

Facts Book on **Ataxia**

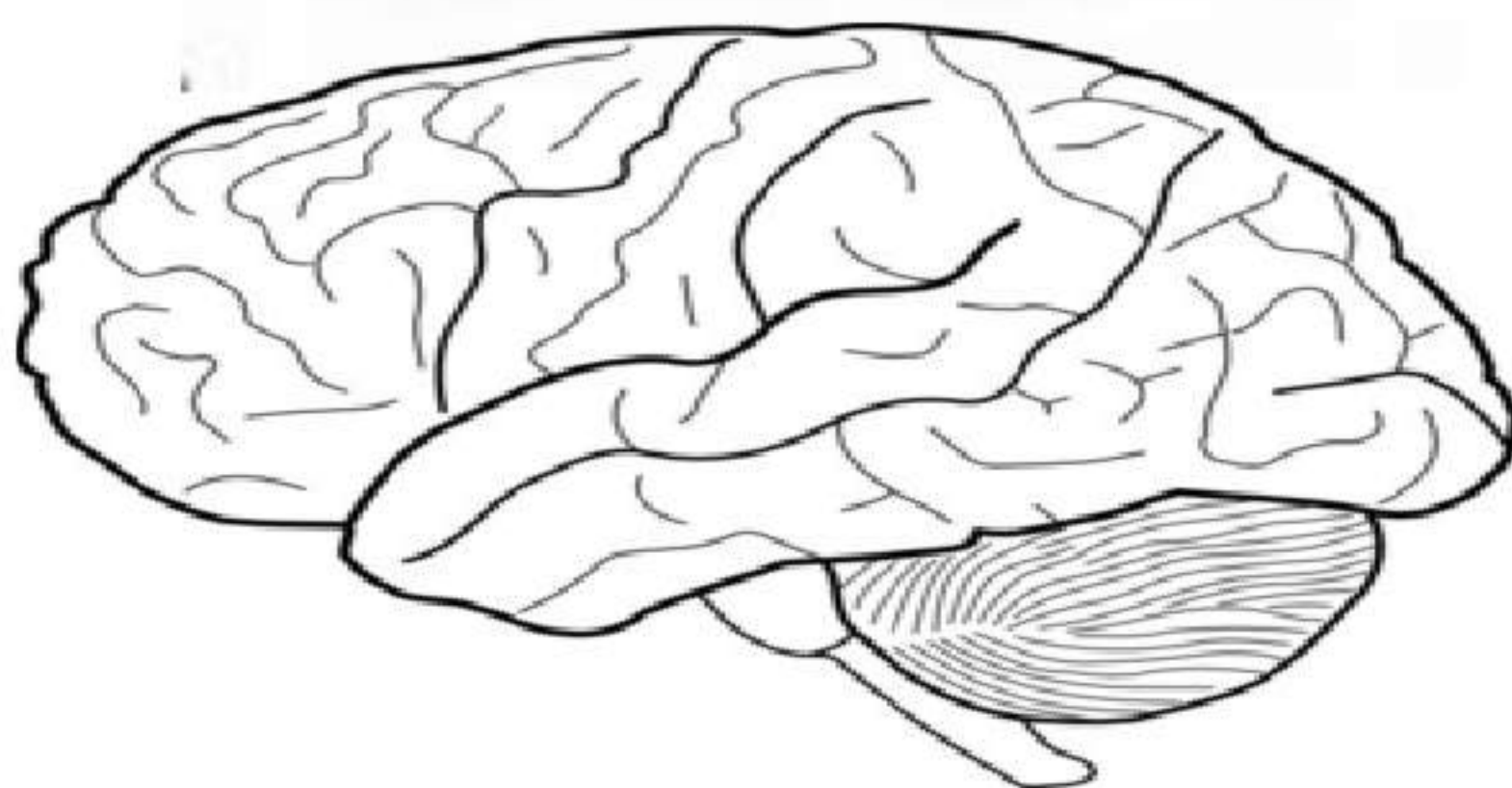
**Neuro Disorder, Muscular Dystrophy,
Movement Disorder &
Speech Disorder Diseases**

I am NOT drunk



My speech may be slurred
I may be clumsy
I may fall over
I may walk as if I'm drunk
I am not on drugs

**I have a medical
condition: ataxia**



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Founder, Chairman



: 23 March 2014

Ataxia[®] PK

Pakistan 1st Research Centre

Neuro Disorder, Muscular Dystrophy, Movement Disorder, Speech Disorder

Let's Join Together for Better Care in Research

A Project Of
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What is Ataxia?

The word "Ataxia" comes from the Greek word "ataxia", meaning "without order or incoordination". Ataxia isn't a word you hear every day. And if we told you it's a condition that slowly attacks the brain, it wouldn't explain what it's actually like to live with ataxia.

The word "Ataxia" means without coordination. People with Ataxia have problems with coordination because parts of the nervous system that control movement and balance are affected. Ataxia may affect the fingers, hands, arms, legs, body, speech and eye movements. The word Ataxia is often used to describe a symptom of incoordination which can be associated with infections, injuries, other diseases, or degenerative changes in the central nervous system. Ataxia is also used to denote a group of specific degenerative diseases of the nervous system called the hereditary and sporadic Ataxias, which is the primary focus of "ATAXIA PAKISTAN-Bin Adam Foundation.

Imagine being told you have an incurable brain condition that's likely to get worse until you are dependent on others to care for you. Imagine that every day it will get a little harder to walk, and talk, and control your body.

If you or someone you loved had ataxia, imagine how desperately you would want to stop the clock type diseases

How is Ataxia Diagnosed?

Diagnosis is based on a person's medical history, family history, and a complete neurological evaluation including an MRI scan of the brain.

Various blood tests may be performed to rule out other possible disorders which may present similar symptoms. Genetic blood tests are now available for some types of hereditary Ataxia to confirm a diagnosis or as a predictive test to determine if someone has inherited an Ataxia gene known to affect other family members. Each child of a person known to carry the disorder has a 50% chance of being diagnosed with Ataxia.

Support is available to people who may wish to access testing and genetic counseling services.

Mission Statement:

To promote and support ATAXIA in all forms and to lead the quest for knowledge, diagnosis, treatment and prevention of ATAXIA with support from communities worldwide.



What are common symptoms?

Symptoms and time of onset vary according to the type of Ataxia. In fact, there are often variations even within the same family with the same type of Ataxia. Dominant Ataxia often begins in the 20s or 30s or even later in life. Sometimes individuals may not show symptoms until they are in their 60s.

Sporadic Ataxia, more difficult to diagnose, affects a large group of people usually in adulthood who have no family history of the disease. Other more typically group called **FRIEDREICH ATAXIA**.

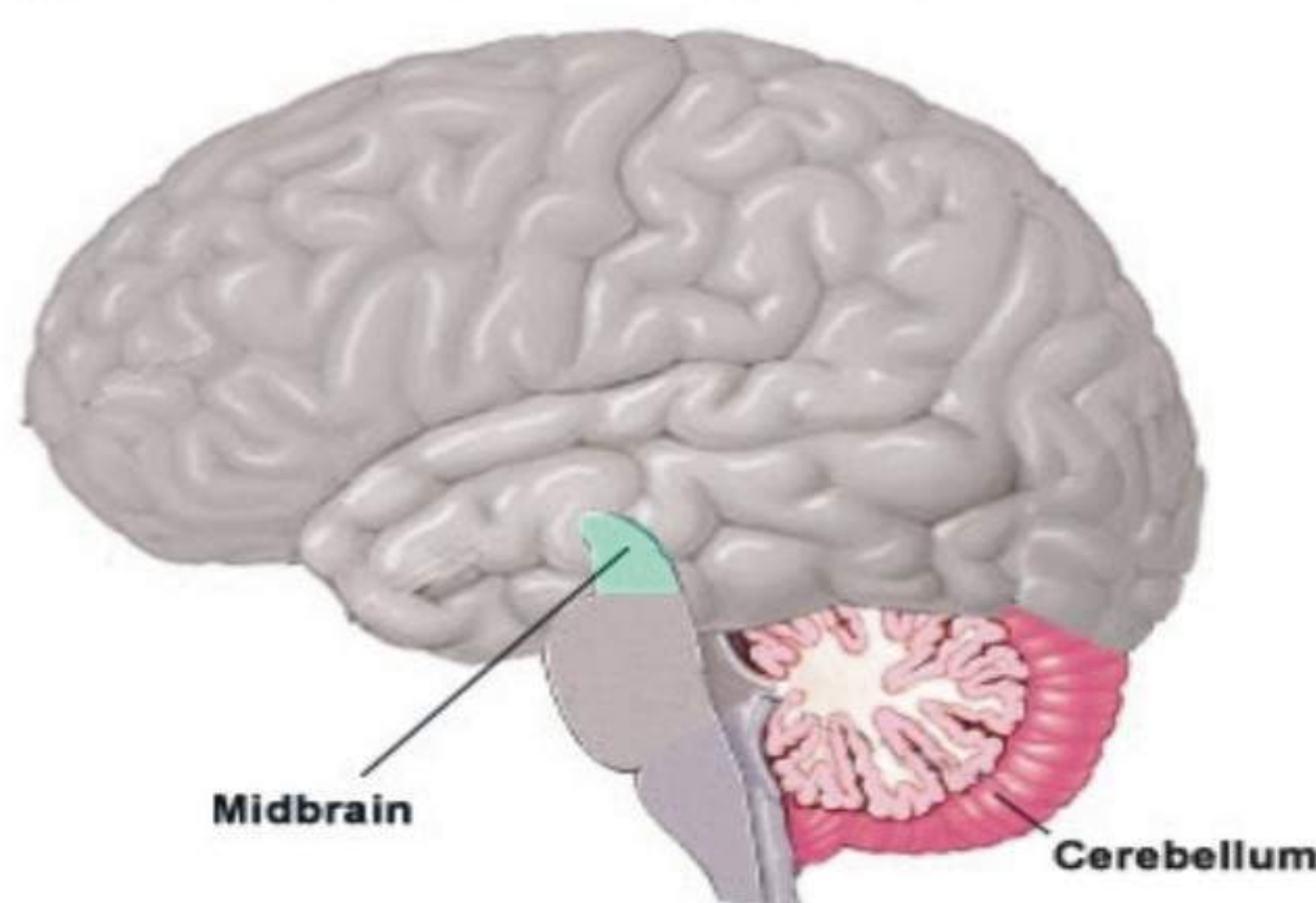
Typically balance & coordination are affected first.

Incoordination of hands, arms, and legs, and slurring of speech are other common symptoms. Walking becomes difficult and is characterized by walking with feet placed further apart to compensate for poor balance. Impaired coordination of the arms and hands affect a person's ability to perform tasks requiring fine motor control such as writing and eating. Slow eye movements can be seen in some form of Ataxia. As time goes on, Ataxia can affect speech and swallowing.

Extreme care must be taken with any anaesthetics and operations. The person may also notice signs or symptoms such as-tremor, stiffness, spasticity, sleep disorder, cold feet and sphincter disturbance to name a few. All people with progressive neurological conditions are susceptible to depressive illness, moods and other psychological conditions. Anti-depressants and counseling may be helpful.

The symptoms of Ataxia are often mistaken as signs of drunkenness.

Misjudgment causes distress.



The cerebellum handles coordination, while the midbrain helps to control eye movement.



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Management of Symptoms:

It is essential to have regular reviews for treating symptoms with a multidisciplinary team which may include Neurologists, Rehabilitation physicians, Speech Therapists, Counsellors, Physiotherapists for critical exercise, Occupational Therapists for walking aids and home improvements, Dieticians in conjunction with a General Practitioner.



The goal of treatment is to improve the Quality of Life through education, timely involvement of other specialists and medical treatment of specific symptoms.

Naturopathic, homeopathic and other natural remedies may prove useful too. Although this is not evidence based.

How Do I Get More Information?

We encourage you to visit our website or facebook for additional information on Ataxia:

www.binadam.net

[Www.facebook.com/binadamfoundation](https://www.facebook.com/binadamfoundation)

Put the person first, not their disability.

Avoid stereotypes and labels such as "the disables".

Avoid using words and phrases that can be demeaning.

Be the change you want to see in the world.

You may never know what results come of your action, but if you do nothing there will be no result.

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