

### what is Ataxia





It's not...

✓ Parkinson's disease

✓ Huntington's disease

✓ Multiple Sclerosis

✓ Muscular Dystrophy





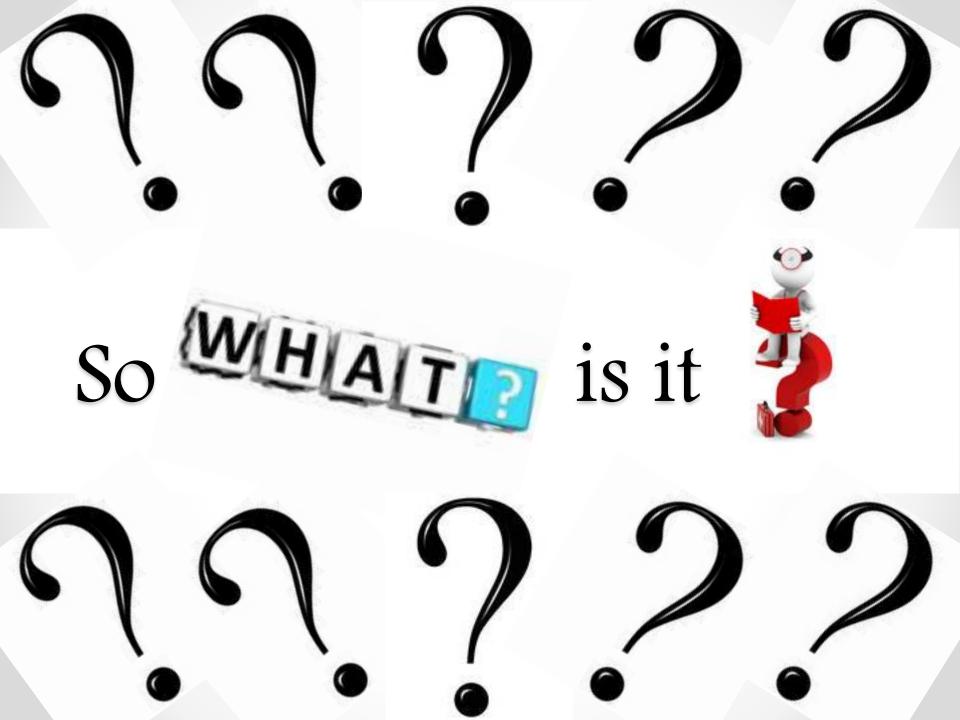


### Ataxia is not a foreign cab!









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



Hold a finger or a toy in front of the child and ask him to touch it on the first try. The child with ataxia cannot do it.

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coordination.





Ataxia is derived from the Greek word ataxis which means "without order".

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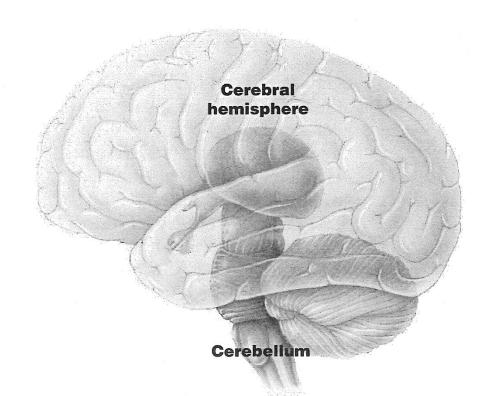
Most often ataxia is caused by loss of function in the cerebellum, which is the part of the brain that controls movement.







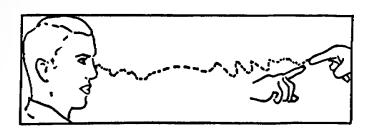
Some forms of ataxia are caused by dysfunction of the pathways leading into and out of the cerebellum.





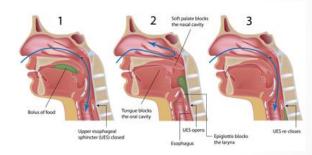


### In addition, ataxia causes symptoms that affect:

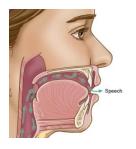


Vision

Swallowing



and



Speech

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#### Ataxia can strike at any age and all too often



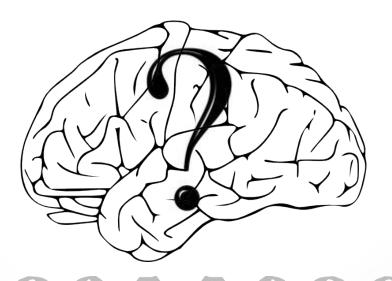


strikes children and young adults





We know that ataxia refers to a symptom and to a group of diseases – but what causes it?



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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

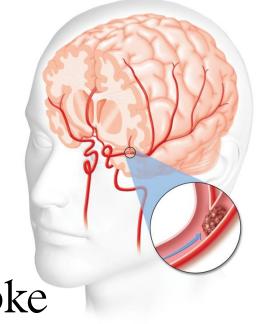


Acquired ataxia means there was an event that caused the person to have the symptom of ataxia. Some of those events may include:





Head trauma



Stroke

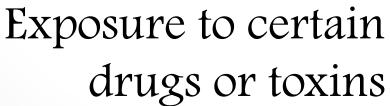


#### Brain tumor

#### Severe viral infection







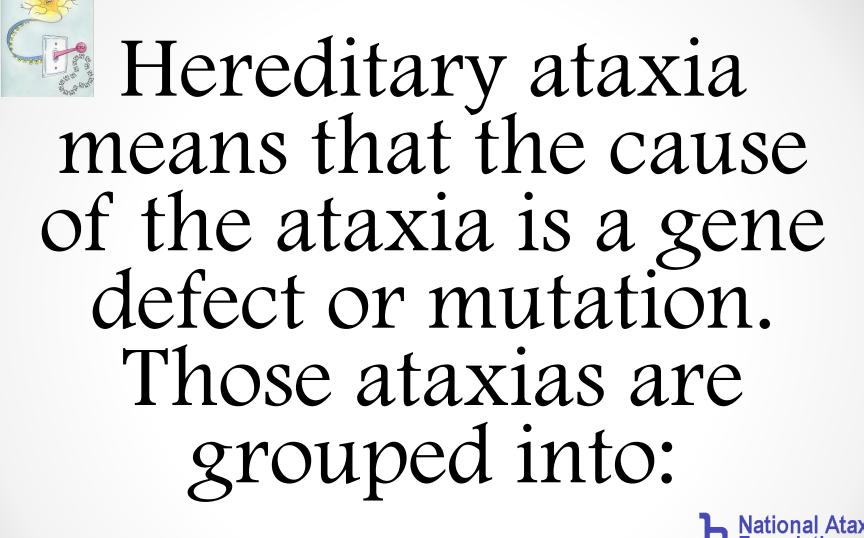


## For now we will talk about the disease of ataxia and what causes it.















## Dominantly inherited ataxias are passed from an affected parent to the child.

Father with one **A** and one **a** (has Ataxia)

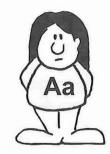


a Mother with two **A's** (does not have Ataxia)

A = normal gene a = disease gene



Offspring who inherit one ataxia-causing gene will have ataxia.



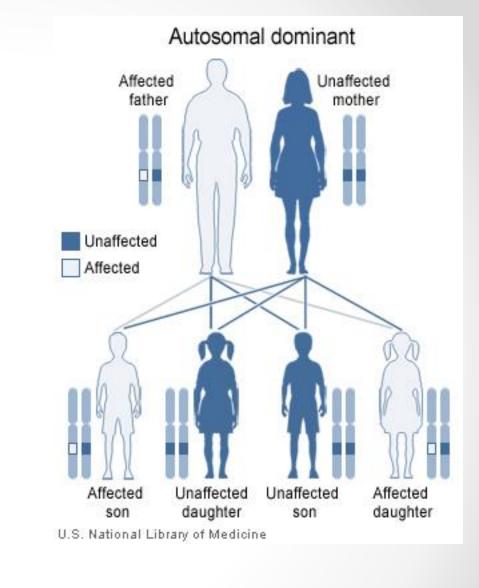
Offspring who inherit two normal genes will not have ataxia.



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- 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.

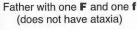


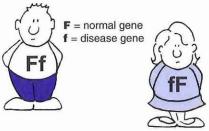


Recessively inherited ataxias occur when both parents are carriers of the mutated gene and the child inherits the mutated gene from each parent.



Fredreich ataxia is a recessive disorder meaning that both parents contribute the defective gene at the time of conception. Denise is affected by the disease and her sister is not.





Mother with one f and one F

(does not have ataxia)

F from father, f from mother (child does not have ataxia but can pass disease)



f from father, F from mother (child does not have ataxia but can pass disease)

F from father, F from mother (child does not have ataxia and has no disease gene to pass on)

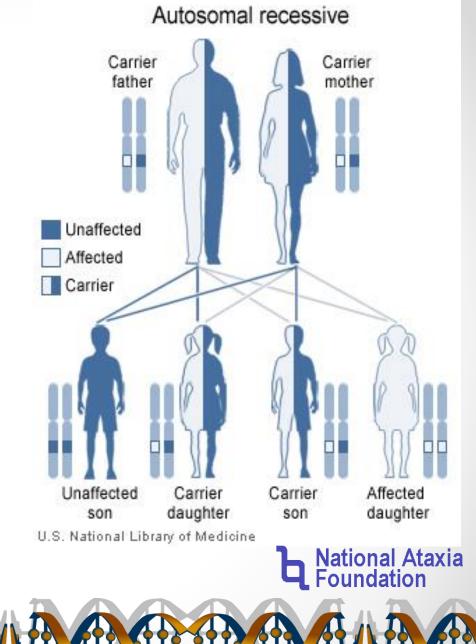


f from father, f from mother (double-dose of ataxia-causing gene means child will have ataxia and will pass disease gene on)





- 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.

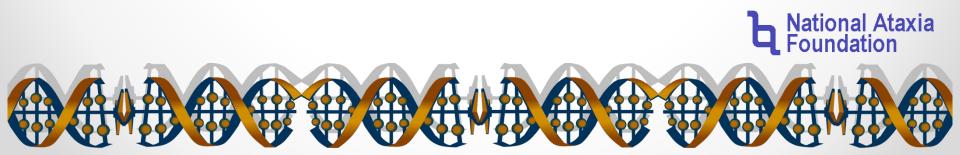


### Unfortunately it may take years before a person is finally diagnosed with ataxia.



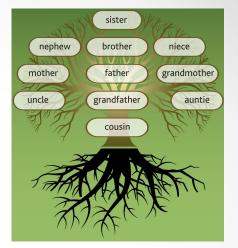


# How is the diagnosis of ataxia made?





Magnetic Resonance Imaging (MRI)



Family History



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.



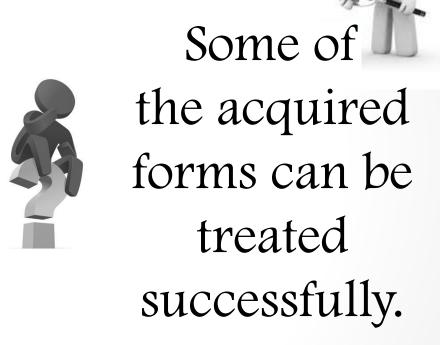


### Is there a



#### for ataxia?

Currently there is no cure for the hereditary and sporadic forms of ataxia.

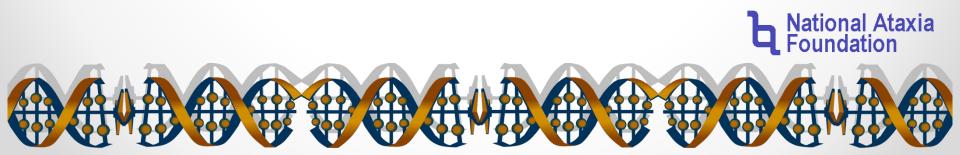




### In dominantly inherited types of ataxia family planning choices may



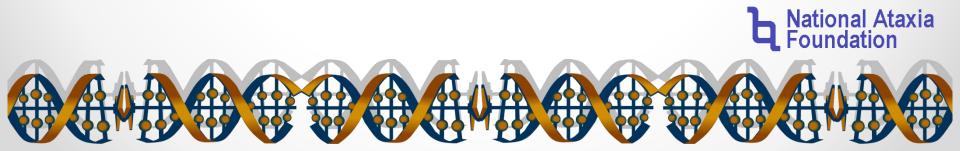
prevent the ataxia gene from moving into the next generation.



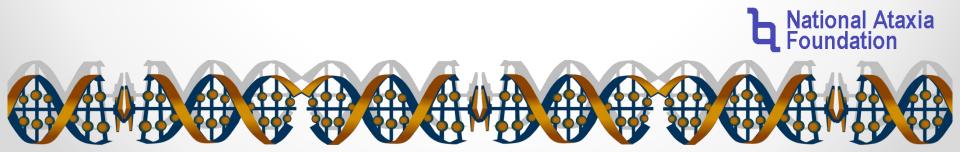
### If there is not a cure,



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.





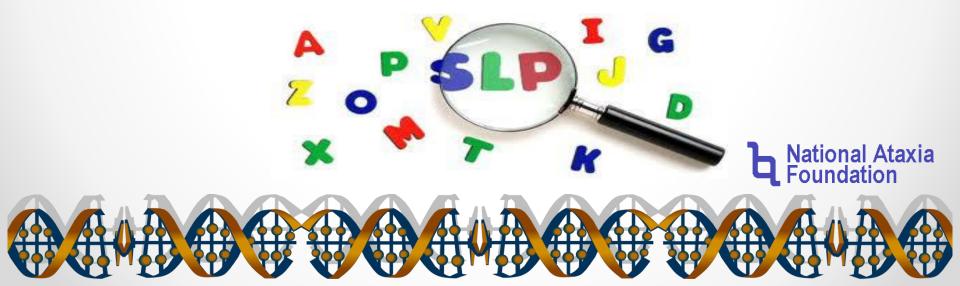








recommended for those who experience slurred speech or difficultly swallowing.



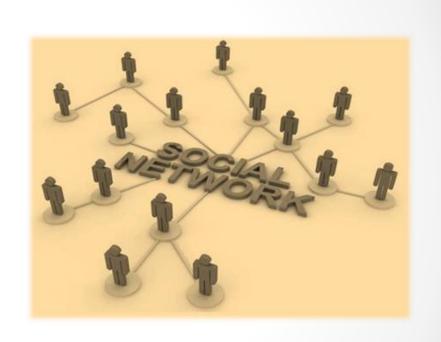
Cultivate a caring network with family, friends, support groups, social media and advocacy organizations to gain knowledge, resources,



and a sense of belonging.

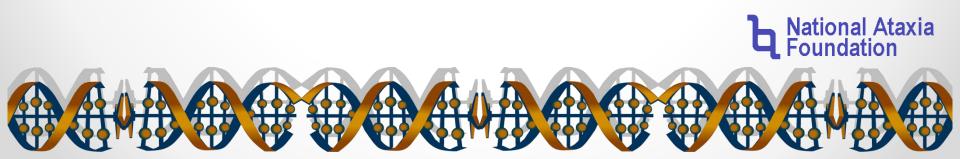


Joining a local support group or participating in social media venues have been helpful for many.





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.





# Making the most of life



with Ataxia.







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# National Ataxia Foundation

Follow us on Social Media:











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















### Faces of Ataxia























# 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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