#WDAD2020

DUCHENNE AWARENESS DAY
7 sept

DUCHENNE AND THE BRAIN

September 7 is World Duchenne Awareness Day. On this day we raise awareness for Duchenne and Becker muscular dystrophy (DMD and BMD) around the globe. As every year, we have a special theme that deserves more attention. This year that will be Duchenne and the brain.

The same protein that is missing in the muscle causing muscle breakdown, is also missing in the brain. This can cause problems like learning difficulties and behavioral issues such as ADD, ADHD, OCD and autism. For many families, these issues result in more stress and worries in daily life than the physical problems.

This crucial neurological aspect of DMD/BMD was already recognized in 1861, when Duchenne de Boulogne first described this neuromuscular condition. In the last decades however, most of the efforts have focused on improving outcomes related to muscle weakness. Brain involvement received less attention.

What we plea for is early screening, appropriate testing, more research and better care on this aspect of the disease. This is absolutely needed in order to have everyone reach their full potential.

ABOUT DMD/BMD

Duchenne and Becker muscular dystrophy (DMD and BMD) are two muscle wasting conditions. Both are caused by mutations in the dystrophin gene. A certain part of the DNA is missing, duplicated, or changed so the code cannot be read properly by the body. This leads to the absence of the dystrophin protein, that plays an important role in the muscle and brain.

Without dystrophin, muscle cells easily get damaged, leading to a loss of these cells and thereby muscle function. This can also happen in the brain, where dystrophin is missing as well.

Where Duchenne individuals have a complete lack of dystrophin, people affected with Becker muscular dystrophy have lower levels or a shorter version of this protein.

KEY FACTS

- Duchenne and Becker muscular dystrophy are rare genetic diseases defined by muscle weakness.
- The dystrophin protein cannot be made due to an error on the X chromosome.
- Currently, there is no cure available for this fatal disease.
- Each year, 1 in 5.000 newborn boys receive the diagnosis DMD.
- Lack of awareness contributes to an average delay of diagnosis of 2,5 years

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