

DUCHENNE AWARENESS DAY

7 sept



PRESS KIT



WORLD
DUCHENNE
ORGANIZATION
UPPMD



BRING YOUR LIGHT FOR THE WORLD DUCHENNE AWARENESS DAY ON SEPTEMBER 7

World Duchenne Organization launches its global campaign to raise awareness of the disorder.

On September 7, all over the world, World Duchenne Awareness Day (WDAD) will be celebrated, an important initiative created and coordinated by the World Duchenne Organization (formerly UPPMD). The aim of the World Duchenne Awareness Day is to raise awareness of Duchenne Muscular Dystrophy: the most common type of muscular dystrophy in children. It is a progressive disorder that causes muscles to become weaker over time until it affects the whole body.

The first edition of the WDAD took place on 7 September 2014: since then, the event has become bigger and now involves patient organizations from many different countries, institutions, families, clinicians, scientific researchers, public figures and civil society. From that day on, the red balloon became the symbol of the WDAD to let Duchenne fly away from this world.

For the 2019 edition, World Duchenne Organization launches the video BRING YOUR LIGHT FOR THE WORLD DUCHENNE AWARENESS DAY. This video derives from the spontaneity of the children, from the power of emotions. The children were asked to enter a dark room, follow a path of lights and reach a box, open it and see what would happen. Upon opening, the box fills the room with a beautiful light and suddenly a red balloon, the symbol of this world day, flies upwards. A smile appears on each of their faces. A smile that comes from the light that everyone possesses and can give to others: boundless love is the light of a family member, commitment is the light of a volunteer, attention is the light of the experts who take care of children and the boys with Duchenne and seeking a cure, presence is the light of a friend, altruism is the light of a donor. Everyone can bring their own light to celebrate this day, to join this important cause and make a smile appear on thousands of faces.

World Duchenne Organization is a worldwide collaboration between Duchenne Parent organizations in order to improve treatment, quality of life and long-term outlook for all individuals affected by Duchenne muscular dystrophy (DMD and BMD).

FACTSHEET

- Duchenne Muscular Dystrophy
- Genetic Disorder
- Mutation on X-chromosome
- Primarily affects boys
- Very few girls affected
- Women can be carriers
- One third caused by new spontaneous mutations
- Progressive muscle degeneration
- Caused by an absence of dystrophin
- Progressive weakness
- First signs in toddlers
- Diagnosis on average at the age of 4 to 5 yrs
- All muscles affected, also heart and smooth muscle
- Dystrophin also absent in the brain
- Sometimes learning and behavioral problems
- 20.000 new diagnosis per year worldwide
- Wheelchair bound early teens
- Needing assisted ventilation around 20 yrs
- Life expectancy has increased in recent years
- Good care is essential for life expectancy
- First described in 1860's by Duchenne de Boulogne
- Cause (dystrophin deficiency) identified in 1986

KEY MESSAGES

- On behalf of people living with #Duchenne and #Becker Muscular Dystrophy, I join this year's World Duchenne Awareness Day. Let's spread the word! Take a look at the @duchenneday toolkit with useful material and suggested messages for #WDAD2019
- Today is World Duchenne Awareness Day, a day celebrated to raise awareness on the rare muscle condition #Duchenne and #Becker Muscular Dystrophy #WDAD2019
- Every year, 5.000 newborn boys in the world are born with a rare muscle disease called #Duchenne or #Becker. On #WDAD2019 it's important to remember early screening and diagnosis of this #RareDisease!
- On #WDAD2019 I raise awareness on this rare muscle wasting disease by letting up this red balloon. Together, we can lighten up the fight for #Duchenne and #Becker.
- Each year, there are 20.000 new diagnosis per year worldwide by rare and fatal disease #Duchenne Muscular Dystrophy. On World Duchenne Awareness Day, raise awareness of this #RareDisease. #WDAD2019
- Appropriate care and treatment of symptoms can help many boys and men with #Duchenne or #Becker. Nutrition and supplements are key for living their life to the fullest! #WDAD2019
- Lack of awareness of #DMD and #BMD in (first line) healthcare professionals seeing children is a major factor that contributes to an average delay of diagnosis of 2.5 years. On World Duchenne Awareness Day, I help spread the word for timely diagnosis of #Duchenne and #Becker.
- Today, I bring my light for World Duchenne Awareness Day to support families affected by #Duchenne Muscular Dystrophy. #WDAD2019 @duchenneday

INFO

Website: www.worldduchenneday.org
Website: www.worldduchenne.org/
Facebook: facebook.com/WorldDuchenne
or @WorldDuchenne and #WDAD19
Instagram: instagram.com/worldduchenneday
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TECHNICAL INFO VIDEO

The video is produced by World Duchenne Organization. All rights reserved.

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A special thank you to the children of Parent Project Spain who participated in the video