

WORLD DUCHENNE AWARENESS DAY

7 SEPTEMBER 2021



ONLINE EVENT: ADULT LIFE & DUCHENNE

Every year, on the 7th of September during the [World Duchenne Awareness Day](#), a different thematic is chosen to raise awareness for people living with Duchenne.

This year, for the World Duchenne Awareness day 2021, the [World Duchenne Organization](#) is organizing an online educational event on [Adult Life & Duchenne](#). The free event will be held on September 7th from 14:00 to 16:00 Central European Summer Time, and it will be accessible for everybody via Zoom.

Nicoletta Madia will also dedicate a few moments to talk about the [Social Duchenne project](#), an international project highlighting psychosocial issues in Duchenne and Becker Muscular Dystrophy.

How Patient Organizations Can Drive FAIR Data Efforts to facilitate Research and Health Care - Report



Last March, the World Duchenne Organization in collaboration with the Duchenne Data Foundation organized the second [Meeting on FAIR Data Sharing for Duchenne](#). During this meeting, 120 participants from 22 countries discussed how they could drive FAIR data efforts to facilitate research and healthcare.

Attendees included representatives of Patient Organizations, clinicians, clinical and academic researchers, pharmaceutical companies, regulators, FAIR experts and EU organizations. The report summarizes the presentations and discussions of the meeting and provides an overview of the key lessons learned since the first meeting, held in March 2019.

[MORE INFORMATION](#)

#SPREADTHEWORD for World Duchenne Awareness Day



The [official promo video](#) for the [World Duchenne Awareness Day 2021](#), is initiated and produced by the [World Duchenne Organization](#) and coordinated by Nicoletta Madia. "Words are important. Words can help make a difference". This is the theme that emerges from the video for World Duchenne Awareness Day 2021. The video shows various portraits of people living with Duchenne in their daily life.

With the help of many patient organizations throughout the world, the promo video is available in 16 languages.



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