DUCHENNE AWARENESS DAY

7 sept

DUCHENNE AWARENESS DAY 2026

The World Duchenne Awareness Day 2026 theme is **Access changes lives.**

World Duchenne Awareness Day (WDAD) is an annual event held on September 7.

KEY FACTS

- Duchenne and Becker muscular dystrophy are rare genetic diseases causing progressive muscle breakdown.
- It is caused by a mutation on the X-chromosome, that is why mainly boys are affected.
- There is currently **no cure** for Duchenne muscular dystrophy (DMD). However, treatments are available to manage symptoms and improve quality of life. New treatments are becoming available and others are currently in development, giving hope to the community.
- Each year, **1 in 5.000** boys are born with DMD worldwide.
- The average age of diagnosis for DMD is **4.5 years.**
- On average there is a delay of **2.5 years** between when symptoms first appear and when the diagnosis is made.
- With optimal care, individuals with DMD can live into their **30s and even beyond.**

Access changes lives

Access is a fundamental driver of better outcomes for people living with Duchenne. It means ensuring equitable access to accurate information, early and timely diagnosis, multidisciplinary standards of care, specialist services, clinical trials, and innovative therapies. As scientific understanding advances and new treatment options continue to emerge, it is essential that these developments translate into meaningful benefits for every individual and family affected by Duchenne—regardless of where they live, their socioeconomic circumstances, or the limitations of their healthcare system.

Beyond healthcare, access is about inclusion and participation. People living with Duchenne should have the opportunity to engage fully in all aspects of society, including education, employment, sports and recreation, cultural activities, travel, and social life. Achieving this requires accessible environments, improved mobility and transportation, the removal of physical and social barriers, and a collective commitment to ensuring equal opportunities for all.

WHAT YOU CAN DO

We urge everyone to share the theme with the wider community. By working together, we can create a more inclusive and supportive society for people living with dystrophinopathies (Duchenne- and Becker muscular dystrophy).

Organizing meetings and events, illuminating landmarks and monuments in red we can raise awareness all together.

RAISE AWARENESS | ORGANIZE EVENTS | LIGHT UP IN RED | MAKE AN IMPACT

ABOUT DUCHENNE AND BECKER MUSCULAR DYSTROPHY

Duchenne Muscular Dystrophy is a rare disorder that causes muscles to become weaker over time until it affects the whole body. Approximately one in every 5.000 boys is born with the disease. It is caused by a mutation on the X-chromosome, that is why mainly males are affected. First walking becomes difficult, then other motor functions follow and ultimately it affects the ability to breathe as well as the function of the heart, as the heart is a muscle too. The missing protein also has a function in the brain, so learning- and behavior issues can also be part of the disease.

Becker Muscular Dystrophy (BMD) is considered to be a less severe form of DMD.

ABOUT WORLD DUCHENNE AWARENESS DAY

World Duchenne Awareness Day (WDAD) is an annual event held on September 7. WDAD is a global event aimed at raising awareness about Duchenne and Becker muscular dystrophy. The day promotes education, advocacy, and social inclusion initiatives to improve the quality of life for people living with dystrophinopathies. Secondly, it is providing a platform to share personal stories and experiences of those living with the disease.

The United Nations has marked a momentous milestone for the global rare disease community by officially designating September 7th as World Duchenne Awareness Day, set to be observed annually from 2024.

For more information about Duchenne Muscular Dystrophy and the World Duchenne Organization, please visit

worldduchenne.org

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