated time. Another thought is having each candle lit, followed by a moment of silence for those who have died from ataxia and for those who are suffering from the disease. Following is a script that you may consider reading at the lighting ceremony:

The [blue and white] candles you see before you are symbolic of the hope and unity shared by all who are here today. As (name of person lighting the candles) lights the blue candle, we can all reflect upon the hope held by all individuals with ataxia and those who love and care for them. Hope for a treatment to arrest the progression of the disorder, and hope for a cure for future generations, and hope for an ataxia free future.

The white candles symbolize the unity of purpose shared by all people affected by ataxia. The selfless sharing of information, the friendships shared by all (chapters/support group), the unfailing commitment towards a cure for ataxia and the constant support from each other are all symbols of unity.

Today is the beginning of a new dawn that hope and unity is our shield and strength for us to fight on for all who suffer from ataxia. The progress made in ataxia research the past decade is proof positive that a group of dedicated individuals with hope for the future and unity in purpose has no limits.

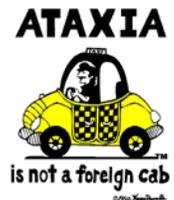
Blue “Gene” Day:



A Blue “Gene” Day is great for school or business. Each person wanting to wear blue jeans to work or school on the Friday before September 25 would need to pay a dollar or two for the “privilege” of doing so. You will need to coordinate this with school officials or office managers.

T-Shirts and Sweatshirts:

International Ataxia Awareness Day T-shirts are a great way to promote awareness. NAF also has “Ataxia is not a Foreign Cab” T-shirts and sweatshirts available. To order, please visit NAF’s online Store.



Collaborate with Local Businesses:



Approach a coffee shop, pizza place, or restaurant and ask them to donate a portion of the proceeds of sales from a certain menu item or all sales made on IAAD. Ask to place a brochure or table top sign on each table describing the partnership. Many grocery chains and local markets provide “brat” stands where the local grocery store provides the product and grill and the charity provides the volunteers. A percentage of the sales are donated back to the charity. Brochures on ataxia and an NAF banner at this venue can help increase ataxia awareness. Some national chain stores offer charities matching donations from sales in front of their store. Check out the stores in your area which offer these types of fund raising opportunities and if they do not, ask them if they would consider a fund raising/ataxia awareness event at their store. Ataxia information booths at shopping malls and other high traffic areas such as county fairs are other ways to help increase ataxia awareness.

NAF Membership & NAF Support Groups:

Through your public awareness efforts, ask another person to support IAAD by becoming a member of the National Ataxia Foundation. You can become a member on NAF's website www.ataxia.org.

You can also get involved in your local NAF Chapter or Support Group. To locate a Chapter or Support Group near you please visit our website www.ataxia.org or call 763-553-0020. A listing is also available in our "Generations" newsletter.

Book Sales / Donations to Local Libraries:



Most libraries have nothing, or very little, on ataxia. Consider purchasing a book or DVD from NAF and to donate to your local library.

Partner with Civic Groups:

Contact local civic groups such as the Lions or Jaycees. These groups may welcome the opportunity to take on "International Ataxia Awareness Day" as part of their own projects.

Letter Writing Campaign:

Let your friends, co-workers, and others know about IAAD through a letter writing/e-mail campaign. Don't forget to ask them to help support NAF's important work by making an online donation at www.ataxia.org. Sample letters are available by contacting NAF.

How to Create Awareness

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By: [Robin Smothers, owner of RMS Public Relations](#)

With International Ataxia Awareness Day coming up, now is the perfect time to begin with planning how you can generate publicity and increase awareness of ataxia in your community.

Getting the media to cover an issue is not as daunting as it may seem. Most reporters, editors, and producers are more than willing to cover an issue or event that affects their community, but, they can't know everything. They need you to tell them about ataxia and why it's important. Here are a few tips to help you do just that:

1) Prepare a press release

The National Ataxia Foundation includes a sample press release on page 4. Simply customize the release to your community by adding your name and telephone number as the local media contact, and if possible, the name of someone in your community affected by ataxia.

2) Gather media contact information

Create a list of media in your community. Make sure to include your local community paper, related blog website, social media networks, and the nearest television and radio stations. Try to reach as broad a range as possible – include everyone you can think of! Get the addresses and telephone numbers from the local directory, magazine, and newspaper mastheads or from the Internet. Call each media outlet and ask for the names of the assignment editor (television and radio stations use these) or the health or medical editor at the newspaper or magazine. Also, ask for a fax number.

3) Pitch the story

Beginning 10 days before IAAD (September 25), mail or fax out your press release. A few days later, call those folks who received the releases and ask them to run a story on ataxia. Emphasize how the disease affects those in your community and offer interviews with yourself and others who are affected by ataxia. Also, explain that you can send them additional materials (e.g. fact sheets, and other materials available from the NAF, other appeal letter, etc.).

4) Don't get Discouraged

You've accomplished two very important goals just by contacting them:

- You've increased their own personal awareness about ataxia
- You've primed them for when you contact them next year

If you'd like additional suggestions, or have questions or concerns about how to approach the media, please feel free to contact the National Ataxia Foundation at 763-553-0020 or naf@ataxia.org.

“Tell me and I forget, show me and I remember, involve me and I understand.” ~ Unknown

Conclusion / Follow Up

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Ideas are limitless! Please remember to keep the awareness theme with each project and fundraiser that you do. Please contact your local public officials before you begin any fundraiser to make sure you are acting in accordance with your local laws.

Please forward a copy of any signed proclamations to NAF. We would like to keep a file of these successes. Also, please send us a copy of any newspaper articles published as a result of IAAD or any public awareness that you do throughout the year. We will display these at the Annual Membership Meetings. And, lastly, write to us. Tell us what you and your groups are doing for International Ataxia Awareness Day 2017. Share your experiences with us at naf@ataxia.org. Thank you!