

About Dystonia Europe

Dystonia Europe was formed in 1993 as European Dystonia Federation - the European umbrella organisation for national dystonia patient groups.

From 2012, Dystonia Europe has become the platform at the European level for all dystonia stakeholders, to benefit patients and their families by promoting more interest in dystonia and by working together with:

- patient advocacy groups
- medical students and junior doctors
- healthcare professionals
- researchers and scientists
- neurologists with expertise in dystonia
- pharmaceutical and medical device industries

Dystonia Europe's Objectives

- To improve the quality of life for people living with dystonia.
- To stimulate research for more effective treatments and, ultimately, to find a cure.

Our Partners

We have good working relationships in a number of areas with well-respected organisations and companies.

DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EFNS – European Federation of Neurological Societies, EBC – European Brain Council, MDS – Movement Disorder Society, Medtronic Foundation, Allergan, Ipsen Pharma, Merz, Medtronic.

A Neurological Movement Disorder

Dystonia causes sustained muscle contractions, leading to twisting and repetitive movements or abnormal postures. Dystonia can affect just one part of the body or several different areas. Dystonia does not affect other functions of the brain.

Multiple Causes

The disorder may be hereditary or caused by other factors such as birth-related or other physical trauma, infection or reaction to certain pharmaceutical drugs. In the majority of cases (referred to as primary) dystonia does not have a clear underlying cause.

Dystonia can affect both men and women of all ages. When onset occurs in childhood, it is often particularly disabling. Dystonia which first shows symptoms in adult life tends to remain focal (affecting one muscle group) rather than becoming generalised over the whole body.

More Than Half a Million People Living with Dystonia in Europe

Dystonia can be difficult to diagnose, which means that many patients remain untreated, their symptoms unrecognised.

Recent epidemiological studies indicate that there are more than 500,000 people across Europe with some form of the disorder, many of whom are unaware that they have dystonia.

Treatment Options

Since there is no cure available, treatment has been limited to minimising the symptoms of the disorder.

The treatments used today are injections of botulinum toxin in the affected muscles, certain drugs to relax muscle spasms and reduce tremor, as well as surgical procedures such as DBS – deep brain stimulation.

A number of studies have shown that many patients find additional benefit from additional treatments such as physiotherapy.

Research Initiatives

Several institutes around the world carry out research in dystonia. These cover all aspects from genetics and cell biology to imaging and neurophysiological studies and clinical research including clinical trials.

Researchers collaborate in different networks such as the Dystonia Coalition in the US and through the European Network for the Study of Dystonia Syndromes.

In the last few years the number of publications on dystonia research has increased substantially. In addition, more congresses are being organised, specialising in dystonia - such as Hamburg in 2008, Hannover in 2010 and 2013, and Barcelona in 2011.

The David Marsden Award

This award was introduced by Dystonia Europe in 2003 and is presented every two years to stimulate research on dystonia, especially by young scientists in Europe.

The European Network for the Study of Dystonia Syndromes

Dystonia Europe supports the COST-funded project - European Network for the Study of Dystonia Syndromes and has been appointed grantholder and administrator of the Network. Working groups are active in:

- Genetic Studies
- Animal Models
- Clinical Practice
- E-infrastructure

The Network supports training schools and short term scientific missions (STSMs) each year. More information can be found on the Network website at www.euro-dystonia.org



Action BM1101

MSAB – Medical and Scientific Advisory Board

12 dystonia specialists from a number of disciplines are appointed to give scientific support to the DE Managing Board.

Members of Dystonia Europe

Dystonia Europe has member organisations from the following countries:

Austria, Belgium, Croatia, Denmark, France, Germany, Ireland, Italy, The Netherlands, Norway, Poland, Portugal, Spain, Sweden, Switzerland and the UK.

“Work with Dystonia Europe to provide information, raise awareness, increase research, and improve everyday life of patients and their families!”



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