

DUCHENNE AWARENESS
DAY

7 sept



WORLD DUCHENNE AWARENESS DAY 2022

#WDAD2022
INFORMATION PACK



WORLDDUCHENNEDAY.ORG

WHAT IS WORLD DUCHENNE AWARENESS DAY?

World Duchenne Awareness Day is the official global annual campaign to raise awareness for people living with Duchenne & Becker muscular dystrophy. The international day is taking place each year on **September 7**.

On this day we involve all stakeholders to raise awareness and inspire action to improve the lives of people living with dystrophinopathies.

World Duchenne Awareness Day is an initiative coordinated by the World Duchenne Organization and launched in 2014.

AIMS & OBJECTIVES

1. Raise global awareness on Duchenne and Becker muscular dystrophy (DMD and BMD)
2. Engage and educate all stakeholders to adopt effective strategies to improve the lives of people living with DMD/BMD
3. Call for urgent and sustainable actions by all stakeholders
4. Advocate for the adoption of best practices regarding Standards of Care

ABOUT DUCHENNE & BECKER MD

Duchenne and Becker muscular dystrophy are rare genetic diseases defined by muscle weakness. Muscles are getting weaker over time. This ultimately affects the ability to breathe as well as the function of the heart, as the heart is a muscle too.

There are over 250.000 people worldwide living with Duchenne and Becker muscular dystrophy.

People born with Duchenne and Becker need care from many specialists throughout their lives. With the current standards of care, people living with Duchenne can live into their early 30s and beyond.



WHAT CAN I DO?

There are many things you can do to spread awareness before and during World Duchenne Awareness Day on September 7. We listed some tips below, but feel free to create your own ideas!

1. Share the official promo video

The official World Duchenne Awareness Day 2022 awareness raising video will be published on September 1.

2. Get involved in social media

Share the press release and key messages, and update your social media profile picture with the red balloon, symbol for WDAD.

3. Create a communication campaign

Post on social media using the materials and tag your posts with **#WDAD2022** and mention **@duchenneday** or **@worldlduchenne**.

4. Show your solidarity by donating

Support the activities of local and global patient organizations to help Duchenne families: we can really make the difference together!

5. Promote education & set up a meeting

Share the educational materials available on our website, organize an educational meeting or attend a local initiative.

6. Illuminate a landmark

Illuminating a monument helps to raise awareness to the general public. Join other iconic monuments by turning your local landmark red on September 7.

For questions and assistance, please contact suzieann.bakker@worldlduchenne.org



2022 THEME

Beside the general awareness action there is a specific theme that deserves more attention. This year, the theme is **Women and Duchenne**.



By creating specific educational materials World Duchenne Organization will highlight all the aspects connected with Duchenne and the female world:

- Carriers: genetic and clinical aspects
- Care considerations for female carriers
- Mothers as primary caregiver
- Girls living with Duchenne
- Spouses and girlfriends
- Female family member network of support
- Women in science
- Female international advocacy leaders

EDUCATIONAL CONFERENCE

On Wednesday September 7, an online event is hosted by the World Duchenne Organization. During this interactive conference, multiple aspects of Women and Duchenne are discussed.

In addition to this, interviews are displaying the stories of women with a relation to Duchenne throughout the world.

The **free event** will be accessible for everybody via Zoom, and is available with live Spanish interpretation. More information about how to join will be published on the social media channels of the World Duchenne Organization.

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KEY FACTS

List of key facts on carriers and girls living with Duchenne muscular dystrophy:

- Females carriers are usually not affected with Duchenne or Becker MD as they can produce dystrophin
- However, they can have some symptoms, such as cardiomyopathy, mild muscle weakness, being tired or having muscles cramps and probably also learning problems
- The severity of these symptoms can vary.
- A girl being diagnosed with Duchenne or Becker is very rare, but possible.

Visit worldduchennday.org for more information and materials.

STAY CONNECTED

Stay on top of the latest information about World Duchenne Awareness day and the information and materials that are created.

Follow the World Duchenne Organization on social media and **subscribe to the newsletter** to receive updates.

For inquiries, please contact Suzie-Ann Bakker suzieann.bakker@worldduchenne.org



@worldduchenne



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THE HISTORY OF WORLD DUCHENNE AWARENESS DAY

The first World Duchenne Awareness Day **started in 2014**, when Elizabeth Vroom and Nicoletta Madia wanted to raise global awareness for Duchenne and Becker muscular dystrophy.

Although the condition Duchenne Muscular Dystrophy was first described more than 150 years ago, not many people are aware of the impact of this disease on the lives of individuals with Duchenne themselves, their siblings and their entire family.

More awareness among a wider audience would help to avoid a delay in diagnosis, better understanding of their problems, **improvement of medical care** and more support in general.

With this in mind, World Duchenne Organization's President Elizabeth Vroom and Community Coordinator Nicoletta Madia, initiated in 2014 the first World Duchenne

Awareness Day on September 7th. Over the years, this event has grown to an **international event** with participants from all continents.

"The World Duchenne Awareness Day started as a plan and is becoming something magical" says Nicoletta Madia. "I use the word magical because when you see the world united for one cause, when you see the power of the community, the activism, you understand that the reality exceeds your expectations".

"World Duchenne Awareness Day really became a global movement, so powerful and so united, I can only be happy and grateful", says Elizabeth Vroom. "It is emotional for me as a Duchenne mother to realize **we are stronger together**, so many parents feel alone after the diagnoses but they will see during WDAD, how strong we are together".



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