FREQUENTLY ASKED QUESTIONS ABOUT... ATAXIA

What is ataxia?

The word "ataxia" refers to clumsiness or a loss of balance and coordination that is not due to muscle weakness. Ataxia is not a specific disease, but rather a symptom of many diverse conditions that affect the nervous system. People affected by ataxia may experience problems with using their fingers and hands, arms or legs, walking, speaking or moving their eyes. This loss of coordination may be caused by a number of different medical or neurological conditions. For this reason, it is important that a person with ataxia seek medical attention to determine the underlying cause of the symptom and to receive the appropriate treatment.

What causes ataxia?

Damage to different parts of the nervous system can cause ataxia but many cases are caused by damage to a part of the brain called the cerebellum, which serves as the balance and coordination center. The cerebellum assists in muscle coordination and helps maintain balance while walking or performing other movements. The cerebellum also helps to coordinate eye movements, speech and swallowing.

Ataxia may also be caused by dysfunction of the pathways leading into and out of the cerebellum. Information comes into the cerebellum from the spinal cord, inner ear and other parts of the brain and signals from the cerebellum go out to the spinal cord and to the brain. People with damage to the inner ear or loss of feeling in their feet may also notice clumsiness or poor coordination, as these systems are also very important to maintaining balance and their damage also leads to ataxia.

How does a physician diagnose ataxia?

A physician (typically a neurologist) will perform an examination which can often determine whether the ataxia is caused by impairment in the cerebellum, its associated pathways or other parts of the nervous system. Blood tests and imaging, including an MRI of the brain, can show whether the cerebellum or nearby parts of the brain or spinal cord have been affected by a stroke, tumor, infection or other degenerative disease that can cause ataxia. While genetic testing is available for some rarer types of ataxia, there are many different kinds, so it is generally recommended to see a specialist in ataxia, neurogenetics, or movement disorders before taking these tests. You can assist the physician in making a diagnosis by being honest about all of your symptoms, being accurate about the dates and details of your medical history and by collecting information about your family history. Keep copies of all your medical records and imaging and bring them with you in case your doctor needs them.

Below is a list of some of the many medical and neurological conditions that can cause ataxia to appear suddenly:

- Head trauma
- Stroke
- Brain hemorrhage
- Brain tumor
- Certain viral infections
- Exposure to certain drugs or toxins (alcohol, some drugs or medications)

Here is a list of some of the many medical and neurological conditions that can cause ataxia to appear more gradually:

- Problems with the liver, kidney, or thyroid
- Deficiencies of certain vitamins (especially Vitamin E or Vitamin B12)
- Exposure to certain drugs or toxins (heavy metals, alcohol, certain drugs)
- Sensitivity to gluten (wheat, rye and barley)
- Diabetes
- Multiple sclerosis
- Neurosyphilis (Tabes dorsalis)
- Problems with the immune system
- Hidden cancers
- Various genetic disorders

The list of conditions that the physicians must think about as causes of ataxia is extremely long. Proper diagnosis may require a number of examinations, blood tests, MRIs and other studies. It is recommended that patients see a doctor who specializes in ataxia.

How are ataxia and its symptoms treated?

There is no medicine which specifically treats ataxia. If the cause of the ataxia can be identified, in many cases it may be modifiable or treatable. Most genetic causes are not yet treatable but research into these disorders continues to make advances which may someday find treatments or cures.

At this time, the primary goal of treatment is to improve the quality of life through education and medical treatment of specific symptoms. Exercise is very helpful in maintaining and improving balance. Other treatments typically involve physical, occupational and speech therapy and, in some cases, the use of adaptive devices to allow the individual with ataxia to remain as independent as possible. Devices to assist with writing, eating and self-care as well as communication devices for those with impaired speech may also be helpful. Many individuals with ataxia may have other symptoms which can include tremor, stiffness, depression, spasticity and sleep disorders. Medication or other therapies might be appropriate for some of these symptoms so it is important to let your doctor know about all your symptoms.

How can the National Ataxia Foundation help?

The National Ataxia Foundation (NAF) is interested in all forms of acquired and hereditary ataxia. The treatment and prognosis of ataxia due to identifiable causes, such as stroke or tumor, depends primarily on the treatment of the underlying cause. While little is understood of the underlying causes for the various hereditary ataxias and no cures are currently available, NAF has been in the forefront for nearly 60 years funding promising worldwide research to find answers.

NAF has entered into an agreement with Sanford Research to host an ataxia patient registry through its CoRDS patient registry. Individuals diagnosed with or those who are at risk for any form of ataxia may enroll at http://www.sanfordresearch.org/cords/ enroll/. This will enable you to receive notices about upcoming research studies.

The National Ataxia Foundation is committed to education about ataxia, service to individuals affected with the various forms of ataxia and promoting research to find the causes, better treatments and a cure for ataxia. NAF can help by providing information for you, your family and your physician about ataxia.

NAF encourages you to visit our website at www. ataxia.org for additional information on ataxia, a listing of ataxia support groups, online chat groups, and social media venues. For additional questions please contact NAF using the contact information below.