

American Dystonia Society

What is Dystonia?

Dystonia is a neurological movement disorder due to an abnormality in an area of the brain called the basal ganglia which manages and coordinates muscle function. The defect interferes with normal function and results in uncontrollable muscle spasms and/or sustained postures with extreme pain and disability. People with dystonia have difficulties performing simple everyday tasks. There is no cure for dystonia and treatments to mitigate symptoms are limited.



What does Dystonia look like?

There are various presentations of dystonia. Some are visually obvious and others are not. The most common form is Cervical (neck) dystonia characterized by neck muscle spasms that cause the head to tilt, twist, tremor, and/or pull back. A less common form is Generalized Dystonia in which much, or all, of the body is affected. Many people who suffer from Generalized Dystonia can be partially to fully incapacitated. Other forms of Dystonia include: Oromandibular (jaw) , which is often misdiagnosed as TMJ; Blepharospasm, which causes excessive blinking or eyelid closure; Dysphonia/vocal cord, which affects speech and swallowing; and task-specific focal hand dystonia.

What Causes Dystonia?

About 10% of dystonias are genetic , but the majority are of unknown causes. Traumatic brain injuries during birth, auto accidents, sports concussions, and military combat, anti-psychotic drugs, and antidepressant medications have been linked to Dystonia. Dystonia can strike at any age.

What can I do to help?

Dystonia is largely unknown to the American public although researchers estimate that 300,000 Americans may have it. First diagnosed in 1911, no medication has been developed specifically for Dystonia. Biowarfare toxins such as Botulinum Toxin have found peaceful uses for Dystonia symptoms. In 2008, only \$1.5M was spent on research out of \$5.5M raised. You can donate money to fund research or give your time to raise awareness. Visit our web site at www.dystonia.us to help.

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American Dystonia Society, a 501c3 non-profit organization guarantees 100% of all donations will benefit dystonia directly. We have no paid directors or staff. We are very efficient.