



Dystonia Medical Research Foundation Fact Sheet

What is Dystonia?

- Dystonia is a brain disorder that causes muscles to contract. These muscle contractions result in abnormal movements and postures, making it difficult for individuals to control their body movements.
- Dystonia can affect any region of the body and may look quite different from person to person.
- Robert Kennedy Junior has a form of dystonia called laryngeal dystonia that affects the muscles around his voice box resulting in his speech being affected.

Who is Affected by Dystonia?

- Dystonia affects adults as well as children of all ages and backgrounds.
- Dystonia is the third most common movement disorder. It is estimated that 250,000 Americans have dystonia, and up to 70% are misdiagnosed.

What Causes Dystonia?

- There is so much we still don't know but there are many causes of dystonia.
- It may be caused a genetic mutation, changes in brain activity caused by another health condition, traumatic brain injury, or as a side effect of certain drugs.
- There are many people who develop dystonia without an identifiable cause which adds to the challenges of getting a proper diagnosis.



What treatments are available for dystonia?

- Treatments for dystonia may include a combination of oral medications, botulinum neurotoxin injections (like Botox®), and/or surgical procedures such as deep brain stimulation.
- There may be complementary therapies such as occupational or physical therapy or pain management.
- People with dystonia may experience depression and anxiety, which need to be addressed by health care professionals.

What is the Dystonia Medical Research Foundation?

- The Dystonia Medical Research Foundation or the DMRF is the leading dystonia patient advocacy organization working to support all who are affected by this little-known disorder.
- For almost 50 years, the DMRF's mission has been to advance research toward improved treatments and a cure, promote education and awareness, and provide support resources to affected individuals and families.
- If people want to learn more they can go to the Foundation's website: <https://dystonia-foundation.org/>