

#WDAD2023



DUCHENNE AWARENESS DAY
7 sept

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.
- Currently, there is no cure available.
- 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.

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WORLD DUCHENNE AWARENESS DAY 2023

The World Duchenne Awareness Day 2023 theme is 'Duchenne: Breaking Barriers'. World Duchenne Awareness Day (WDAD) is an annual event held on September 7. With this, WDAD supports creating a society that provides equal opportunities for all. This year we organize the 10th edition.

DUCHENNE: BREAKING BARRIERS

People living with Duchenne and Becker muscular dystrophy (DMD/BMD) face physical, healthcare and social barriers. This severely limits their ability to participate fully in community life and activities.

On September 7th we call on you to take on responsibility and help break down barriers for people living with DMD/BMD. Only together as a society can we create an inclusive society and build a better future. Some examples of topics aimed at breaking down barriers in DMD include:

- 1. Access to care:** Ensuring that individuals with DMD/BMD have access to comprehensive and affordable medical care to manage their condition and improve their quality of life.
- 2. Accessibility:** Ensuring that public spaces, such as schools, workplaces, and community centers, are accessible for people with DMD/BMD.
- 3. Advocacy:** Raising awareness about the challenges faced by individuals with DMD/BMD and advocating for policies and programs that promote social inclusion and equal opportunities for people with disabilities.
- 4. Community engagement:** Encouraging individuals with DMD/BMD to participate in community activities and providing resources and support to help them do so.
- 5. Employment opportunities:** Creating job opportunities for people with DMD/BMD and providing support for them to find and maintain employment.
- 6. Inclusive education:** Providing opportunities for people with DMD/BMD to attend mainstream schools and participate fully in the educational experience.

WDAD DOCUMENTARY

On September 7, the World Duchenne Organization will launch a WDAD documentary that portrays the lives of people living with Duchenne Muscular Dystrophy across the globe and how they are each breaking barriers in their personal lives.

Using storytelling techniques, the organization aims to provide insight into the barriers someone living with this rare condition may face, and provide encouraging and inspiring ways to overcome these challenges.

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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.

In the upcoming months, materials that can be used to raise awareness for breaking barriers in DMD/BMD will be made available on the website. These materials include banners, visuals, key facts and stories.

For more information about Duchenne Muscular Dystrophy and the World Duchenne Organization, please visit worldduchenne.org and worldduchenneday.org

For inquiries, please contact:
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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.

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