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**Self-help organization**

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**We are a nonprofit self-help organization and work on a voluntary basis**



## **Self-help group Myoclonus- Dystonia**



**Self-help organization  
Dystonie-und-Du e. V.**

**Myoclonus dystonia is a very rare disease. The exchange of information, experiences and support between those affected and their loved ones helps them to better understand and accept the disease, and to live better.**

**We will meet once a year with our Myoclonus Dystonia group.**

**Myoclonus Dystonia (“MD”) is a rare form of dystonia, with which ticking, involuntary muscle twitches and tremors (myoclonus) occurs alongside dystonia.**

### **Background**

**MD (also known as DYT11) typically begins in childhood or early adolescence and is partly genetically detectable. Where inherited from the maternal side, MD is usually very mild and in some cases without visible motor disturbances.**

**In 30-50% of cases, MD is attributable to a change (mutation) in a special gene - the epsilon sarcoglycan gene. Researchers are currently seeking to identify additional genetic mutations that may also cause MD.**

### **Therapy**

**In some patients, the myoclonus is so pronounced that usually only one surgical procedure, deep brain stimulation, promises success. In other cases, botulinum toxin can be used.**

**Medication can be taken at intervals and, as the patient gets better control over his movements through the therapies, the symptoms of MD can be alleviated and improved. Ergotherapy and physiotherapy can also be useful.**

***Not lonely - rather together***

### **Our Group**

**Our support group offers support and advice to MD patients, their relatives and their friends.**

**In addition to offering support, our aim is to shorten the long ordeal many face until diagnosis by promoting this rare form of dystonia. We also are committed to helping doctors and therapists to gain a better understanding of MD and its symptoms and to develop further treatment options.**

**In order to achieve our goals faster, we have set up a pan-European self-help group. We would like to encourage MD patients to (anonymously) pass on their experiences to help support others affected by MD and their relatives. In this group experiences can be exchanged across national borders.**