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OCTOBER 2022

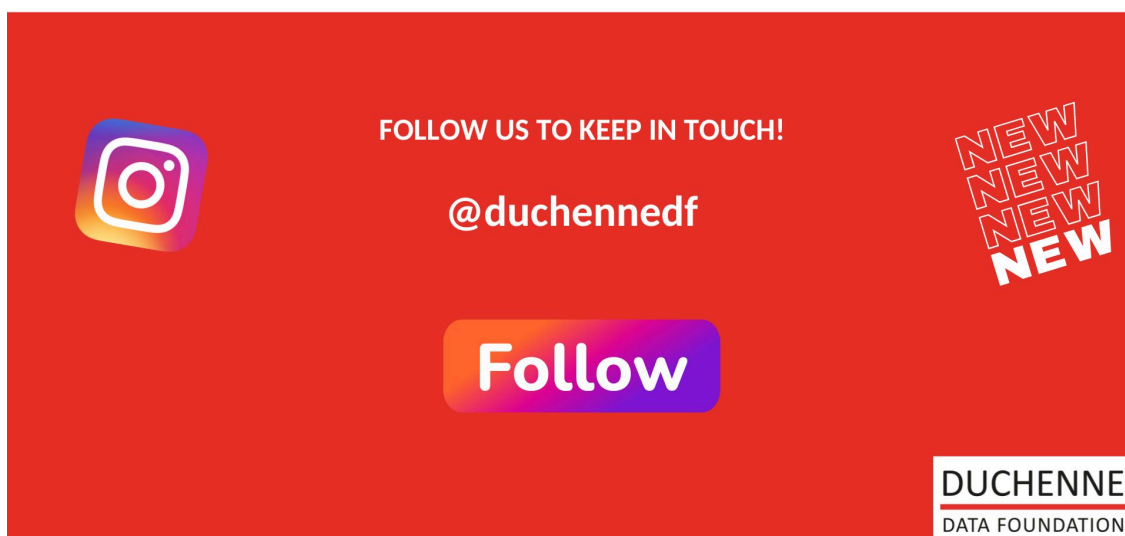
DUCHENNE

DATA FOUNDATION

Bringing data to life to improve
the world of Dystrophinopathies

WE JOINED INSTAGRAM

NEW INSTAGRAM ACCOUNT LAUNCHED



We have launched our **Instagram account!**

Follow us to stay in touch and learn about our projects, training opportunities and collaborations.

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DUCHENNE PATIENT ACADEMY 2022

CHANGING PERSPECTIVES

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Connecting DMD/BMD patient advocates of the future

December 1 – 3, 2022
duchennepatientacademy.org



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This year's Duchenne Patient Academy will be held on **December 1 - 3, 2022** and the theme is "Changing Perspectives". The Academy is organized every year in collaboration with the [World Duchenne Organization](https://www.wduo.org).

For 3 days, participants will be able to follow presentations, panel discussions and share their experiences.

Applications will open this week, stay tuned!

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FAIR DATA SHARING WITHOUT OVERSHARING

LEVERAGING FAIR DATA TO BENEFIT PEOPLE LIVING WITH RARE DISEASES



How to share data available in registries and at the same time protect patient privacy?

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pre-defined queries automatically, without exposing sensitive patient details.

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NEWS FROM OUR NETWORK

QUALITY OF LIFE IN NEUROMUSCULAR DISEASE

A EURO-NMD WEBINAR



Quality of life in Neuromuscular Disease

Robert Pangalila, MD, PhD

Rijndam Rehabilitation Clinic, the Netherlands

Erasmus University Medical Centre, the Netherlands

Robert Pangalila, MD, PhD will host a webinar on **Quality of life in Neuromuscular Diseases** on October 13th, 16:00 CET.

The talk will be followed by patient testimonies, experiences and views on what quality of life means to them.

This webinar is a collaboration with ERN-RND (rare neurological disorders) and the European Academy of Neurology.

4TH NEUROMUSCULAR TRANSLATIONAL SCHOOL

ORGANIZED BY EURO-NMD AND TREAT-NMD



The Translational School is composed of lectures about the current state of the art of acquired and genetic neuromuscular diseases, the different steps of drug development and the tools needed for this. At the same time, it highlights the importance of patient involvement in these steps and how to communicate research to patients and the general public.

The 4th Neuromuscular Translational School will be held on **November 21-25** in **Leiden University Medical Center, the Netherlands**.

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