#WDAD2020

SEPTEMBER 7, 2020

WORLD DUCHENNE AWARENESS DAY

TOGETHER, WE ARE STRONGER

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An initiative coordinated by the
World Duchenne Organization

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DUCHENNE AWARENESS DAY
7 sept

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ABOUT DMD/BMD

Duchenne and Becker muscular dystrophy are rare genetic diseases defined by muscle weakness. Muscles are getting progressively worse over time and ultimately affects the heart and lungs. People born with Duchenne and Becker will require care from many medical providers throughout their lives.

WHAT YOU CAN DO

- Promote the 'Stronger Together' campaign video
- Illuminate a landmark or building in red
- Contact your local media to raise awareness
- Organize a virtual educational or fundraising event
- Show your solidarity by releasing a virtual balloon

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TOGETHER, WE ARE STRONGER

The current Corona pandemic is profoundly impacting our daily lives. It changes the way we spend time, altering our habits. Although it is changing our daily life, it cannot overrule our projects and voices.

As Duchenne community, we are very aware how strongly this affects us in terms of isolation, facing emergencies and adaptation. We are familiar with words as fear, pain and distance. However, we are trying to turn fear into hope, pain into resilience, and distance into closeness.

This World Duchenne Awareness Day 2020 we share a message that many people have experienced, and are still experiencing: Together we are stronger. Even after the emergency will finish, our cause will still be there, our engagement is still there and we need every single person to be involved.

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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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