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OCTOBER 2022

# DUCHENNE

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## 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.

FOLLOW US

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## DUCHENNE PATIENT ACADEMY 2022

### CHANGING PERSPECTIVES

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EMY

PATIENT ACADEMY

PATIENT ACADEMY

## Connecting DMD/BMD patient advocates of the future

December 1 – 3, 2022  
[duchennepatientacademy.org](http://duchennepatientacademy.org)



WORLD  
DUCHENNE  
ORGANIZATION  
UPPMD

DUCHENNE  
DATA FOUNDATION

DUCHENNE  
PATIENT ACADEMY

DUCHENNE  
PATIENT ACADEMY

DUCHENNE  
PATIENT ACADEMY

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](#).

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

**Applications will open this week, stay tuned!**

[LEARN MORE](#)

## FAIR DATA SHARING WITHOUT OVERSHARING

LEVERAGING FAIR DATA TO BENEFIT PEOPLE LIVING WITH RARE DISEASES



European  
Reference  
Network  
for rare or low prevalence  
complex diseases

Network  
Neuromuscular  
Diseases (ERN EURO-NMD)



FAIR  
DATA SYSTEMS

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

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

[READ THE PRESS RELEASE](#)

## 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.

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## 4TH NEUROMUSCULAR TRANSLATIONAL SCHOOL

ORGANIZED BY EURO-NMD AND TREAT-NMD



European  
Reference  
Network  
for rare or low prevalence  
complex diseases  
Network  
Neuromuscular  
Diseases (ERN EURO-NMD)



TREAT-NMD  
Neuromuscular Network

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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