So, what is Ataxia

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It’s not . . .

✓ Parkinson’s disease
✓ Huntington’s disease
✓ Multiple Sclerosis
✓ Muscular Dystrophy
Ataxia is not a foreign cab!
So WHAT is it?
Ataxia is a term used to describe a group of neurological disorders that cause problems with balance and coordinated movement.
Ataxia is also a term used to describe the symptoms of loss of coordination.
Ataxia is derived from the Greek word *ataxis* which means “without order”.
Most often ataxia is caused by loss of function in the cerebellum, which is the part of the brain that controls movement.
Some forms of ataxia are caused by dysfunction of the pathways leading into and out of the cerebellum.
In addition, ataxia causes symptoms that affect:

- Vision
- Swallowing
- and Speech
Ataxia can strike at any age and all too often strikes children and young adults.
We know that ataxia refers to a symptom and to a group of diseases – but what causes it?
When we talk about the symptom of ataxia, you could say that being drunk causes ataxia, spinning around and around like children do, can cause ataxia. You could even say that ataxia (the disease) causes ataxia (the symptom).
First, we need to understand that there are three classifications of ataxia, based on the cause:

- Acquired
- Hereditary
- Sporadic or Idiopathic
Acquired ataxia means there was an event that caused the person to have the symptom of ataxia. Some of those events may include:
Head trauma

Stroke
Brain tumor

Severe viral infection

Exposure to certain drugs or toxins
For now we will talk about the disease of ataxia and what causes it.
Hereditary ataxia means that the cause of the ataxia is a gene defect or mutation. Those ataxias are grouped into:
Dominant Ataxias and Recessive Ataxias
Dominantly inherited ataxias are passed from an affected parent to the child.

- Father with one A and one a (has Ataxia)
- Mother with two A's (does not have Ataxia)
- Offspring who inherit one ataxia-causing gene will have ataxia.
- Offspring who inherit two normal genes will not have ataxia.

A = normal gene
a = disease gene
• Only one copy of the mutated gene is needed for a person to have dominant ataxia.
• Each child of an affected parent has a 50% chance of inheriting dominant ataxia.
• Males and females are equally likely to be affected.
Recessively inherited ataxias occur when both parents are carriers of the mutated gene and the child inherits the mutated gene from each parent.
• Two copies of the mutated gene is needed for a person to have recessive ataxia.
• There is a 25% chance of having a child who has two copies of the mutated gene. This child would be affected by recessive ataxia.
• There is a 50% chance of having a child who is a carrier of the mutated gene.
• There is a 25% chance of having a child who does not inherit the mutated genes. This child would not be affected or be a carrier of recessive ataxia.
• Males and females are equally likely to be affected
Sporadic or Idiopathic ataxia means that the cause is unknown and there is no family history.

Approximately 50% of those with a non-acquired form of ataxia, may never know the cause.
Unfortunately it may take years before a person is finally diagnosed with ataxia.
How is the diagnosis of ataxia made?
Genetic Tests

Magnetic Resonance Imaging (MRI)

Family History

Clinical evaluation by a neurologist

Laboratory Tests
Sometimes the type of ataxia is diagnosed while looking for the cause of other symptoms.

Cardiomyopathy is often a complication of Friedreich Ataxia

Vision loss is often a complication of Spinocerebellar Ataxia 7 (SCA7)
Most of the ataxias are progressive. This means that the symptoms increase in scope and severity.

The rate of progression varies for each type of ataxia. It can also vary between family members with the same type of ataxia.

Too often the earlier the onset of symptoms, the faster the rate of progression.
As the disease progresses, assistive devices such as canes, walkers and wheelchairs are recommended when the lack of balance is causing an impact on safety.

Are you okay?
Is there a cure for ataxia?

Currently there is no cure for the hereditary and sporadic forms of ataxia. Some of the acquired forms can be treated successfully.
In dominantly inherited types of ataxia family planning choices may prevent the ataxia gene from moving into the next generation.
If there is not a cure, is there a treatment?
There are no medications which treat ataxia or slow the rate of progression.
There are medications which may help some of the symptoms of ataxia.
So what can a person with ataxia do if there is no treatment or cure?
Develop a Care Team with medical service providers and family.
EXERCISE, EXERCISE, EXERCISE! Research has shown that practicing a physical therapy regimen that includes repetitive coordinative exercises can help sustain mobility as the disease progresses.
is recommended for those who experience slurred speech or difficulty swallowing.
Cultivate a caring network with family, friends, support groups, social media and advocacy organizations to gain knowledge, resources, and a sense of belonging.
Joining a local support group or participating in social media venues have been helpful for many.
Many attend the annual meeting of the National Ataxia Foundation where leading ataxia researchers and clinicians give presentations on ataxia related topics and lifelong friendships are made.
It is one of the few times that being disabled is normal and expected.

Attending enables me to network and mingle with ataxians from around the country.

Being around other people with ataxia at the meeting helps me feel less alone.
Making the most of life with Ataxia.
National Ataxia Foundation

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The National Ataxia Foundation is dedicated to improving the lives of people affected by ataxia through support, education and research.
Date Founded:
1957 as a nonprofit organization 501(c)(3)

Primary Focus:
Serving the ataxia community

Program Focus:
◊ Funding world-wide ataxia research
◊ Providing services and programs to ataxia families
◊ Development of ataxia publications
◊ Offering international ataxia research symposiums
◊ Hosting annual ataxia family conferences
◊ Development of ataxia support groups
◊ Partnering with others to foster ataxia research
International Ataxia Awareness Day
September 25th

National Ataxia Foundation
Dear Ms. Sue,

Thank you so much for helping me with my senior project. I couldn't have done this without you.

Thanks so much!

Sincerely,
How can you help be part of the solution?

- Help raise ataxia awareness in your community.
- Embrace those with ataxia into your community.
- Support the work of the National Ataxia Foundation.
We would like to thank you for your interest in Ataxia.

For more information please contact:

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